A Case of Need

Proposal for a Specialty in Special Care Dentistry

A Joint Advisory Committee for Special Care Dentistry Document

October 2003

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Forward by the Chairperson

Joint Advisory Committee for Special Care Dentistry

Dr Janice Fiske

Dear Colleague,

The issue of raising standards of care for people requiring special dental care has been strongly debated within the profession in recent years. In response to this debate the Royal College of Surgeons (England) established the Joint Advisory Committee for Special Care Dentistry (JACSCD) to consider the development of training programmes, curricula and standards, and the assessment process required for Special Care Dentistry in the future.

The Committee considers that the appropriate way forward is through the development of a new Specialty in Special care Dentistry. It has worked towards establishing the case for need for such a Specialty and developing a training curriculum for new Specialists.

We are now at the stage where we are disseminating these documents for your information.

The timing of this publication is particularly appropriate in view of the commissioning of a Review of Dentally Based Specialties under the direction of the Standing Dental Advisory Committee (SDAC), which is due to report in November 2003, and the Chief Dental Officer's Review of Salaried Primary Care Services, which reports early in 2004.

The committee would very much value your support and would welcome your comments on the subject. Please send them to the address below.

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Executive Summary

Purpose:

This document outlines the case of need for a Specialty of Special Care Dentistry in line with the requirements of the Department of Health for new medical specialties (2002). It is based on a review of demographic trends and the literature on oral health needs. Furthermore, it includes examples of good practice and identifies the challenges faced by people providing care for individuals with additional complex needs. It seeks to quantify the level of need for this Specialty and outline its specific roles and future challenges, including the creation of a Specialist list to be held by the General Dental Council (GDC) and subsequent training programmes within the National Health Service (NHS). The paper argues that a Specialty of Special Care Dentistry is required to meet public need across primary care and hospital settings. It outlines how this need would appear to be increasing, rather than decreasing and that the need will be for a service rooted in the National Health Service.

Definition:

Special Care Dentistry is concerned with providing and enabling the delivery of oral care for people with an impairment or disability, where this terminology is defined in the broadest of terms. Thus, Special Care Dentistry is concerned with the improvement of oral health of individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of a number of these factors. This Specialty is defined by 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.

Current health and social policy:

Current health and social policy is focussed on the reduction of health inequalities. The recent Department of Health document "Tackling Health Inequalities: A Programme for Action" sets out plans to tackle health inequalities over the next three years in order to see changes in the next ten years. It recognises that this will not be easy, but that inequalities in health are widening and will continue to do so unless things are done differently through better co-ordinated activity that cross traditional boundaries so that agencies work in partnership. It particularly refers to improving the quality of life, access to services and addressing health care needs for older people, people with mental illness, people with learning disability, and asylum seekers and refugees. The ethos of Special Care Dentistry echoes this philosophy. The development of a Specialty in Special Care Dentistry (based on evidence of service need) would provide a better balance between need and provision and between prevention and treatment, which is exactly what the Government is working towards in "Tackling Health Inequalities".

Inequalities in Oral Health:

People with disabilities and complex additional needs should have equal access to oral health care services and equitable oral health outcomes in terms of self-esteem, appearance, social interaction, function, and comfort. This document illustrates that this is

not the case. Indeed, whilst people with disability and complex additional needs (particularly those with learning disability or mental health problems) have similar patterns of oral disease they have poorer oral health and poorer health outcomes from care than the general population. Furthermore, when oral diseases are treated they are more likely to result in extractions than fillings, crowns and bridges. The British Society for Disability and Oral Health has produced guidelines for oral health care and the development of integrated oral health care pathways to encourage the move towards equitable access, care and outcomes. A recognised Specialty and training pathway would promote Specialist training in Special Care Dentistry, establish a skilled workforce, provide people with disability with access to appropriate services (including Specialist care), and provide General Dental Practitioners with appropriate support.

Demography of Disability:

It is difficult to accurately quantify the volume of people who fall within the stated scope of Special Care Dentistry. As many as one in four adults in the UK has experienced, or will experience, a disability during their life time Many of these disabilities are minor or moderate and these people should, and possibly do, receive care in mainstream services, supported by Specialist backup if required. Looking only at the complex end of the spectrum of disability to inform service planning for Special Care Dentistry, within the UK there are in the order of 175,000 adults with severe learning disability alone. There is also a substantial group of adults with complex medical conditions and almost 9.5 million people (18.2% of the population) self-report say that they have a long-term illness, health problem or disability which limits there daily activities or work. If only some of the people with the wide range of other disabilities and complex medical conditions served by this Specialty are added, then the volume of adults would easily exceed 200,000 people. The majority of this group would require ongoing total care by Specialists or shared care with colleagues in other Specialties or the primary care setting. As many disabilities can impact on oral health, which in turn can impact on general health and quality of life, it is essential that oral health care becomes an integrated part of health care planning for people with disability.

Meeting the Inequalities in Accessing Oral Care:

Current *ad hoc* arrangements for people requiring Special Care Dentistry are anecdotally reported as being insufficient. The document uses real cases to illustrate this situation. It explores some of the reasons why existing Specialties are unable to meet this need and provides examples of models of good practice within Special Care Dentistry that can be built on through the development of a Specialty in Special Care Dentistry to start to address the shortfalls. The document attempts to calculate the number of Specialists required to meet the needs of those adults at the more severe end of the spectrum of disability. It recommends that, based on a *'best fit calculation'*, 100 to 200 Specialists are required. This workforce should be supported by 10 to 20 recognised Specialist training places in the first instance, followed by five training posts a year to maintain the workforce numbers.

Proposals for rectifying the situation:

The Joint Advisory Committee in Special Care Dentistry makes the following recommendations as a result of the information set out in this document:

1. ***Mechanisms should be put in place forthwith to recognise the Specialty of Special Care Dentistry*** within the NHS, Royal Colleges and to create a Specialist Register at the GDC. The latter move will enable existing dentists with the requisite skills and experience to be mediated into the Specialty.
2. ***JASCD should become a Specialist Advisory Committee for Higher Training in Special Care Dentistry*** to oversee training to provide quality care in line with health policy to meet identified health needs.
3. ***There should initially be 10-20 training posts in the Specialty*** with a minimum of one per Strategic Health Authority.
4. ***The model of care of a Specialist in Special Care Dentistry who is involved in treatment planning, and then either providing care (predominantly in the community) or being involved in shared care with other Specialists, Specialist Practitioners or interested Generalists is the way forward to ensure quality care for people with severe disabilities.***

Membership of the Joint Advisory Committee for Special Care Dentistry (JACSCD)

JACSCD was established (under the aegis of the RCS of England) as a free-standing committee, to promote and oversee the introduction of training programmes and the development of curricula, training standards and the assessment process. Its14 person membership reflects the stakeholders who have a legitimate interest in developing the postgraduate education and training of Special Care Dentistry through a Specialty framework and, in particular, clinicians already providing Special Care Dentistry.

The Committee currently comprises:

2 Members of the British Society for Disability and Oral Health

- Dr Sue Greening
- Professor June Nunn

1 Member of Academia in Special Care Dentistry

- Dr Janice Fiske (*Chairperson*)

1 NHS Consultant in Special Needs Dentistry

- Dr Roger Davies

1 Senior Clinician in Special Care Dentistry

- Dr Mark Taylor

1 Member of the former Faculty Development Group

- Dr Marcus Woof (*Vice chairperson*)

1 Restorative Dentist actively involved in Special Care Dentistry

- Dr Shelagh Thompson

1 Paediatric Dentist actively involved in Special Care Dentistry

- Mrs Vanita Brookes

1 Member of the Consultant in Dental Public Health Group of BASCD

- Dr Carol Mander

1 Member of the Specialist Advisory Committee (SAC) in Restorative Dentistry

- Mr Paul King

1 Member of the Specialist Advisory Committee (SAC) in Paediatric Dentistry

- Dr Lindsay Hunter

1 Member of the Committee of Postgraduate Dental Deans

- Mr David Thomas

1 Representative of the Board of the Faculty of Dental Surgery of the Royal College of Surgeons of England

- Dr Selina Master

1 Lay Member from the field of disability

- Mr Peter Holland of the Disability Partnership

Former members of the Committee are:

Representing the Consultant in Dental Public Health Group of BASCD

- Dr Jenny Gallagher

Representing the Committee of Postgraduate Dental Deans

- Mr Richard Juniper

Representing the Board of the Faculty of Dental Surgery of the Royal College of Surgeons of England

- Professor Bernard Smith

The Case of Need for Special Care Dentistry

1.0 Introduction

This paper outlines the case of need for a Specialty of Special Care Dentistry in line with the requirements of the Department of Health for new medical specialties (Department of Health, 2001). It is based on a review of demographic trends and the literature on oral health needs. Furthermore, it includes examples of good practice and identifies the challenges faced by people providing care for individuals with additional complex needs. It seeks to quantify the level of need for this Specialty and outline its specific roles and future challenges, including the creation of a specialist list to be held by the General Dental Council (GDC) and subsequent training programmes within the National Health Service (NHS).

