Disability and Oral Health

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1. Introduction

This chapter will address the oral health needs of people with learning disabilities and access to oral healthcare, drawing on policy, research and action in the UK. It will provide insight to the principles and practice of dental care including the creation a new dental specialty, 'Special Care Dentistry'. This dental specialty was developed to provide oral health care for vulnerable people including those with a learning disability; it provides a case study of a public health approach to developing specialist services. The case study highlights how the process has significantly improved the profile of the oral health needs of vulnerable adults in general, including people with a learning disability. The importance of promoting health using the common risk factor approach and empowering people with a disability to make healthy choices is stressed, drawing on the current evidence base. The chapter concludes with the challenges for the future which will be pertinent to those involved in the care of people with a disability worldwide.

2. Disability and oral health

This section will examine the disability from a UK perspective, the principles of providing healthcare for people with a learning disability and the challenges faced in doing so. Traditionally, it has been found that people with a disability or other impairment (such as a mental illness or a learning difficulty) may have worse oral health than those without such disabilities or impairments; not only can this cause physical problems, but it can potentially have a wider reaching impact as poor oral health can have a negative effect on self-esteem, quality of life and general health. Improving the levels of oral health in those with impairments or disabilities is, consequently, a major issue for the dental care services.

2.1 Disability in the UK

At a global level, it is suggested that approximately 10% of the world's population, more than half a billion people, are disabled and it is predicted that this number will rise dramatically in the next quarter of a century (International Disability Foundation, 1998). It is estimated that between 1.3% and 3.5% of the population in the UK has a learning disability (Department of Health, 2007). The government strategy for people with a learning disability for the 21st century entitled 'Valuing People' defines learning disability as including the 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.

(Department of Health, 2001)

Estimates suggest that there are somewhere between 230,000 and 350,000 people with a severe learning disability and a further 0.58M to 1.75M with a mild to moderate learning disability in the UK alone (Department of Health, 2007). This means that learning disabilities are common; however, the nature and extent of disabilities vary widely. It is therefore important that adults with learning disabilities should not be viewed as a homogeneous group (British Society for Disability & Oral Health et al., 2001). Learning disabilities may be associated with a physical disability or medical condition which further adds to the complexity of their lives, and those of their carers (British Society for Disability & Oral Health et al., 2001). This has implications for the level of support that they require in daily living.

2.2 The principles

There is ongoing debate about how disability should be defined and the impact of definitions on the provision of care; whereby disability is defined either as 'functional limitations based on an impaired body' or 'oppression caused by a social world which is not made accessible to everyone regardless of impairment' (Scambler et al., 2011). The argument hinges on the extent to which disabled people are seen as tragic victims to be 'helped' (the medical model approach) or individuals who happen to have an impairment but have the same rights and needs as their non-disabled peers (the social model approach). Whilst much dental training adopts, often unconsciously, a medical model approach, there is a growing awareness of the need for a social, patient-centred approach as demonstrated in health policy and professional action.

Following on from the general strategic document 'Valuing People', the Department of Health (2007) published 'Valuing Oral Health: a good practice guide for improving the oral health of disabled children and adults'. This placed great importance on 'choice, rights and inclusion' for disabled people in relation to health care. The report recommended that:

1. Primary care should be the main provider of oral care for disabled people.
2. Disabled people should be enabled to access and make use of health information to promote choice and inclusion.
3. Disabled people have the same right to good quality health care as all other groups in the population.
4. Disabled people have an equal right to oral healthcare that is responsive to their specific needs.
5. Oral Healthcare should be an integral part of holistic care packages for disabled people.

(Department of Health, 2007)

The ethos behind these principles is a social approach, with acknowledgement that disabled people have the same rights in relation to their oral health care as their non-disabled peers. This echoes the earlier strategy on 'Valuing People' which stated that the main objective for

the NHS was to "enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a high standard, and with additional support where necessary." (Department of Health, 2001).

In addition to the Department of Health guidelines, dental practices in the UK are required to comply with the Disability Discrimination Act (Qureshi and Scambler, 2008). This Act was partly subsumed into the 2010 Equality Act which aims to protect disabled people and prevent discrimination and to provide legal protection in relation to education, employment, access to goods and services (UK Government, 2010); this requires dental practices as providers of healthcare to make 'reasonable adjustments to physical features'. In the context of the General Dental Service (Disability Rights Commission, 2003, Disability Rights Commission, 2004) physical features may be regarded as those 'structural/inanimate aspects' of a service which are used integrally as part of the service uptake and make the experience, or service, use acceptable. Such features may include: steps, stairways, kerbs, exterior surfaces, paving, parking bays, entrances and exits, internal doors, gates, toilets, washing facilities, public facilities (such as telephones, counters, service desks), lighting, ventilation, lifts and escalators. When combined with national guidelines, the Disability Discrimination and Equality Acts ensure that oral health care provision for disabled people should be accessible, both physically and philosophically, and of a high quality.

2.3 The challenges

There are three broad challenges associated with promoting oral health and the delivery of oral and dental healthcare; first, the challenge of preventing oral disease and maintaining oral health; second, the challenge of accessing appropriate dental care in a timely manner, and third, obtaining informed consent for care. Each of these topics will be dealt with in turn starting with 'oral health'.

2.3.1 Oral health

As already outlined, good oral health contributes to general health and wellbeing. There is relatively little epidemiological research on the oral health needs of people with a learning disability. Children and adults with a learning disability suffer from the same common oral diseases and conditions as the rest of society (Fig 1); however, there is evidence that they experience poorer outcomes and the impact of oral disease on quality of life can be profound as it impairs eating, speaking socialising and comfort.

Data on the oral health needs of adults with disabilities are limited. Overall within the UK oral health has improved considerably in the past three decades across the population; however, inequalities persist. Oral health surveys of adults with learning disabilities in the UK have found: poor oral hygiene and high prevalence of periodontal (gum) diseases; a wide range of prevalence estimates of tooth decay; more missing teeth than general population and more untreated disease for adults living in the community than those in institutions (British Society for Disability and Health et al., 2001).

Even where needs are not significantly different across settings, an Australian survey demonstrated a number of important trends: higher odds of 'dental caries experience' were associated with age and having no oral hygiene assistance; higher odds of 'missing teeth' were associated with the type of disability, requiring a general anaesthetic for dental

treatment, and both low and high carer-contact; finally, higher odds of having 'filled teeth' were associated with age, having no oral hygiene assistance and having high carer-contact (Pradhan et al., 2009). This underlines the importance of high quality daily care as well as regular dental care.

It is also recognised that trauma to teeth can present a challenge to some people with learning disabilities. 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 (Department of Health, 2007).

It is vitally important to ensure that children and adults with learning disabilities, and their carers, are sufficiently supported to care for their oral health and prevent disease as outlined in Section 3.1, rather than just treating disease once it has developed. The main diseases and conditions are outlined in Table 1.

Disease or condition	Description
Dental caries *Tooth decay*	one of the most prevalent conditions in adults and children worldwide, associated with a high sugar consumption (food/drink{
Periodontal diseases *Gum diseases*	affect most people to some extent. Moderate gum disease, demonstrated by bleeding gums and the presence of plaque and or calculus (calcified plaque), is much more prevalent, particularly in adults
Tooth wear: *attrition, erosion or abrasion of tooth surface*	a natural phenomena of ageing; however it becomes pathological when it is excessive either through erosion by means of acidic food, drink or acid reflux, attrition or tooth-wear through excessive grinding and abrasion by wear caused by devices such as a toothbrush
Oral cancer *Mouth cancer*	cancer of the mouth, the majority of which are squamous cell carcinoma; this is a particularly emotive cancer because of its impact on eating, speaking and socialising and poor outcomes including long term survival
Orthodontic need *Need for braces*	Significant need for orthodontic care is prevalent in just over one third of 12 year olds (35%) in the general population in the UK.
Trauma *Damage*	trauma to teeth is a greater risk for some people with learning and physical disabilities through falls or accidents

Table 1. Common oral diseases and conditions

2.3.2 Barriers to oral healthcare

There are a number of barriers to oral healthcare for people with learning disabilities that need to be overcome if their oral health needs are to be fully met (Alborz et al., 2004, Scully et al., 2007). Scully et al have categorised these as:

- Barriers with reference to the individual
- Barriers with reference to the dental profession
- Barriers with reference to society
- Barriers with reference to government.

(Scully et al., 2007)

Individual barriers include a lack of perception of need by individuals (Halberg & Klingberg 2004) or their carers (Cumella el al. 2001); difficulty following instructions (Bollard 2002); and access problems (Dougall & Fiske 2008). Barriers relating to the dental profession include a lack of training (Gallagher and Fiske, 2007, Scambler et al., 2011); poor communication skills (Sentell 2007); high staff turnover (Pratelli and Gelbier, 1998) (Scambler et al., 2011) and a lack of time and resources (Scambler et al., 2011). Societal barriers include a general lack of awareness of the importance of oral healthcare, and a lack of positive attitudes towards oral health promotion (Owens et al., 2011). Finally, governmental barriers include a lack of resources for oral health services (Dougall and Fiske, 2008a). This suggests that whilst the oral health needs of people with learning disabilities are broadly similar to their non-disabled peers, there are significantly more barriers to timely oral health care of good quality.

2.3.3 Consent for care

In addition to the barriers listed above, there is the issue of 'capacity to consent' to treatment to consider (Dougall and Fiske, 2008c). The Mental Capacity Act (UK Parliament, 2005) introduced a broad *diagnostic* threshold to determine whether a person has capacity to make a particular decision. The Act identified that a person lacks capacity where: '…at the material time, he is unable to make a decision for himself in relation to a matter because of an impairment of or disturbance in the functioning of the mind or brain' (section 2(1). 'The impairment may be temporary or permanent' (section 2(2)).

A person is considered unable to make a decision if (s)he is unable to:

- understand the information relevant to the decision
- retain that information
- use or weigh up that information as part of the process of making the decision
- communicate his/her decision.'

(UK Parliament, 2005)

The principles of consent remain the same whether or not people have full capacity to consent. Informed consent is based on freewill, capacity and knowledge (Dougall and Fiske, 2008c). This means that there are certain key stages which clinicians need to work through with patients, from an introduction of self and the purpose of the visit and establishing what is already understood, right through to giving and obtaining informed consent:

- Introduction
- Establishing what is already understood
- Explaining the nature of the clinical condition
- Outlining treatment options
- Explaining risks and benefits
- Checking what has been understood
- Inviting further questions
- Confirming the preferred treatment mode
- Giving and obtaining consent

(King, 2001, Dougall and Fiske, 2008c)

The legal framework and basis for obtaining consent will vary from country to country; however, the principles above should prove helpful whatever the context. The big challenge exists in relation to adults who are unable to provide informed consent. This clearly has implications for many people with moderate to severe learning disabilities and has led to the introduction of 'best interest meetings' to ensure that the patient is fully represented where they are not able to fully participate in their own right and the most appropriate care programme for the individual is agreed (Dougall and Fiske, 2008c).