Specialties in medicine and dentistry may be defined by an anatomical region, patient group, disease or condition. The NHS dictionary of terms and standards suggests the following definition of Specialties, with the rider that only titles recognised by the Royal Colleges and Faculties should be used:

> "Specialties are divisions of clinical work which may be defined by body systems (dermatology), age (paediatrics), clinical technology (nuclear medicine), clinical function (rheumatology), group of diseases (oncology) or combination of these factors."
>
> (NHS Information Authority, 2002).

2.0 Special Care Dentistry

2.1 Definition

Special Care Dentistry is concerned with providing and enabling the delivery of oral care for people with an impairment or disability, where this terminology is defined in the broadest of terms. Thus, Special Care Dentistry is concerned with:

> 'The improvement of oral health of individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of a number of these factors'
>
> (Joint Advisory Committee for Special Care Dentistry, 2002a).

2.2 Scope of the Specialty

This Specialty is defined by a diverse client-group with a range of disabilities and complex additional needs. For convenience sake, the term disability will be used throughout the text to refer to all people falling within the remit of the definition of Special Care Dentistry set out in paragraph 2.1. Clearly, not every individual captured by this definition requires specialist care and this issue is addressed within the document.

The ethos of Special Care Dentistry is its broad-based philosophy of provision of care. It achieves the greatest benefit for patients by taking a holistic view of oral health, and liaising and working with all those members of an individual's care team (be they dental, medical or social) to achieve the most appropriate care plan and treatment for that person through integrated care pathways. As a Specialty it would remain broad-based. It is the broad base, the complexity of the management of individuals with additional needs, and the knowledge, skills and expertise associated with Special Care Dentistry that set it apart from existing specialties.

Special Care Dentistry is proactive to the needs of people with disabilities rather than solely reactive. Recognising that some groups of people are unable to access oral health care unaided, to express a desire or need for oral health care or to make an informed decision about its benefits to them, Special Care Dentistry includes screening, preventive and treatment programmes tailored for and taken to specific groups.

The following factors unite these groups suggesting that there is a need for one Specialty to meet their range of needs:

⇒ A large proportion of people with complex additional needs have significant lifelong conditions (Disability Partnership, 2000b), therefore the majority of them will require regular ongoing dental care as well as one-off interventions.

⇒ Many of them will require liaison with a range of other professionals within health and social care and it is important that oral health is part of an integrated care pathway.

⇒ Patients from a range of these backgrounds have problems in receiving dental care through the mainstream services of the primary dental care sector due to a lack of access to specialist knowledge and skills.

2.3 The Focus of the Specialty

The focus is on adults requiring special care to meet their needs. It includes those people in the transition period from paediatric to adult services when it is so easy for them to be lost in the system without direct referral (Zoitopoulos, 1998). This recognises the important role that paediatric dentists play in providing care for children with special needs in both hospital and community settings, and the need for patients who require specialist adult care to be transferred seamlessly to another specialist service that will provide ongoing care throughout adolescence and adulthood. Within this broad case mix of patients it is likely that there will be some element of sub-specialisation providing the scope for lateral transition as outlined within the 'Developing Specialties in Medicine' (Department of Health, 2001a).

The Specialty seeks to address the oral health needs of people with a range of primary conditions which may result in their oral health being compromised directly through the condition itself or indirectly through medication or poor access to care. Furthermore, there may only be access to limited dental care with practitioners unwilling or unable to provide routine dental care because of the skills, experience, facilities or remuneration available to them (Fiske *et al*., 2002). The provision of care for this group of people is often more complex and time

consuming as a result of their disability. Additionally, for those with certain impairments (such as some learning disabilities and mental illness) the issues of informed consent present an extra challenge. A holistic approach is needed to meet the complex requirements of people in these situations. The quality mark of a specialist service with the creation of a specialist list will be important to secure resources and to provide care for people with complex dental needs. Specialists will also play an important role in supporting mainstream care for people with mild and moderate needs in planning preventive and treatment services. Furthermore, it recognises that there is a need for clinicians who demonstrate the knowledge and expertise to serve this complex patient group to be appropriately trained (See Figure 1) within the NHS and rewarded through the opportunity for career progression. Without a recognised, structured training programme leading to specialist appointments, recruitment and retention of dentists to Special Care Dentistry will be limited and the service will be jeopardised. This situation is already becoming apparent. Case Scenario 1 describes a real and recent event that demonstrates this point.

Figure 1. Knowledge and Skills Appropriate to Special Care Dentistry

i.	Biological sciences of relevance to Special Care Dentistry
ii.	Concepts of health, impairment and disability
iii.	Conditions leading to impairment and disability
iv.	Behavioural science
v.	Sociology of health, impairment and disability
vi.	Understanding the way that conditions leading to impairment and disability can impact on oral health and quality of life
vii.	Understanding the way that oral health can impact on impairment, disability general health and quality of life
viii.	Planning and management of service delivery
ix.	Management and delivery of oral health care
x.	Development of oral health care promotion programmes
xi.	Provision of appropriate dental treatment based on the development of skills for history taking, examination, diagnosis, treatment planning and delivery of clinical dentistry
xii.	The use of behavioural management, local analgesia, conscious sedation and general anaesthesia
xiii.	Provision of comprehensive operative dentistry
xiv.	Links with other Specialties
xv.	Inter-professional and inter-disciplinary working
xvi.	Life support skills and management of medical emergencies
xvii.	Legislation and ethics relevant to dental practise and, in particular, to Special Care Dentistry
xviii.	Clinical governance
xix.	Research and Development

Source: JACSCD, Training in Special Care Dentistry: 2003

Case Scenario 1

⇒ A Community Dental Service advertised a Senior Dental Officer (Special Care Dentistry) post

⇒ There were no enquiries and they were unable to recruit to the post

⇒ It was essential to the service that they recruit, so they decided to convert the job into a training post

⇒ Within a few days of the advertisement appearing, there were 8 enquiries

2.4 Reducing Inequalities

The Report of the Independent Inquiry into Inequalities in Health (Acheson, 1998) highlighted the need to reduce inequalities in the health of vulnerable groups. Although reducing inequalities requires action far beyond the scope of health services, it does include the need for health services to be re-orientated in the promotion of health (WHO, 1986) and draws on evidence that oral health services can improve quality of life for special groups (Locker, 2001). Acheson recommended that health and social services should be improved and that they should be provided on the basis of need. The volume of people within the community with disability and complex additional needs is significant (see section 4.0 of this document) and it is important that their oral health needs are addressed by the appropriate level of care.

The recent Department of Health document "Tackling Health Inequalities: A Programme for Action" (2003a) sets out plans to tackle health inequalities over the next three years. It states that "health inequalities are stubborn, persistent and difficult to change" and that "they are also widening and will continue to do so unless we do things differently". The Government recognises "the need to better co-ordinate activity across traditional boundaries and work in partnership". It particularly refers to improving the quality of life for older people through the National Service Framework, improving access to services for people with mental illness and addressing the health care needs of asylum seekers and refugees.

The ethos of Special Care Dentistry echoes the philosophy of this document. The development of a Specialty in Special Care Dentistry (based on evidence of service need) would provide a better balance between need and provision and between prevention and treatment which is exactly what the Government is working towards in "Tackling Health Inequalities".

2.5 Philosophy of Care

The health movement in developed countries fosters consumer choice and self-determination within contemporary health services (Secretary of State, 2000). After a period of de-institutionalisation for special groups, (Department of Health,

2001a) it is clear that health and health promotion should play a key role in maintaining independence and inclusion of people with disabilities.

Frey *et al.* (2001) suggest that central to this paradigm shift is the idea that individuals with disabilities may be at increased risk for a number of preventable health problems, commonly referred to as secondary conditions. There is a tension between the medical and social models of health, and these approaches are explored here in the light of UK health policy. The Disability Partnership (2000a: 2000b), which promotes the care and understanding of people with disabilities, highlights that:

> "It is too easy to become complicit in a system which delivers poor healthcare to people with learning disabilities who do not have the intellectual abilities or history to demand good healthcare."
>
> and states that:
>
> "it is not enough to assert social inclusion" as "people with learning disabilities have to be helped to achieve it".

Whatever the label, it is important that the environment minimises the impact of disability and promotes good oral health. It is recognised that some people with a disability may wish to access mainstream dental services, whereas others may wish to access dedicated services (Disability Partnership, 2000a; Pratelli and Gelbier, 2000). The Specialty would provide appropriate health care for those people unable to access the care of, or who were unsuitable to be cared for in, mainstream dental services. At the same time it would provide appropriate health care knowledge, advice and a support base for primary care sector dental teams. Morris and Burke (2001a; 2001b) describe the ideal interface between primary (generalist) and secondary (specialist) care under the headings of equity, seamless care, and efficiency and effectiveness (See Figure 2).

Figure 2. The Ideal Qualities of the Interface between Primary and Secondary Care

Equity	All appropriate cases are referred for specialist care
	No barriers to receiving specialist care once referred
Seamless Care	All required treatment is available and accessible in either primary (1^o) or secondary (2^o) care services
	Transition between 1^o and 2^o care is easily arranged
Efficiency & Effectiveness	
	All referrals are appropriate and timely, and 1^o care mechanisms for filtering are foolproof
	There is no inappropriate capture and retention of patients by 2^o services and patients are referred back to 1^o care once specialist care is complete

Source: Morris and Burke, 2001a.

Whilst this is the philosophy of care, they go on to explore the shortcomings of the current situation related to 1^o and 2^o dental services (Morris and Burke; 2001b) highlighting the inequities that exist. They recommend "the development of anything which improves access to 1^o and 2^o dental care" and in particular "the development of outreach services and NHS specialist care outside of consultant-led [hospital] units". In doing so, they acknowledge the barriers to these developments, one of which is the skills shortage.

2.6 Impact of Health and Social Policy

The Strategy for Learning Disability in the 21st Century (Department of Health, 2001a) reports the Government's commitment to raising standards and improving the quality of services for people with learning disabilities. It highlights the need for effective partnership working across agencies. Similar themes emerge in the National Service Framework for Older People (Department of Health, 2001b). The majority of both these groups live in their own home or a community setting with only the more vulnerable people living in residential care. It is recognised that there may be problems with transport and access to dental care (Health Select Committee, 2001; Department of Health, 2002b). Furthermore, older people will increasingly be living on their own in the community. Policy initiatives are beginning to recognise the need for better services for such groups (Department of Health, 2001a & 2001b; 2002; British Dental Association 2003; Tinker, 2003).

The Department of Health for England (2001a) made recommendations to address the objective of good health for people with learning disabilities (See Figure 3).

Figure 3. Recommendations for Good Health for People with Learning Disability

⇒ **Access to a tailored health service** designed around the individual's needs with fast and convenient care delivered to a consistently high standard and with access to additional support if/as necessary.

⇒ **The commission and provision of high quality services,** that are evidence-based and continuously improving, by all agencies in order to promote both good outcomes and best value.

⇒ **Appropriately skilled, trained and qualified staff** to work with people with learning disabilities in order to ensure that they are able to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

⇒ **Effective partnership working,** between all relevant local agencies

Source: Department of Health, 2001a.

Not only can their recommendations be equally applied to other special care groups, but they can also be equally applied to dental services in order to achieve

good oral health. Indeed, the Welsh Assembly Government Strategy for Older People (2003) sets out its objective as follows:

> "To develop high quality services that are responsive to the needs of older people through development of strategies and programmes for optometry, dental care, nutrition, hearing and pharmacy sources."

This presents a challenge for the dental profession to ensure that where possible people with a disability receive high quality care in mainstream services. Additionally, that within the profession there are members of the dental team who can provide leadership, training and strong inter-agency working, providing care for people at the more complex end of the spectrum. The Specialty of Special Care Dentistry would seek to support a move to practitioners having the training, skills, support, appropriate facilities and financial remuneration to provide the majority of care for people with mild or moderate disabilities.

Primary and specialist dental services are increasingly provided within the private sector (Audit Commission, 2002; Office of Fair Trading, 2003). Current policy initiatives focus on retaining a minimum level of NHS dentistry as outlined in Options for Change (Department of Health, 2002) and the current Health & Social Care Bill (United Kingdom Parliament, 2003). This shift in policy provides a challenge to ensure that the barriers to care of socially disadvantaged people (such as those with various disabilities) are addressed and not overlooked. In reviewing access (in its broadest terms) to dental care, Rosen *et al.* (2001) highlight the requirement for further work to evaluate the needs and service perceptions of marginalised groups and the professional barriers to the development of services for these groups.

This document argues that a Specialty of Special Care Dentistry is required to meet public need across primary care and hospital settings. It outlines how this need would appear to be increasing, rather than decreasing and that the need will be for a service rooted in the National Health Service. A service within the NHS is particularly important as many people with a disability are not employed and thus may be financially challenged (Department of Health, 2001a) even though there is some evidence that a significant proportion of older people are more affluent or have a higher discretionary income than younger people (Tinker, 2002).

There is clarity that a Specialty in Special Care Dentistry will not seek to provide all care to all sections of the public with special needs. Rather it recognises the spectrum of need, much of which is a generalist function that may be undertaken by primary care dentists, with only the more complex end of the patient-base requiring the services of Specialists, as with any specialty (Freeman *et al.*, 1997). This section of the public not only requires that dental services recognise and value their social role but that they should do so in an equitable manner which promotes *"rights", "independence", "choice"* and *"inclusion"* in line with the national strategy (Department of Health, 2001a).

3.0 Background to the Debate on Special Care Dentistry

3.1 The Context

Throughout the 1990's, the General Dental Council and the Department of Health have sought to formalise and regulate the provision of Specialist care within the UK. Enactment of EU regulations on specialisation, which was required to

facilitate movement of professionals, provided the stimulus for the Department of Health to examine the range and scope of Dental Specialties (GDC, 1992; 1998; Seward, 1998). This included a review of existing Specialties and exploration of Additional Specialties that may be required for the future. The report recognised the case for a future Specialty in the Special Care Dentistry (Department of Health, 1994; NHS Executive, 1995).

During this consultation period, there were two further emerging strands relating to Special Care Dentistry that were later to come together. Firstly, the British Society for Disability and Oral Health (then the British Society of Dentistry for the Handicapped) developed standards for a Specialist training framework. Secondly, the debate about specialisation in Community Dental Practice began.

Discussion over the potential for Specialists in Community Dental Practice was fuelled by two additional factors:

i. The emergence of Dental Public Health as a separate non-clinical Specialty coupled with recognition of the need for formal structured training for staff in the salaried Community Dental Service (CDS), in light of its expanded remit to provide oral health care for particular groups of adults with disability (Department of Health, 1989; 1997).
ii. The need for such training to be formalised, within the career structure of Community Dentistry, and recognised with the development of a Specialty.

These discussions have continued with increasing debate. Firstly, over the need for a Specialty that would provide high quality care for people with a range of primary conditions with recognised special oral health care needs and management requirements. Secondly, it would formalise training and professional development within the CDS and/or associated hospital or university appointments (Gelbier, 1998; Davies *et al.*, 1999).

As a result, the Faculty Development Group for Community Dental Practice was established in 1995 under the aegis of the Faculty of Dental Surgery of the Royal College of Surgeons of England. This group published a report 'Moving Forward – Establishing the Specialty of Special Care Dentistry' (Davies et al., 1999; Woof, 2000). This report confirmed the need for further education and training, through a specialist framework, to improve and safeguard care for people with disabilities. Independently, and simultaneously, the Standing Committee on Postgraduate Medical and Dental Education acknowledged that:

> "there is a strong case for formal education and training of dentists in the care of patients with special needs."

In 1999 the Dean of the Faculty of Dental Surgery of the Royal College of Surgeons of England established a Working Group to provide a broad-based expert view to the Faculty of Dental Surgery later that year. The Group recommended the establishment of a Joint Advisory Committee for Special Care Dentistry (JACSCD) (Faculty of Dental Surgery, 2000). JACSCD was thus established as a free-standing committee, to promote and oversee the introduction of training programmes, the development of curricula and training standards and formative assessment processes.

The Committee (JACSCD), with its 14 person membership, reflects the main stakeholders with a legitimate interest in developing postgraduate education and training of Special Care Dentistry through a Specialty framework that parallels existing Specialties. Its membership includes clinicians already providing Special Care Dentistry (many of whom have created their own training pathways, in following their desire to serve the oral health needs of a complex range of patients) together with representatives from the main consultant-led Specialties.