3. Disability and oral care

'Valuing people's oral health' (Department of Health, 2007), is a national policy concerned with improving the oral health of children and adults with a disability. It is a good example of health promoting public health action in support of the oral health of people with a disability. The policy document recognises that disabled children and adults have the same right to good oral health as the rest of the population (Department of Health, 2007). Oral health may depend on a whole series of factors, some of which are relevant across the population, and which include the following which include oral care:

Personal predisposing factors

- Age
- Psychological status
- Socio-economic status
- Behavioural risk factors
- Nature and severity of the individual's learning disability
- Presence of co-morbidities
- Medications
- Ability to undertake regular oral hygiene procedures or receive care from others
- Importance placed on oral health by carers whether family or paid
- Previous dental history including attendance pattern

Health systems factors

- Capacity to consent to oral care
- Access to local dental services: regular, specialist and emergency dental care
- Nature of local dental services: willingness and skills of the dental team to treat people with learning disabilities
- Access to sedation or general anaesthetic services in conjunction with the provision of dental care (If required)
- Location and mode of delivery of care: domiciliary, mobile surgery, routine dental surgery/office, dental hospital
- Support to access care: transport, carers, etc
- Processes in place to achieve agreement on dental care plans where the individual is unable to provide informed consent

Sources: (BSDH et al., 2001, BSDOH, 2009, Dougall and Fiske, 2008a, Dougall and Fiske, 2008b, Dougall and Fiske, 2008c, Dougall and Fiske, 2008e, Dougall and Fiske, 2008f, Lewis et al., 2008a, Lewis et al., 2008b)

3.1 Evidence-based self care

Good oral health starts in infancy with a supportive environment including the active support of parents and/or carers. Personal care and a healthy lifestyle are fundamental to having and maintaining good oral health, but this can be more challenging to people with a disability. As already highlighted, the pathology of oral diseases is well understood, particularly in relation to tooth decay which is the most prevalent dental conditions in children worldwide; so too is the evidence base for prevention. Much of the contemporary evidence base is outlined in 'Delivering Better Oral Health: an evidence–based toolkit for prevention' (Department of Health and British Association for the Study of Community Dentistry, 2009). It outlines appropriate health behaviour at a population and an individual level from birth onwards. It highlights what is should be emphasised by the dental team for the population in general and what additional preventive care is appropriate for those of giving special concern. In all categories there is an emphasis on a healthy diet, good hygiene and the use of fluoride to strengthen teeth as shown in Table 2.

Tooth decay is prevented by minimising the volume and frequency of sweet food and drink. As soon as teeth appear, around the age of six months, they ought to be brushed regularly with a smear of fluoride toothpaste. It is really important to avoid non-milk extrinsic sugars - include adding sugar to bottles of milk and prolonged night time feeding. From the age of one year, it is good to progress to using a trainer cup; however children with learning disabilities may take longer to do so. Once children are old enough to begin brushing teeth themselves, parents should continue to supervise brushing until the child is able to undertake thorough cleaning themselves and a 'pea-sized' amount of toothpaste should be used. It is very important to clean teeth last thing at night and at one other time during the day with family-strength fluoride toothpaste (1450-1500ppm fluoride) and to spit out excess toothpaste without rinsing away the fluoride toothpaste. Many people are not aware that rinsing with lots of water after tooth-brushing dilutes the effect of fluoride in toothpaste and is not advised.

Where clients are cared for in institutions it is very important that there is an oral health assessment incorporated into their general assessment on entry to a care home to inform their daily regimen or 'care plan'. Standards for daily oral hygiene should be agreed and care givers trained in the provision of daily oral care (Fiske et al., 2000, BSDH et al., 2001). This will involve cleaning teeth and/or dentures effectively.

		Children 0-3 years
Dental caries	Diet	Breast feeding provides the best nutrition for babies From six months of age infants should be introduced to drinking from a cup and from age on year feeding from a bottle should be discouraged Sugar should not be added to weaning foods
	Fluoride	Use only a smear of fluoride toothpaste containing at least 1,000ppm fluoride
	Tooth brushing	As soon as teeth erupt in the mouth brush them twice daily Parents should brush or supervise brushing
	Medicines	Sugar-free medicines should be recommended

		Children over 3 years
Dental caries	Diet	Sugars should not be consumed more than four times per day Sugary food and drink should be reduced and when consumed, when limited to mealtimes
	Fluoride	Use a pea-sized amount of toothpaste containing 1,3500-1,500 ppm If over 7 years of age, and giving concern, use a fluoride mouth-rinse daily (0.05%NaF) at a different time to brushing
	Tooth brushing	Brush last thing at night and on one other occasion Brushing should be supervised by an adult Spit out after brushing and do not rinse
	Medication	Ensure medication is sugar-free
	Dietary supplements	Any supplements containing sugar and glucose polymers at mealtimes when possible unless clinically directed otherwise) and not last thing at night.
		Adults
Dental caries	Diet	Sugars should not be consumed more than four times per day Sugary food and drink should be reduced and when consumed, when limited to mealtimes
	Fluoride	Use a toothpaste containing at least 1,3500ppm fluoride If giving concern, use a fluoride mouth-rinse daily (0.05%NaF) at a different time to brushing
	Tooth brushing	Brush twice daily Brush last thing at night and on one other occasion Brushing should be supervised by an adult Spit out after brushing and do not rinse
Periodontal (gum) diseases	Tooth brushing	Brush teeth systematically with either a manual brush with a small head and round end filaments, a compact angled arrangement of long and short filaments and a comfortable handle OR A powered toothbrush with an oscillating/rotating head Clean interdentally using inter-dental brushes or floss
	Tobacco	Do not smoke
Oral (mouth) cancer	Tobacco	Do not smoke
	Alcohol	Limit alcohol to moderate levels (if drunk)
	Diet	Maintain balanced healthy diet with at least five portions of fruit or vegetables per day

Source: Delivering Better Oral Health (Dept of Health & BASCD, 2009)

Table 2. Prevention of oral disease for those at high risk of developing oral disease

3.2 Professional care through dental services

In looking at professional dental care it is important to understand that within the UK there has been a significant shift in the provision of social care for people with learning disabilities and this has had implications for oral healthcare. Tiller et al (2001) outline how adults with learning disabilities were largely cared for in residential establishments until the 1980's when a process of 'normalisation' resulted in adults with a learning disability moving from residential homes to live in the community over the subsequent decade or two. Many moved to live in residential homes in the community, supported by carers. Tiller et al (2001) undertook a study to compare the oral health of adults remaining in residential homes with those still living in the community. It provided dramatic insight to the fact that adults living in the community in the Sheffield area of the North of England were particularly disadvantaged. Despite the fact that people living in residential care were significantly older than those based in the community, both groups had similar levels of caries experience; however, adults living in the community had significantly more untreated decay and poorer oral hygiene than their counterparts in residential care. In contrast, adults in residential care had significantly more missing teeth. Stanfield in another study across settings demonstrated that compared with institutionalised people with learning disabilities, attendance patterns were less regular for residents in the community; furthermore, individuals in the community were also less likely to receive operative dental treatment (Stanfield et al., 2003). There is evidence from south east London that amongst adults with learning disabilities the prevalence of plaque, calculus and gingivitis were high, however those living in with their families had less untreated disease (Naidu et al., 2006). A study conducted about the same time involving structured interviews of 257 learning disabled adults and/or carers in Lambeth, Southwark & Lewisham (Pratelli and Gelbier, 2000). The majority (63%) reported no difficulty in obtaining dental care for people with learning disabilities, with general dental services (40%), community (36%) and hospital services (15%) being the main providers. Subjects with a history of difficulty in obtaining an appointment were more likely to perceive an unmet treatment need and have a greater professionally defined need for treatment at time of interview than their counterparts. This was also for case for those with higher levels of disability or requiring assistance with cleaning. Almost half of subjects perceived a need for care, only 30% of whom had obtained a dental appointment. Support systems to facilitate access to dental care, identified for and by this client group, were advocated including good information systems across health and social care (Pratelli and Gelbier, 2000).

It is salutary to note that a review of access to healthcare across the lifespan of people with learning disabilities (Alborz et al., 2004) highlighted the dearth of research on access to dental care and that the published material at that time, which only related to first line services, did not include access to specialist care. In a review of the five studies available Alborz et al (2004) also reported that adults with learning disabilities living in informal family settings in the community were found to have higher levels of tooth decay than those living in more formal residential settings. They were reported as less likely to see a dentist regularly, or to have no dentist, and only seek care when experiencing pain.

All of the above research raises two key questions. First, how often should people attend for dental care; and, second, where should they seek care? Guidance, from the National Institute for Clinical Excellence on dental recalls recommends that children should attend a

dentist for a check-up at least once a year and that the equivalent period for adults is at least once every two years (NICE, 2004). The recommendation is based on assessment of an individual's risk of developing further disease and should ideally be discussed, and agreed, by the patient and health professional. It is recognised the some people with learning disabilities may be at higher 'risk' of oral disease and may therefore need to be seen more frequently by the dental team. Exactly, 'where patients with a learning disability may most appropriately seek care' will vary depending on a number of factors including their oral health needs and the complexity of their condition as outlined in the following sections.

3.2.1 Primary dental care

Within the UK, the majority of dental care is provided by general dental practitioners in their 'dental practice' or 'office'. This is the case for dental care in general and for people with learning disabilities. Primary dental care practitioner's act as the 'gatekeeper' to specialist services, which are only used when required. Historically a much smaller salaried dental service, known as the 'community dental service' played an important role in providing primary dental care for hard to reach groups such as people with learning disabilities. As outlined in Sections 3.2.2 and 4, much of this service is becoming more specialised with the emergency of a new specialty of 'Special Care Dentistry'.

The policy documents on learning disabilities (Department of Health, 2001; 2007) advocate 'choice' and 'inclusion'; however, this may require further work on the part of clinicians in line with principles for holistic care and ensuring patient empowerment (Owens et al., 2010).

Contemporary evidence-based oral health care, where-ever it is received, involves much more than just treating disease. There are many interventions for children and adults who give cause for concern and are at higher risk of developing oral disease. Following an in-depth case history and examination, this includes:

- Regular application of a small amount of fluoride varnish to susceptible tooth surfaces
- Prescription of high fluoride toothpaste, fluoride supplements or fluoride mouthwash
- Providing fissure sealants on newly erupted teeth to reduce the risk of tooth decay
- Ensuring timely and appropriate advice and support on diet and other health behaviours such as tooth-brushing.

(Department of Health and British Association for the Study of Community Dentistry, 2009)

Much of the above preventive care can be effectively provided by other members of the dental team such as dental therapists and dental hygienists on prescription from a dentist. There is evidence that dental hygienists could make a greater contribution to the care of people with a disability (Christensen et al., 2005). Carers play such an important role in healthcare and require regular support from the dental team. Valuing people's oral health recognises that 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 (Department of Health, 2007). It is therefore important for carers to ensure that they receive the appropriate information and guidance to help support and maintain oral health (Dougall and Fiske, 2008d).