3.2 Ability of Existing Specialties to Provide Special Care Dentistry

The current volume of Specialists in Paediatric and Restorative Dentistry (the two areas that are most likely to contribute to Special Care Dentistry) is small (See Figure 4). The majority of the people registered in those two Specialties and the Restorative Dentistry Monospecialties gained entry, based on their experience in the Specialist area, through the mediation process. There are relatively few Specialists registered as a result of following recognised, formal training pathways. However, this latter is currently the only avenue open for people to gain entry to the recognised Dental Specialist lists. The numbers of people able to do so is limited by the number of National Training Numbers (NTN) available for entry to a Certificate of Completion of Specialist Training (CCST). The present situation is that the numbers of people leaving Specialist lists (due to retirement) outstrips those gaining entry. Recognition and concern of the difficulties in achieving and maintaining sufficient numbers of Specialists is reflected at a Government level by the call for the current review of Specialities. This need is so acute that, within medicine, there is pressure to reduce the period of Specialist training.

The Chief Dental Officer for England has commissioned the Standing Dental Advisory Committee, which reports to the Secretary of State for Health, to review the arrangements for the dental-based Specialties and to make recommendations for their future development. According to Lowry (2003) the terms of reference indicate that the review should take account of the need to increase patient choice. Currently, many people with disability and complex additional have no choice when it comes to accessing appropriate dental care.

Figure 4. Volume of Specialists in Paediatric and Restorative Dentistry

Specialist List	Number		
	Registered	**NTN**	**CCST**
Paediatric Dentistry	220	14	4
Restorative Dentistry	266	55	10
Restorative Monospecialties			
Prosthodontics	343	20	3
Periodontics	264	14	4
Endodontics	159	6	3

Source: General Dental Council, 2003.

The number of Specialists in training is hampered by the difficulty of funding training posts and a somewhat small number of fully funded national training posts are available. Those dentists able to fund their own Specialist training are more likely to have aspirations to provide Specialist care in the private, rather than in the public, dental sector limiting their accessibility to people in low income groups.

3.3 Special Care Dentistry Requirements within Restorative Dentistry Specialist Training

The current Specialist Advisory Committee (SAC) training requirements in Restorative Dentistry advocate that experience is gained in both Special Care Dentistry and Conscious Sedation. It goes on to state that five cases in Special Care Dentistry per year of training is an acceptable number. Clearly, this provides very limited experience.

A draft report following a recent SAC visit to Restorative Dentistry Programmes at a United Kingdom Dental Institute recognised a lack of experience and reported that:

"Treatment sessions for all trainees for Special Care Dentistry were lacking".

However, within the same report, both the space for the Institute to propose changes and that for the SAC visitors to make suggestions for change was left blank (Fiske, 2003).

A recent survey of consultants in Restorative Dentistry demonstrated that, of the 80% who replied, 95% felt that specialist registrars in Restorative Dentistry should have training in sedation. Ninety four percent of them considered a limited core course of 12 clinical sessions would be appropriate (Morgan, 2003). Again this provides a very limited experience. Eighty six percent of the consultants in Restorative Dentistry had access to sedation facilities in their main NHS hospital or clinic, with others referring patients requiring sedation to the Community Dental Service. Despite their access to sedation facilities, only 30% of them provide treatment for patients under sedation and only seven consultants provide this service on a weekly basis (Morgan, 2003).

Whilst it is accepted that consultants in Restorative Dentistry are all, to a greater or lesser extent, involved in the dental management of special care patients, very few of those additional practitioners that are currently on one of the monospecialty lists within restorative dentistry are regularly involved with Special Care Dentistry (King, 2003). Interestingly, Morgan's survey (2003) states that 77% of consultants considered themselves to have 'subspecialised' in one or more of the following areas – fixed prosthodontics, endodontics, periodontics, and implants. This begs the question of just how much they remain involved in, or can contribute to, the delivery of Special Care Dentistry.

3.4 Enhancement of Other Specialties by a Specialty in Special Care Dentistry

A Specialty for Special Care Dentistry will enhance the role of other specialties rather than detracting from them. As Special Care Dentistry is a broad-based Specialty it would work with other Specialists to ensure that special care patients

have access to the most appropriate Specialist care. It would provide positive support to Specialist Paediatric Dental Services where there is a desire to have appropriate teams to hand for patients who outgrow their care to move seamlessly from paediatric to adolescent and adult services. This recognises the professional and health care focus on adolescents (Fiske, 2002), where there is concern in medicine about both the transition from paediatric to adult dental services, and the appropriateness of those services to the target group (Royal College of Paediatrics and Child Health, 2002). It is increasingly important that a seamless specialist service exists as the age at which this transition occurs varies from 12 to 16 years dependent on locality. For example, in parts of Northern Ireland individuals are transferred from child to adult medical and dental services at 12 years of age (Nunn, 2003).

Additionally, it will streamline and improve access to appropriate Specialist Restorative Care in two ways. Firstly, it would bring those people who would not otherwise have reached this Specialty to the attention of the Restorative Dentists. Secondly it would provide the Specialist care for those people with complex additional management (including complex integrated pathways of care), rather than those requiring Specialist Restorative Dentistry skills. This would allow the Specialists in Restorative Dentistry to focus on patients with craniofacial and dental developmental anomalies, where their expertise lies, rather than on the management of those patients with complex behavioural or medical issues. Where appropriate, Specialists in Special Care Dentistry would also provide support, experience and patient management (with tools such as intravenous sedation and general anaesthesia) for other Specialists.

4.0 The Demography of Disability

4.1 Concepts of Need

There is on-going debate as to what constitutes need, how need changes over time and how need should best be assessed in public health services (Stevens and Gillam, 1998; Williams and Wright, 1998; Wright *et al*, 1998; Wright and Walley, 1998; Department of Health, 2003).

Just as Culyer (1976) did over twenty-five years ago, Stevens and Raftery (1994; 1997) continue to define need as "the population's ability to benefit from health care". This definition makes the link between health needs and evidence-based health care which will affect a positive outcome. Consequently, Stevens and Raftery (1994; 1997) recommend that services provided should be examined against the background of epidemiological data, the effectiveness and/or the cost-effectiveness of care, where such data exist. Stevens and Gabbay's paper (1991) has become a seminal work defining need, supply and demand through a conceptual model. They highlight the fact that need is not static but open to interpretation and change over time, and is influenced by a range of forces.

Workforce planning for Dental Specialties has always presented a challenge and currently the Standing Dental Advisory Committee is examining this issue for dental care as a whole. The need will change over time and is influenced by supply and demand. The existence of clinicians with expert knowledge and skills related to the oral health care needs of clients with a range of special care requirements,

from which this section of society may benefit, starts to formalise a professional group and begins to define the case of need for Specialists in the field of Special Care Dentistry. Case studies which demonstrate good outcomes exist and provide the basis for this emerging Specialty to undertake research into good models and outcomes of care.

This approach is used to examine demographic and epidemiological data, including published literature. Models of service delivery and organisation draw on good clinical practice and case histories, where available.

4.2 Volume and Spectrum of Need

It is difficult to accurately quantify the volume of people who fall within the stated scope of Special Care Dentistry. Demographic data outlined in Annex 1 provide the best current estimate of the volume of people with each type of disability. However, it is not possible to arrive at an exact number of people with a need for Special Care Dentistry as there is no one register for disability, and a proportion of people have multiple disabilities so that the categories of disability and impairment may overlap. It is estimated that within the UK, as many as one in four adults has experienced, or will experience, a disability during their life time (Disability Partnership, 2000b). Within London, 20% of households include a disabled person (Greater London Authority, 2002). Many of these disabilities are minor or moderate and therefore these people should, and possibly do, receive care in mainstream services, supported by Specialist backup if required. Within England, an estimated 210,000 people have a severe learning disability, just under one third of whom, 65,000, are children and young people. A further 1.2 million people have a mild or moderate disability (Department of Health, 2001a).

Many people have more than one type of impairment or disability (Disability Partnership, 2000a; 2000b; Friedlander *et al*, 2003; Tinker, 2003). For example, people with learning difficulties have an increased prevalence of associated disabilities such as physical or sensory impairments, behavioural problems, and epilepsy (Kerr *et al.*, 1996; Fiske & Shafik, 2001). With age, they also have a higher rate of dementia than the general population (Cooper, 1997). Multiple disabilities are more likely to occur in older age (Disability Partnership, 2000b; Tinker, 2002) and 60% of people with disabilities in the UK are over the age of 65 years. There is also a substantial group of adults (including those under the age of 65 years) with complex medical conditions for whom there is little demographic data. Recently published Census data ('Census 2001', 2003) for England and Wales indicate that almost 9.5 million people (18.2% of the population) say that they have a long-term illness, health problem or disability which limits there daily activities or the work they could do. Of these, 4.3 million are of working age (16-64 for men and 16-59 for women), more than 1 in 8 of the age group. The proportion of people with a limiting long-term illness has increased since 1991, when 13.3% of the population of England and Wales were recorded as having a long-term illness. Not only are the numbers of people with a long-term illness, health problem or disability extensive but they have increased significantly between the 1991 and 2001 censuses.

Many disabilities can impact on oral health. Friedlander & Norman (2002) highlight this with a description of the impact that late life depression [LLD], which typically occurs after 65 years, can have on oral health:

> "It [LLD] is frequently associated with disinterest in performing oral hygiene, a cariogenic diet, diminished salivary flow, rampant dental decay, advanced periodontal disease and oral dysaesthesias."

They emphasise that its treatment with anti-depressants means that dentists need to be cognisant of not just how to safely and compassionately provide care to those already receiving mental health services but, also, to make timely referral to physicians of people with occult or relapsing disease. People with various genetic conditions such as Down's syndrome have an increased risk of epilepsy and other medical conditions including congenital cardiac conditions, hypothyroidism, leukaemia and early onset Alzheimer's disease (Fiske & Shafik, 2001: Disability Partnership, 2000b). Furthermore, there is a spectrum of complexity amongst people with a disability ranging from very mild to severe (Freeman *et al*, 1997; Tinker, 2003).

Looking only at the complex end of the spectrum to inform service planning for Special Care Dentistry, it would involve consideration of adults with severe disabilities. If there are an estimated 145,000 adults with severe learning disabilities within England (Department of Health, 2001a), then extrapolated to the UK population, this would involve in the order of 175,000 adults for this condition alone. If only some of the people with the wide range of other disabilities and complex medical conditions (outlined in Annex 2) served by this Specialty are added, then the volume of adults would easily exceed 200,000 people. The majority of this group would require ongoing total care by Specialists or shared care with colleagues in other Specialties or the primary care setting.

It must be realised that impairment and disability are not static throughout life (Disability Partnership, 2000b). The level of disability increases with age. Whereas only 9% of teenagers aged 16-17 years have a current long-term disability, this figure increases to 33% of those people aged between 50 years and state pension age (65 years); and over 15% of the population and 60% of disabled people are aged 65 years or more. Furthermore, the number of people with a disability is predicted to increase at 1% per year (Department of Health, 2001a) for reasons outlined in section 4.3 of this document.

4.3 Location of people with a disability

Many people with disability are functionally independent living in their own homes. Others are dependent on regular support but still live independently or with their families. Only a very small proportion of older people live in residential care, accounting for 5% of all older people. However, the proportion increases with age such that 20% of people aged 85 years and over and 84% of those aged 95 and over live in residential care. Fifteen percent of independent-living older people reside alone (Office for National Statistics, 2002) and a further 50% live in pensioner only households (Tinker, 2003).

Long stay patients and residents are not limited to older people. Care is provided by the statutory, voluntary and private sectors for a variety of groups in a wide range of accommodation which include residential and nursing homes, hospitals, hostels, group homes and secure units (BSDH, 2000a). Admission to such accommodation should not mitigate against the maintenance of residents' health. However, it is recognised that within long-term care facilities, numerous problems mitigate against routine provision of oral health and encourage neglect. Groups in

residential care, where there is evidence of poor oral health and inadequate or restricted access to dental services, include older people, people with a learning disability or mental health problem, people who are physically or medically compromised and people in secure units (BSDH, 2000a). Such is the concern over the health of people in secure units that the Department of Health has just put out a call for bids for "the establishment of an academic and research base in prison healthcare". It is stated that a specific dental partner will be needed and funding for this aspect of the work will be approximately 25% of the project's total financial support (Department of Health, 2003b).

Homeless people are a further group for whom health and oral health are compromised (Waplington *et al*., 2000; freeman, 2002). This group includes asylum seekers and refugees, ex-prisoners, people with mental health problems, substance mis-users. The British Dental Association has tasked an expert reference group to compile a policy document on the oral health care for homeless people.

All the groups mentioned in this section have disability and additional complex needs. A proportion of them require Special Care Dentistry from experienced, appropriately trained Specialists.

In the year 2000, in the order of 84,000 adults in England received community-based services (day-care, home help, meals, etc), with a further 10,000 based in NHS accommodation (Department of Health, 2001a). Adults who live in recognised residential care or visit health and social care facilities regularly are easier to access for the provision of dental care. People living in the community may be more difficult to access with care. Whereas it is possible to set up dental services in residential homes and at day centres, it is more challenging to provide domiciliary dental care for individual's who are confined to their home. Delivery of these types of services to individuals confined to their home (because of agrophobia, progressive degenerative disease, terminal illness, Alzheimer's disease, etc.) requires great skill and training.

4.4 Factors Likely to Increase the Need for Special Care Dentistry

Whilst there is already a need for Special Care Dentistry, there are many factors that are likely to add to both the need and the demand as a result of changes in: the demography of the population, public values and expectations, reconfiguration of health services delivery and dental service developments. They include:

- Lower mortality rates of children with complex and multiple disabilities and increasing numbers surviving into adulthood.
- Higher than average morbidity rates of children conceived as a result of in vitro fertilisation.
- Higher than average morbidity rates of children born prematurely.
- Increased life expectancy of people with disabilities and improvements in medical care leading to increased survival rates for all groups of special care patients.
- A change in focus through clinical governance and quality standards related to continuing care to provide seamless services as patients move through the age groups.

- Increased numbers of patients who have complex and long-term medical treatment and consequently require special care in the provision of their dental management.
- Increased life expectancy of people with learning disabilities surviving into their 50s and 60s. Increasingly there will be people with learning disabilities facing the challenges of older life and they do so at an earlier age (Department of Health, 2001a).
- Increasing prevalence of disability amongst some ethnic minority groups. Increasing volume of older people, particularly old and very old people who are more likely to develop disability coincidental to, or consequential with, their age.
- 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 an increased retention of natural teeth so that more teeth are at risk of decay and periodontal disease in the older population. Maintaining oral health and dentitions, where a large number of fillings or advanced restorative dentistry (crown, bridge and implant work) has been carried out whilst the person was fit and well, becomes a huge challenge when the status quo of personal oral care is affected by disability.
- Restorative dental treatment for the increasing numbers of patients undergoing and surviving treatment for head and neck cancer or conditions requiring total body irradiation. The post-radiotherapy effects of decreased saliva production and impaired blood supply to the bones of the jaw can result in rampant decay and post extraction osteomyelitis, respectively.
- Changing public expectations away from the acceptance of tooth loss towards dental interventions to retain teeth.
- Changing public expectations regarding the importance of appearance and image with a consequent demand for implants, adult orthodontics and cosmetic dentistry from people with disabilities.
- A change in focus through clinical governance and quality standards (as well as “defensive dentistry”) towards centralisation of care on experts rather than generalists who undertake occasional cases of high complexity.
- A reconfiguration of services as a result of National Service Framework guidelines that certain patient groups, or types of care, may be restricted to designated Specialists in dedicated centres who provide a high volume of the type of care required.
- Fewer members of the Oral-Maxillofacial Surgery team (the historical home of Special Care Dentistry) providing care for people with a disability, as they move from general oral surgery to more specialised surgery.
- An increase in the complexity of care for patients with multifaceted medical histories and physical disabilities (including those with a high body mass index) who are unsuitable for day case surgery, and who require inpatient admission for comprehensive dental treatment. Although surgical dentists may provide the surgical elements of care for people with complex additional needs, patients require holistic treatment planning by a Special Care Dentist prior to surgical intervention to minimise extraction of teeth, provide restorative care and avoid repeat general anaesthetics.
- A reduction in the availability of general anaesthetic dental services and an increased awareness of conscious sedation for dental treatment will increase the demand for sedation services for dental care of people with disability

(including dental phobia) in community settings. This includes the use of intranasal, oral, intravenous and inhalational sedation.