Several reviews and policy documents have identified issues relating to physical access to dental care, issues relating to clinicians' understanding of people with a disability and how

care is delivered and the information needs of patients and carers (BSDH et al., 2001, Gallagher and Fiske, 2007, Department of Health, 2007). One of the challenges for dental practitioners in providing dental care for people with disabilities relates to the physical setting. Many dental practices were established in buildings which are not ideal in relation to the disability legislation outlined in Section 2.2 and they may not have appropriate car parking facilities (Baird et al., 2008). Whilst some modifications can be made, it is important for carers to find the practices in an area which are easily physically accessible. This is where local planners and policymakers, together with professional leaders, can ensure that there is good local information on the availability of dental services and how best they may be accessed.

Although general dentists are the main providers of dental care, not all care can, or should, be provided by general dentists or even in a primary care setting. Patients and carers may also need to negotiate their way through to specialist services, and possibility hospital specialist services either as a one-off process, because of a particular need or condition, or on an ongoing basis if their needs and/or management are complex.

3.2.2 Specialist care

In the UK, patients do not normally have direct access to specialist services and primary dental care practitioners refer those patients who are beyond their skill and competence to manage. There are now 13 dental specialties including Paediatric Dentistry and Special Care Dentistry (see Section 4 below). Paediatric Dentistry is concerned with the care of children who require specialist care and this includes children with learning difficulties. Special Care Dentistry (SCD) is concerned with the improvement in 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, 2003). The focus on providing care for adults and ideally often take over the care of teenagers with a learning disability from their paediatric colleagues, particularly when patients require additional skill and expertise which is beyond the competence of a general dental practitioner.

Management of people with disabilities may range from simple care in a complex patient through to complex care in patients who do not find it a challenge to receive care. Specialists are able to manage the medical, legal, social and clinical health issues that arise in patient care. They also have access to a range of facilities and agencies to support care. Special Care Dentistry is often provided across community and hospital settings so that care may be provided in the location most appropriate for the patient. For example if general anaesthetic is required this must be done in hospital, whereas the use of sedation as well as local anaesthetic for clinical care may be provided in a community setting, providing it is equipped and staffed to do so. Careful assessment and treatment planning are crucial for patients. A cross-sectional study of 210 children, with varying degrees of disability and attending special schools in three inner London boroughs, provides insight to treatment planning and patient management. It revealed that 67% required treatment and amongst the 52% of children who required a combination of treatment procedures, 64% could be treated in a primary care setting without sedation and the remaining 36% would require sedation (27%), or a general anaesthetic (9%), because of inability to comply with care (Taylor et al., 2001).

In addition to the above, oral healthcare may be delivered to people with learning disabilities on a domiciliary basis, i.e. carried out in an environment where a patient is resident, either permanently or temporarily, because of frailty, dementia, or disorientation (BSDOH, 2009). It may be provided in an individual's home, a care home or community house or in a day centre or hospital. The type of care that may be provided on this basis and in these settings is often more limited than can be provided in a normal dental surgery; however, with medical advances increasingly sophisticated care is possible. The British Society for Disability and (oral) Health (2009) provide publically accessible guidelines on the provision of domiciliary care. Another option is to provide dental care in a mobile caravan, which is fully equipped as a dental surgery and this provides the opportunity to treat groups of individuals at a school, day centre or residential home and reduces barriers to care.

3.2.3 Integrated Care pathways

Access may be defined as the 'fit between clients and services' (Penchansky and Thomas, 1981). There are five key areas for practical action to facilitate access and reduce barriers to care outlined in Table 3. It is important that people with a disability are facilitated to access oral healthcare and therefore greater work is required by planners and providers to make services more accessible to patients, thus 'improving the fit'. Bringing services to patients in a mobile or domiciliary service outlined above are good examples of practical action to improve availability and accessibility of services; however, it is important that mainstream services are similarly accessible.

5As	Descriptor
Available	in a geographic area, both real and perceived (Where do dentists like to set up practices? Low availability may suppress demand)
Accessible	Location, eg transport/walking/parking, physical, e.g. disabled access
Acceptable	feel welcome, treated professionally, treated as an individual, language, waiting areas, quality of care appropriate (posh/shabby)
Affordable	costs of care (direct) and cost of attending (indirect), information on costs/ understanding of costs
Accommodating	opening hours: evenings, weekends, drop-in service vs appointments

Adapted from Penchansky & Thomas, 1981

Table 3. Access: 5 As

In addition to the above practical issues, psychosocial barriers to care must also be recognised as fear is a general barrier to dental care (Finch et al., 1988, Kelly et al., 2000), and thus anxiety management must be part of care provision. Adjuncts to behavioural management include sedation and general anaesthetic for anxious or restless patients (Boyle et al., 2000, Manley et al., 2008, Department of Health and Faculty of GDPUK, 2008, Glassman et al., 2009).

As already intimated, carers have an important role in initiating dental treatment whether routine or emergency. It may not always be clear that an individual client has a dental problem but it should be one of the considerations when someone is out of sorts and there is no obvious cause, particularly in clients who have difficulty in expressing their needs. Carers need to have easily accessible information on the range of local services and how they may be accessed (Frenkel, 1999).