- Raised expectations amongst children who have received specialist paediatric dental services, and their families, of being able to receive continuing specialist care within specialist services.
- An increased need for delivery of NHS special care dental services to provide equity of access as the current NHS fee per item of service mitigates against practitioners providing Special Care Dentistry within the NHS. Also, many of the individuals requiring the care may be financially challenged and will have limited access to specialist private practice.

4.5 Factors Likely to Reduce the Need for Special Care Dentistry

- Other Restorative Specialties may provide treatment for people requiring special care
- New methods of financing dental care may facilitate the care of people with disability within General Dental Practice.

The former point is unlikely to have a large impact as there is an under supply of such Specialists. Their numbers are limited within the NHS and most of the Specialists working in the 'High Street' do so within the private sector. The training requirement in Special Care Dentistry within the Restorative Dentistry Specialist training is limited to five cases per year, recognising that the trainees' specific final goal is likely to be mainstream Restorative Dentistry. As yet there are no competencies for conscious sedation required in the training of Specialists in Restorative Dentistry other than the requirement (since October 2002) to record "the number of cases treated under inhalational sedation and intra-venous sedation" (Morgan, 2003). This situation raises doubt as to whether this Dental Specialty alone, whilst it is able to make an important contribution, can provide the requisite knowledge, skills and experience to lead the oral health care service for, and its delivery to, people requiring Special Care Dentistry.

The latter point is to be encouraged, as it is appropriate for most people with mild or moderate disability to receive care from a Primary Care Practitioner. This move would release the services of Special Care Dentists allowing them to proactively address the oral health needs of people with more severe disability.

5.0 The Oral Health Needs and Demands of People with a Disability

5.1 Volume of oral disease: need and demand for care

Within the UK, the oral health of adults has improved greatly over the past three decades (Kelly *et al*, 2000). More adults are retaining their teeth into older age and the proportion of adults with dentures has fallen markedly. Although these improvements have occurred across all sections of the community, socially disadvantaged people continue to have the poorest levels of oral health. As people retain their teeth, this presents challenges to the dental profession in providing care to medically compromised, multiply disabled and older people who may require a wide range of interventions in a heavily restored dentition at a time in their lives when they are less able to cope with treatment. Ideally, they should have equitable oral health outcomes in terms of self-esteem, appearance, social interaction,

function, and comfort. However, this requires careful assessment and treatment planning which takes account of all associated factors including the skills required to manage delivery of care in a, sometimes, compromised situation.

The case is well documented that people with learning disability or mental health problems have similar oral diseases but poorer oral health and poorer health outcomes from care than the general population (BSDH, 2000a; BDA, 2003) (See Annex 2). Oral diseases are less likely to have been treated for the people who are living in community settings (Tiller *et* al., 2001). Furthermore, when oral diseases are treated they are more likely to have resulted in extractions than fillings, crowns and bridges, particularly for people living in residential care (Steele *et al*, 1998; Tiller *et al*, 2001; Lawton, 2002). This situation is similar for people with mental health problems (BSDH, 2000d). A seminal work by Kiyak (1988) describes the influence of dentists' attitudes on people's ability to access dental services as well as preventive and restorative dentistry. It underpins the need for positive attitudes towards disability and calls for Specialist training to improve access to care. A recent document published by the British Dental Association (2003) recommends that "Special Care Dentistry must become a recognised Specialty" if older disabled people are to be able to access and receive appropriate dental care.

Friedlander and Marder (2002) report that advanced dental disease is seen frequently in patients with schizophrenia for several reasons (See Figure 5).

Figure 5. Causes of Dental Disease in People with Schizophrenia

- ⇒ The psychotic condition impairs the ability to plan and perform oral hygiene procedures
- ⇒ Some antipsychotic medications have adverse orofacial effects such as xerostomia (dry mouth) and its consequent oral disease
- ⇒ Patients sometimes have limited access to treatment because of their impecunious circumstances
- ⇒ There is an inadequate number of dentists with the skills in providing care for this patient group.
- ⇒ The recent introduction of more effective medications permitting the majority of patients to receive their psychiatric care from community-based providers, places increased demands on primary care dentistry
- ⇒ Such patients are not always welcomed in general dental practice.

Source: Friedlander and Marder, 2002.

Dentists who are practicing Special Care Dentistry are cognisant with the signs and symptoms of specific medical conditions and are likely to feel more confident in treating such patients and obtaining consultative advice from the patients' medical Specialists (Friedlander and Marder, 2002). Furthermore, dentists who can provide a full range of services to such a patient can enhance the patient's self-esteem, and, thereby, contribute to the psycho-therapeutic aspect of the medical

management. Generally, people requiring Special Care Dentistry have needs which are wider than oral health. For example, providing oral care for persons with learning disabilities involves dealing with their inability to consent for care and may involve the use of tools such as '*Makaton'* and '*Easy Read'*; working with advocates; organizing, attending and informing '*Best Interest Meetings'*; and taking responsibility for informed consent.

The above need for oral health care has only been explored for adults. The oral health needs of young people from the same groups in society are also recognised. Their care is firmly promoted by the Specialty of Paediatric Dentistry. However, the key issue for many of these children is the need for a smooth transition of care to community-based adult services. This point has been highlighted nationally in the UK (Royal College of Paediatrics and Child Health, 2002), and internationally in the US (Waldman & Perlman, 1997). Transition usually occurs at 16 years, there is some evidence that this is moving towards 14 years (Fiske, 2002) and in some cases is as early as 12 years (Nunn,2003).

5.2 Evidence that the Current Need is Unmet?

The Government recognises that, despite improvements in oral health, inequalities still exist (Department of Health, 2000). Lower levels of oral health have been have been demonstrated in a range of patient groups, including people with cerebral palsy (Russell and Kinirons, 1992), epilepsy (Ogunbedede *et al.*, 1998), multiple sclerosis (Baird, 2003) and psychiatric illness (Sjogren and Nordstrom, 2000). This situation has also been identified amongst young disabled people (Francis JR *et al.*, 1990), people with learning disabilities (RCS of England and BSDH, 2001) and older people, particularly those in residential care (BDA, 2001).

Current *ad hoc* arrangements for people requiring Special Care Dentistry are anecdotally reported as being insufficient and highlights the fact that providing dental care to people with a disability is low priority. See Case Scenarios 2, 3 and 4 which are real and recent events.

As Special Care Dentistry is not yet an established Specialty, the hospital-based services which do exist often depend on the good will of Specialist and Consultant colleagues and their availability to facilities such as general anaesthesia operating lists. Such arrangements increase the complexity and difficulty of organising all agencies involved in the disabled individual's care. The elements of the service which need to be hospital-based (such as care under general anaesthesia) would benefit from being provided by a dedicated Specialist service that facilitates access to appropriate facilities. However, the Specialist's work (other than that undertaken with general anaesthesia) need not and, indeed, should not be restricted to working in hospitals.

The main thrust of a Specialty in Special Care Dentistry is that it is predominantly community based. This would have a twofold effect of reducing inequality by directly improving physical access to a Specialist service and indirectly improving access through support for interested Generalists in Primary Dental Care Services.

Case Scenario 2

⇒ Mr B, a 70 year old man, lives in residential care and has dementia.

⇒ He was assessed by a local Community Dentist who recognised that he had poor oral hygiene and some decayed teeth which could be filled if Mr B was cooperative enough to accept help.

⇒ The dentist worked with the staff in the home to improve oral hygiene and started to provide conservative care for Mr B at his home since it was felt he would not manage treatment in a surgery.

⇒ The Community Dentist went on maternity leave before the treatment was completed with a view to completing treatment on returning to work.

⇒ While the dentist was on maternity leave the local GMP carried out a health assessment on Mr B. He felt there was a problem with Mr B's mouth and referred him to the Oral Surgery Department of the local General Hospital.

⇒ Mr B was given a general anaesthetic and had all his teeth removed.

⇒ He is unable to tolerate denture wearing.

⇒ There is an issue around consent in this case

Case Scenario 3

⇒ Mr X was due to receive radiotherapy to the head and neck

⇒ Dr Y (a dentist with several years' Special Care Dentistry experience including two years formal training) saw him for a pre-radiotherapy oral assessment. It was decided that three teeth required extraction.

⇒ The treatment was straight forward and Mr X was not anxious. To expedite his treatment he was fast-tracked to a student oral surgery clinic for the extractions.

⇒ Dr Y was surprised to find out, after Mr X had commenced radiotherapy, that only one tooth had been extracted. The dentist supervising the oral surgery clinic had changed the treatment plan because two of the teeth were asymptomatic.