Increasingly there needs to be clear pathways to care which are easily understood and widely available to inform access to dental care. Care should also be seamless across the years, where possible (Dougall and Fiske, 2008f, Lewis et al., 2008b, Lewis et al., 2008a, Dougall and Fiske, 2008g). Care pathways should build on the principles outlined in 'Valuing Peoples Oral Health', outlined in Section 2.2, whereby primary dental care practitioners provide the majority of dental care, mainly in their dental surgery but they may also undertake domiciliary care in people's own homes or in residential institutions. Some interested dental practitioners are now commissioned to provide dental care in this way and they may well, over time, become Dentists with a Special Interest in Special Care Dentistry in future (Department of Health et al., 2009). All institutions which have the care of people with learning disabilities whether care homes or homes within the community should have access to both emergency and routine dental care for their clients. Furthermore, it may be appropriate to have regular screening sessions or dental checkups on site.
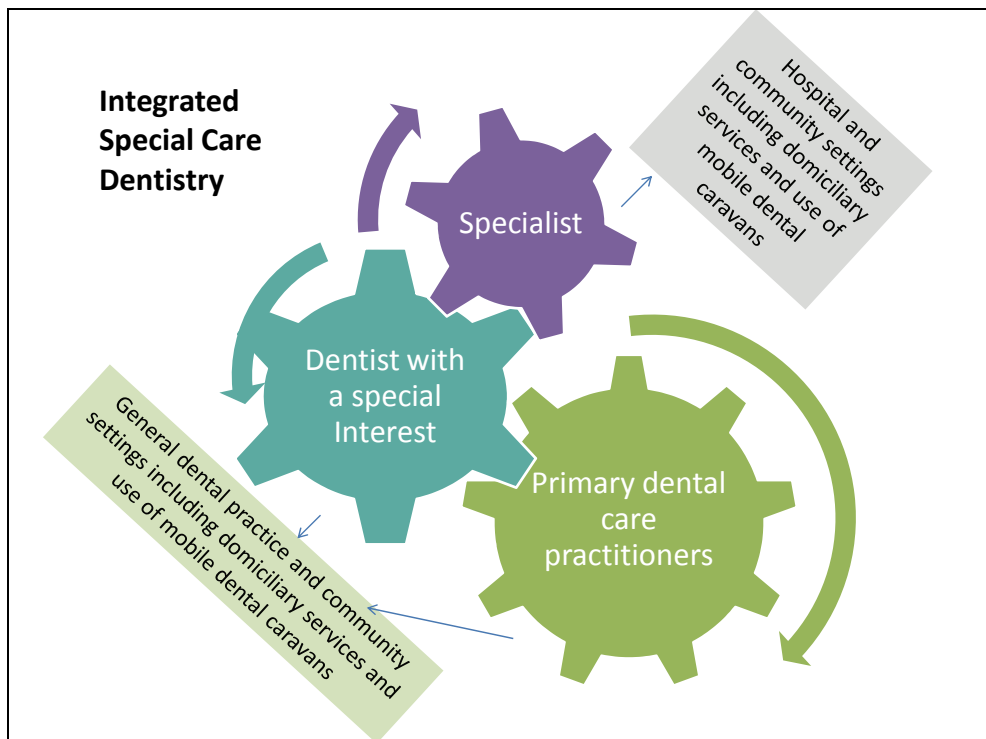

Fig. 1. Integrated network of care

3.2.4 Monitoring care for people with special needs

One of the challenges for a service providing care for people with impairment or disability is the time that is required to plan, organise and deliver care for patients. In a health care system where there is increasing emphasis on 'value for money' and understanding the cost of care, if is necessary to be able to explain the time and costs involved in patient management to commissioners of care. Therefore, a case mix toolkit has been developed and piloted by Sheffield working with a number of other dental services in England and Wales (British Dental Association, 2008). It provides a tool for measuring the level of impairment and disability, of patients in conjunction with the volume of service activity. This should provide meaningful activity data for commissioners about the patient base and reflect the additional time, and resources, required to provide care for many patients with special needs. The toolkit measures:

- Ability to communicate
- Ability to co-operate
- Medical status
- Oral risk factors
- Access to oral care
- Legal and ethical barriers to care.

Together with recommended 'weightings' these provide an overall patient 'complexity score'. This does not include any score for the complexity of the dental care, but rather time and patient management which should therefore explain the time involve and thus the cost of their management.

3.3 Oral health promotion

Promoting oral health includes, but goes beyond, health education for individual patients and their parents/guardians/carers. The Ottawa Charter principles for Oral Health Promotion (World Health Organization, 1986) are fundamental pillars in underpinning oral health promotion. They emphasise the importance of a population approach to health rather than just an individual approach which includes:

1. building healthy public policy
2. creating supportive environments
3. strengthening community action
4. developing personal skills and
5. re-orientating health services

(WHO, 1986)

We have seen greater emphasis on the care of vulnerable groups influencing health policy and action over the past decade, which includes the creation of the new specialty and the beginnings of a reorientation of health services towards prevention. However, action needs to occur on all of the above levels. For example, the environment in residential homes and community homes should be health enhancing with a low sugar diet and policies which promote regular effective oral hygiene. It is important to work with community groups and develop the personal skills of people with learning disabilities and their parents/guardians/carers. Furthermore, oral diseases share common risk factors with many

leading chronic diseases which are the major cause of death in high income countries: cardiovascular diseases, cancer, chronic respiratory diseases and diabetes. The risk factors include unhealthy diet, tobacco, and alcohol. Poor oral hygiene is also a risk factor. This highlights the importance of working on these common risk factors in support of health in general.

4. Special Care Dentistry - how UK addressed this professional challenge

4.1 A Needs-led specialty

Within the past decade in the UK, the dental specialty of 'Special Care Dentistry' came into being. It is an interesting example of a public health approach to planning and implementation of a new specialty. In the early decades of the UK National health Service, i.e. from 1948 onwards, dental surgeons and then oral surgeons, provided extraction services for people with a disability in hospitals. From the 1980's onwards interested dentists in the community and salaried dental services, began to provide care for people with learning disabilities in community clinics as health policy expanded their remit beyond merely treating children.