⇒ No account had been taken of the five year prognosis of these teeth, nor of the effect of the radiotherapy on the blood supply to the supporting alveolar bone.

⇒ Mr X is now at risk of developing pain and/or infection.

⇒ He is also at risk of developing osteoradionecrosis when these teeth are extracted

Case Scenario 4

⇒ Miss T is 25, she has learning disabilities and her appearance is important to her. Carers support her with oral hygiene although this is difficult.
⇒ She has a regular dentist who explains everything and ensures she has consent before carrying out procedures.
⇒ Miss T grinds her teeth. The tooth wear has resulted in exposure of the nerve and an abscess on one of her central incisors.
⇒ Miss T and her carers were informed by the dentist that the tooth would have to be extracted. They were told root canal treatment could not be carried out under general anaesthesia as it required 2 appointments.
⇒ She was told that she would have to live with the gap as she would not cope with a denture and a bridge was contraindicated because of the grinding.
⇒ She was not offered the option of conscious sedation
⇒ She was not offered the option of a second opinion

5.3 The Role of Generalists in the Spectrum of Need

Generalists have the potential to play a huge role in the provision of Special Care Dentistry. This role can only be fulfilled if there is appropriate training in place and if there is a robust Specialist-led support service in place.

The requirement for Special Care Dentistry in the undergraduate curriculum is minimal both in the UK (GDC, 2002; JASCD, 2003) and in other countries (Goodwin et al, 1994; Waldman *et* al, 1999). This has resulted in a dental profession that feels untrained to provide dental services for people with disability, and one that finds it difficult to do so (Baird *et al.*, 2003). The importance of the attitudes of dental personnel towards people with learning disabilities has been raised by Bedi *et al* (1995). This issue can be tackled in the training and education of students but central health policy is required to ensure that care for such patients is adequately planned and funded.

Local studies demonstrate that General and Community Dental Services provide the majority of the currently supplied care for people living in community settings who are on disability registers (Pratelli and Gelbier, 2000; Tiller *et al* 2001), with the latter providing more treatment for people within residential care than those in the community (Tiller *et al*, 2001) (See Annex 2). There is some evidence from local studies that people with more severe disabilities, or their carers, report greater difficulty in accessing care and lower satisfaction with the care received (Pratelli and Gelbier, 2000). There are no national data on the use of NHS dental services by people with physical or learning disabilities. However, registration rates for older people with General Dental Services in England are below the average for the general population (Dental Practice Board, 2002), and are likely to be lowest amongst disabled older people.

O'Donnell *et al* (2002) identified that dentists in Hong Kong see between one and five patients with a disability each year. If this is replicated in England and Wales, at the upper limit, general dental practitioners (of whom there are 16,000 within the General Dental Service) would see up to 80,000 patients requiring special care per year. The provision of such a small volume of care for this group raises the question of whether it is sufficient to keep the practitioners' skills at an adequate level.

Barriers to the provision of care, such as payment systems, may begin to change and thus facilitate more mainstream care in future (Department of Health, 2002). However, it is essential that such care is of high quality and that it is co-ordinated with other agencies (Department of Health, 2001a; 2001b). A further quality issue in the UK is the volume of care that clinicians need to undertake to remain competent. Currently, in certain complex cases, there is increasing acceptance that patients with certain conditions should be treated by a limited number of designated clinicians, rather than by practitioners who only see a low volume of cases (Clinical Services Advisory Group, 1998; Secretary of State, 2002b' STA, 2003). This only strengthens the argument for a Specialty in Special Care Dentistry to care for the more complex end of the spectrum of people with disability.

Looking to the future, the creation of a Specialty of Special Care Dentistry would enhance choice for people with disability and complex additional needs. They may choose to access either mainstream services or designated services in line with wider health care (Department of Health, 2001a) and thus improve on the current situation. Furthermore, it could be argued that the model of care of a Specialist in Special Care Dentistry, who is involved in treatment planning, and then either providing care or being involved in shared care with other Specialists, Specialist Practitioners or interested Generalists, as appropriate, is the way forward to ensure quality care for people with severe disabilities.

5.4 What People with Disability Want

The Service Users Advisory Group (2003) that fed into the Department of Health document Valuing People: A New Strategy for Learning Disabilities for the 21st Century. Patients, state that they "do not get equal health treatment or good health services".

What they say they want from health care services, including dental services, is:

- ⇒ Fast and good health care with support when needed, independent of age
- ⇒ The same health services that are available to everyone else with expert care when it is needed
- ⇒ To be on a GP list and have a Health Action Plan if wished
- ⇒ Support from a health facilitator if wanted
- ⇒ Health care professionals working together with learning disability services

People want teeth in order to look good, feel good about themselves and to be socially acceptable. Additionally, they want their mouths to be comfortable and to be able to enjoy their food. To achieve this end, people increasingly wish to retain their natural teeth (Kelly *et al*, 2000). The emotional effects of tooth loss are

recognised more and more (Fiske *et al*.,1998; Davis *et al*., 2000; Fiske *et al*, 2001*)* and require sensitive handling in all age groups, particularly in older people as total tooth loss (edentulousness) becomes less common and, thus, less socially acceptable. When it does occur, it does so in later life when people commonly find the transition from natural teeth to dentures more of a challenge.

These expectations are likely to be consistent amongst people with a disability and their carers. In the forward of Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities (BSDH & RCS England, 2000) a parent of an adult with learning disability describes the importance of good oral health for his daughter and the contribution it has made to her enjoyment of food, general health and social acceptability. He also points out how, far too often, services for people with a learning disability are relegated to a 'Cinderella' status because of insufficient resources. A survey of adults with learning disabilities living in the community and known to social services in SE London (Pratelli & Gelbier, 2000) revealed that people with learning disabilities and their carers would like more designated services for people with learning disabilities including the use of mobile clinics. Other people wish to have access to mainstream health care services (Disability Partnership, 2000b). A study on the views and experiences of parents of adults with Down's syndrome regarding oral health (Kaye, 2001) identified that people wanted to be treated the same as those without disability. They wanted good access to mainstream dental services with the support of with the support of expert or 'specialist' advice, care and facilities as required. Far from feeling that this was the case, examples of professional diffidence and less than optimal care were cited.

6.0 The Supply of Special Care Dentistry

6.1 The Current Workforce

The current supply of dentists, working in the field of Special Care Dentistry is predominantly based in the salaried Community Dental Service. There is a smaller constituent of Special Care Dentistry based in General and Teaching Hospitals who are either salaried NHS or University staff. General Dental Practitioners contribute to the over all picture of Special Care Dentistry (as outlined in Section 5.3), but only a small number of Practitioners have a Specialist interest in this field.

Those people who have experience and an interest in Special Care Dentistry are likely to apply for entry to its Specialist list through the process of mediation. Their numbers can, at best, only be estimated. Mediation on to the list will require dentists to demonstrate their knowledge and experience against an agreed standard.

The categories of people who might apply to be mediated onto the list (based on current data and best estimate of numbers) include:

a. Established academics in the field of Special Care Dentistry – there are approximately 6.
b. Hospital Dentists – there are approximately 40, not all of whom would be eligible.
c. Senior Community Dental Services staff – there are approximately 137 managers and 537 Senior Dental Officers not all of whom will be

experienced in Special Care Dentistry. These figures include people working in Orthodontics, Epidemiology, Paediatric Dentistry, Dental Public Health, Epidemiology and Administration. Also, a significant proportion of them work part-time so the figures do not represent whole time equivalents.

d. General Dental Practitioners with a Specialist interest – the number is unknown and not obtainable, but is likely to be less than 20.
e. Specialists in related established Specialties – there are 220 Specialists in Paediatric Dentistry of whom a small proportion will have the credentials to be mediated on to the Special Care Dentistry Specialist list; and there are 266 Specialists in Restorative Dentistry plus 343 people on the Prosthodontic list of whom a small proportion will have the credentials to be mediated on to a Special Care Dentistry Specialist list.

This does not give a clear picture of numbers of people who might be eligible for mediation. However, in May 2003, the Specialist Society for Special Care Dentistry, the British Society for Disability and Oral Health, had in the order of 700 members. Two hundred of them belong to professions complementary to dentistry, the remaining 500 are likely to either be eligible to apply for mediation or to aspire to following a training pathway in Special Care Dentistry. Once again the numbers are over represented as they are not whole time equivalents.

It is possible to be more specific about the numbers of people who have completed (or are undertaking) a period of formal training in Special Care Dentistry (See Figure 6).