A Working Group for Special Care Dentistry was established by the Dean of the Faculty of Dental Surgery in one of the Royal Colleges to explore the need for a specialty of Special Care Dentistry in the UK and reported in 1999. They wrestled with both the arguments for creation of a specialty and with the process for achieving change. The need to formalise the care for more vulnerable sections of society that had traditionally been provided by a relatively small number of socially committed dentists was overwhelming. Furthermore, there was clear evidence that services for disabled children within the UK were much better than those for adults and that that the transition to adult care was a particular challenge for healthcare in general (JACSCD, 2003). Children with more extreme disabilities tended to have been managed by paediatric consultants and thus got into difficulties when they had to move to routine services as they reached 16 or 18 years of age and were no longer under the remit of paediatric services. The process of achieving change involved the establishment of a 'Joint Advisory Committee for Special Care Dentistry' in 2000 to build a case, lobby for change, and commence formal training for a new specialty. The case of need for the specialty was used to influence key players such as the Department of Health and the General Dental Council (JACSCD, 2003, Gallagher and Fiske, 2007); it examined the demography of the patient base, oral health inequalities, inequalities in access and models of good practice including how the specialty would work with primary care practitioners in providing care for the spectrum of disabilities. Existing models of good practice reveal that established clinicians working in this field have a patient base of between 850 and 1,500 patients per year and work across primary care and hospital settings, liaising with colleagues in health, social services and the voluntary sector to ensure integrated health care planning. The arguments outlined in a paper in the British Dental Journal focused on it being a professional challenge to ensure better access, outcomes and oral health of individuals and groups who have a physical, sensory, intellectual, medical, emotional or social impairment or disability (Gallagher and Fiske, 2007). On this basis, a conservative estimate of 133 specialists was suggested for the future, working in networks with Dentists with a Special Interest in Special Care Dentistry and primary dental care practitioners.

The new specialty was approved by the General Dental Council in 2007 and the specialist list opened in 2008 (General Dental Council, 2008). Initially dentists with relevant expertise were 'grand-parented' onto the specialist list on the basis of their competence.

Impairment and disability were defined in the broadest of terms, thus Special Care Dentistry is concerned with providing and enabling the delivery of oral care for a diverse client-group with a range of disabilities and complex additional needs and includes people living at home, in long stay residential care and secure units, as well as homeless people. Interestingly, in parallel with the creation of the specialty there has been significant emphasis nationally on meeting the needs of *vulnerable* groups such as people with a disability.

4.2 A growing specialty

In only a few years, Special Care Dentistry has grown to be the seventh largest specialty out of 13 in the United Kingdom, It has achieved this success by recognising the knowledge, skills, and experience of dentists working in the field and accrediting their specialist status. As of December 2010 there were 226 specialists on the dental register (Figure 2) and a number of junior dentists in training to become future specialists(General Dental Council, 2010).
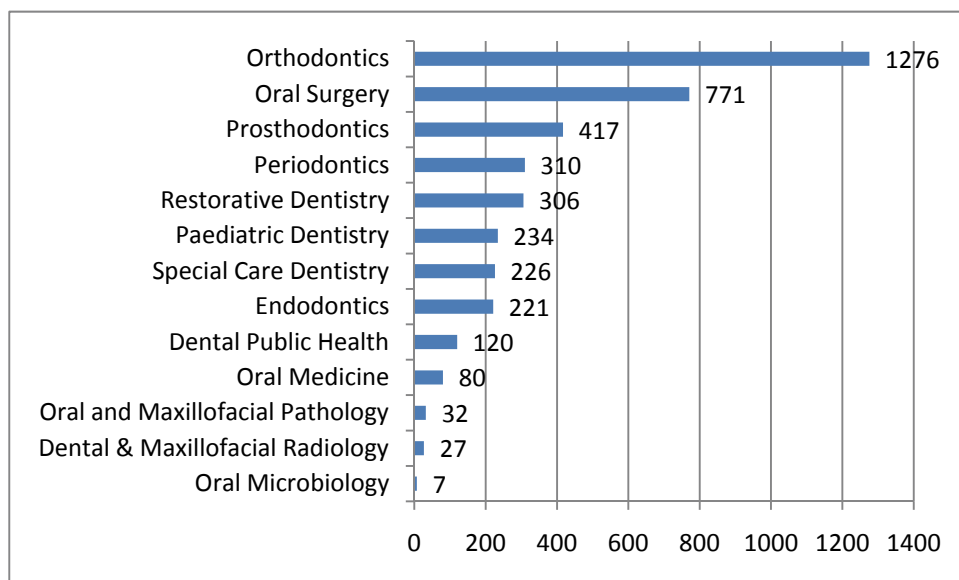
Source: General Dental Council (2010)

Fig. 2. Number of Dental Specialists Registered with the UK General Dental Council, December 2010

A growing body of knowledge on the management and care of patients across their life course is emerging through the specialty of Special Care Dentistry. The specialty association 'The British Society for Disability and Oral Health', has developed a series of relevant

guidelines for the care and management of people with a disability (http://www.bsdh.org.uk/guidelines.html). Furthermore, through the journal of the association the 'Journal of Disability and Oral health' and helpful publications such as in the British Dental Journal in 2008 (Dougall and Fiske, 2008d, Dougall and Fiske, 2008f, Dougall and Fiske, 2008e, Dougall and Fiske, 2008a, Dougall and Fiske, 2008g, Dougall and Fiske, 2008c, Dougall and Fiske, 2008b, Lewis et al., 2008b, Lewis et al., 2008a), they provide a really helpful basis for practical care of people with learning disabilities. The underlying ethos has a number of key themes and is worth reiterating. First, that people providing care share common values, a commitment to adhere to accepted clinical and professional standards and above all operate within the best interests of the service user. Second, that all individuals have a right to autonomy as far as possible in relation to decisions made about them. Third, good oral health has positive benefits for health, dignity and self-esteem, social integration and general nutrition as the impact of poor oral health can be profound.

4.3 Future challenges

Whilst it is recognised that the advances in Special Care Dentistry are significant, there is much action required to promote oral health of people with learning disabilities, build capacity of the dental team and ensure that there is access to high quality evidence-baed care provided in a timely manner as outlined below.

4.3.1 Research

Dental and oral research amongst people with learning disabilities is much needed to improve our evidence base in promoting oral health and the delivery of patient care, but it is sadly lacking. There is little published evaluation of actions to improve service delivery, patient satisfaction and outcomes. Lack of funding for dental research is a general problem and the challenges of undertaking research, particularly amongst adults because of the challenge of obtaining informed consent. The Mental Capacity Act (UK Parliament, 2005) and subsequent guidance (Department of Health, 2008), provide the opportunity for consultees to be identified for research involving adults who lack the capacity to consent; this can either be a 'personal consultee' or a 'nominated consultee'. Local informants will be identified via local organisations. They will be chosen to reflect the diversity of the local disabled population in relation to sex, cultural and ethnic diversity, age and social status. The consultee may act in place of the person alongside a person with a learning disability or as a substitute. This approach requires high level ethics committee scrutiny and research governance approval and is likely to further add to the time, cost and complexity of the research process. Nevertheless it is very important in supporting people with a learning disability that high quality research is undertaken.

4.3.2 Monitoring oral health

There is clear need for methods of assessing the levels of need in this section of the population whether through dental and epidemiological surveys, dental information systems in practices or other means. As dental practice management software becomes more adept at capturing epidemiological data, clinicians should become adept in recording these data during clinical consultations, thus possibly avoiding the need to invest in specific surveys and providing ongoing monitoring data on oral health (Gallagher, 2005).

4.3.3 Networks of care

Gallagher and Fiske (2007) highlighted the importance of developing networks of care to ensure that primary dental care practitioners are supported in their provision of routine care and have access to specialist support and advice as required for their patients. These networks must actively be developed to ensure that dental care for people with a disability does not just become the preserve of specialists. There is not sufficient workforce capacity for this to be undertaken. Whereas there had been substantive progress to building specialists in special care dentistry and train future consultants, and some progress towards building the skills of generalists in the care of special care patients, there has been little action on creating Dentists with a Special Interest in Special Care Dentistry (Department of Health et al., 2009); this is an important step to be considered in reshaping dental services into care pathways.

4.3.4 Information for the public

One area where there has been little action is on information for the public at local level with a few notable exceptions. BSDOH has information for the public on its website (http://www.bsdh.org.uk/public_information.html) which includes a very helpful patient booklet (Manchester PCT, 2011). Further work is required to provide information to the public, health and social care professionals on pathways of care at local level. Information should be provided in places and in media that will reach the local community. (NHS West Midlands, 2008).

4.3.5 Education and training

Education of the dental team to provide mainstream care for people with learning disabilities is much needed. Greater training within the undergraduate or basic curriculum would build capacity within the breadth of services to manage the routine dental care of people with a disability with confidence, only referring on necessary patients to those with specialist or other expertise. The nature and scope of dentists training in the management of patients with learning disabilities may vary depending on when, and where, their qualified. Increasingly it should be part of the undergraduate curriculum and the curricula of other members of the dental team and postgraduate education for qualified dental professionals. As the new specialists in this field contribute to the teaching and training of undergraduates, postgraduates and the wider dental team, this will enable more care to be mainstreamed over time, in line with the strategy and policy recommendations for people with disability (Gallagher and Fiske, 2007, Department of Health, 2007). Many undergraduate programmes are exploring how they provide education and training in special care dentistry for dental students and the wider dental team such as dental nurses, therapists and hygienists.

4.3.6 Finance

It is important that the financial system for remuneration of dental care supports the provision of care for people with minor and moderate disabilities in primary dental care, recognising that they may require more time than the average patient. There is no point in building skills and expertise within the dental team if they are not used and inequalities in

the oral health of people with learning disabilities are not actively addressed. This will most probably require the support of information systems to patient complexity and the time involved in care provision. Improving oral health treatment services may have significant financial implications, thus it is important that there is a strong emphasis on prevention throughout life, with a view to reducing the need for hospital admissions and expensive care under general anaesthetic.

5. Conclusion

Oral health is fundamental to wellbeing and this is particularly the case for people with learning disabilities for whom dental treatment may prove challenging. Good oral health begins from birth with a healthy diet, good mouth hygiene and access to fluoride products which strengthen teeth against decay. It may require the active support of parents and carers in assisting with tooth brushing. Regular dental checkups, at least once per year, are advised to monitor oral health and identify disease at an early stage when it may more easily be treated. There should be access to dental services with specialised support for those with more profound learning disabilities of for whom dental care presents a challenge. In the UK the specialty of special care dentistry provides such care normally on referral from dental practitioners. It is important that dedicated oral health services are established to serve the needs of patients with disabilities or conditions which mean that they require 'special care'.

6. Acknowledgments

This chapter has arisen out of work with UK dental professionals, policy makers, researchers, clinicians and most importantly people with a disability. It is hoped that this chapter will inform the future of oral health care for many who experience disabilities and they will benefit from good oral health.

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Learning Disabilities

Edited by Dr. Wichian Sittiprapaporn

Learning disability is a classification that includes several disorders in which a person has difficulty learning in a typical manner. Depending on the type and severity of the disability, interventions may be used to help the individual learn strategies that will foster future success. Some interventions can be quite simplistic, while others are intricate and complex. This book deserves a wide audience; it will be beneficial not only for teachers and parents struggling with attachment or behavior issues, but it will also benefit health care professionals and therapists working directly with special needs such as sensory integration dysfunction.

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