Figure 6. Numbers Completed / Undertaking Formal Training

Course	Numbers	
	Completed	In Training
MSc in Sedation and Special Care Dentistry	11	3
MSc in Special Needs Dentistry	12	2
MSc in Gerodontics	50	0
Diploma in Special Care Dentistry of the Royal College of Surgeons of England	0	>50
Membership in Special Needs Dentistry of the Royal College of Surgeons of Edinburgh	32	Unknown

Following the period of transition, entry to the Specialist list would require any trainee to undergo, and successfully complete, a formal three-year training as described in the JACSCD Training in Special Care Dentistry document (2003).

6.2 Planning for Specialists

Professional bodies such as the British Medical Association, the Royal Colleges, and the British Dental Association continue to advise on the planning of Hospital Services according to population levels (Joint Working party, 1998; Central Committee for Hospital Dental Services, 1999; BAOMS, 2001). Recent reports from these groups advise a scaling up of services with a consultant-to-population ratio of three consultants to 450,000-500,000 people for OMFS. They also advocate rationalisation of certain Hospital Specialist Services onto a smaller number of in-patient sites. Much of this re-shaping is reported as relating to junior doctors' working hours, the level of sub-specialisation with the concomitant need for larger catchment populations, and the view that concentration of care leads to higher quality.

Based on the figures in Section 4.2 (which form a very conservative assessment of the need for Special Care Dentistry), there are in the order of 200,000 adults with severe disability in the UK.

Specialist planning must recognise that some patients will require lifelong care due to the complexity of their medical, dental and social needs; the resultant requirement for liaison with other health and voluntary sector professionals; difficulties in obtaining consent; requirements for sedation or general anaesthesia services; etc..

6.3 Typical Specialist Caseloads

Typical Specialist caseloads in Special Care Dentistry are difficult to estimate. In an effort to illustrate typical 'Specialist' caseloads, four examples drawn from experienced clinicians working in this field of dentistry in different areas of the UK will be described (See caseloads 1,2,3 & 4). These caseloads will be used alongside other dentist to patient ratios in Section 7.1 of this document to inform a '*best fit calculation'* for the number of Specialists required in Special Care Dentistry.

Caseload 1: South Wales

Dental Hospital (DH)

An audit undertaken over a 3 month period of Special Care Dentistry referrals into a Restorative Department in a DH has been extrapolated into annual figures.

2.4 WTE including day-case and in-patient general anaesthesia sessions and conscious sedation for patients considered to be ASA III and over as they are unsuitable for care in a
primary care setting.

⇒ 668 new Special Care Dentistry referrals a year

⇒ 47% of these referrals exhibited anxiety and requested conscious sedation for their treatment

⇒ 2,600 Special Care Dentistry patients receive continuing care in the Department

⇒ ***The Special Care Dentist to patient ratio is approximately 1:1,000***

Peripheral Hospitals Dental Service (PHDS)

The PHDS serves 8 hospitals including mental health services, elderly mentally infirm services, adults of working age, forensic admissions, drug and alcohol intoxication, neuropsychiatry, acute and acquired brain injury, stroke and older people. One hospital Continuing Care facility is also served.

0.7 WTE dentist and 0.7 WTE hygienist , both of whom are experienced in Special Care Dentistry, provide the dental care.

⇒ The PHDS accepts referrals separate from the Department and has, approximately, 600 referrals per year

⇒ The service targets patients in rehabilitation and continuing care and provides a emergency pain relief service for all in-patients

⇒ ***The WTE Special Care Dentist to patient ratio is approximately 1:950***

Caseload 2: Lothian

Community Dental Service (CDS)

This breakdown was taken from the working practice of 2.0 WTE Senior Dental Officers (SDOs) in Special Care Dentistry. The SDOs have team management and teaching responsibilities. Although they are allocated 6-7 clinical sessions per week, it is more often 6 sessions.

Patient referrals come from the Primary and Secondary Care sectors. Many of them come from colleagues in the Edinburgh Dental Institute who are Consultants and Specialists in Restorative Dentistry, Oral Surgery and Oral Medicine.

⇒ The 2.0 WTE SDOs see between 1350 and 2160 patients per year depending on the patient case complexity and the dentists' involvement in GPT training

⇒ 60 – 70% of patients (810 – 1,300 cases per year) receive continuing care, partly because the service is a regional centre for haemophilia and oncology services

⇒ 30 – 20% of patients are one-off cases, with a further 10% being for advice, second opinions or treatment plans (accounting for 540 – 870 cases per year)

⇒ ***The Special Care Dentist to patient ratio is 1:675 to 1:1080***

Caseload 3: North of England

General Hospital with Specialist Facilities

Lancashire Teaching Hospitals and Ormskirk Hospital have a population base of 490,000 (Chorley and South Ribble 220,000; Preston 11,000; and West Lancashire 160,000).

The hospital-based Special Care Dentistry service is provided by 1.0 WTE experienced, senior Special Care Dentist per district hospital.

During 2002 / 2003 the 2.0 WTE Special Care Dentists:

⇒ Received 3,000 Special Care Dentistry referrals

⇒ Dental care was completed under GA for over 500 patients, and with conscious sedation for a further 270

⇒ Provided no continuing care service (due to their restricted facilities), and referred all patients back to the Primary Dental Care Sector for continuing care after one appointment or a course of treatment (as appropriate)

⇒ ***The Special Care Dentist to patient ratio is at minimal 1:1,500***

Caseload 4: London

Dental Hospital (DH)

This breakdown comes from the clinical practice of Special Care Dentistry of a London Dental Hospital.

3.5 WTE NHS employed, experienced, Special Care Dentists (who all have additional teaching, administrative and research responsibilities.) provide the bulk of the service. The majority of their clinical practice involves close clinical supervision and support for undergraduate and postgraduate students.

Patient referrals come from the Primary and Secondary Care sectors including from Consultant and Specialist colleagues in Paediatric Dentistry, Restorative Dentistry, Oral Surgery and Oral Medicine.

During a twelve month period, in the order of:

⇒ 2,700 Special Care Dentistry referrals were received

⇒ 200 patients had dental care completed under GA (either day-stay or main-theatre cases)

⇒ 1,500 patients had dental care with conscious sedation (inhalational or intravenous)

⇒ Continuing care services are limited due to the large numbers of new referrals received and as many patients as possible are referred back to the Primary Dental Care Sector for continuing care

⇒ ***The Special Care Dentist to patient ratio is approximately 1:750***

7.0 Delivery of Special Care Dentistry

7.1 Future Specialist and Training Numbers

JACSCD is unaware of any existing Specialist to population numbers. Previous Specialty numbers have, on the whole, been the result of the number of eligible applications for mediation. As far as we are aware no other Specialty has looked at the numbers required on a population basis. Consequently, the following calculations are based on the only model available (that is the Consultant to population numbers) to provide a *'best fit calculation'*. This section examines the workforce to population ratio and the patient base for other Specialties and Generalists, respectively, testing the model and numbers outlined this section of the document.

First, it is helpful to look at other Specialties which base their service planning on the total local population. Planning based on Oral Maxillofacial Surgery Consultant numbers provides the following *'best fit'*:

- Platt norms of 1 Consultant to 150,000 population (BDA, 1999) would mean that there should be 400 Consultants nationally (333 of whom are in England, 20 in Wales and 33 in Scotland, 10 in N Ireland)
- This is equivalent to at least 10 Consultants per Strategic Health Authority population of 1.5 million in England
- Thus, if each Strategic health Authority has in the region of 6,000 patients with severe disability, 250 Specialists would be required nationally

In contrast, in the Primary Dental Care sector there is:

- A notional GDS ratio of 1: 3,000 population for the provision of Primary Dental Care.
- However, many general dental practitioners appear to have smaller numbers of registered patients, e.g.1000-2000 which may relate to their hours of working or their mix of NHS and private care.

Specialists in Special Care Dentistry would have parallels in both the above systems as they will provide a secondary referral base and ongoing care for people with more complex disability and additional needs.

Based on the 'typical caseloads' set out in Section 6.3 of this document, a caseload of between 850 and 1,500 patients is appropriate for a whole time Specialist in Special Care Dentistry. Using this premise, planning for regular care of a UK population of 200,000 people with severe disabilities, Special Care Dentistry would require between 235 and 133 Specialists respectively for a population base of 200,000 where ongoing care is provided. If the population base is only 175,000, the number of specialists required would be 117 and 205, respectively.

These calculations assume annual dental visits for the patients that make up this complex caseload. A Specialist service contract should specify at least annual assessments plus care packages based on individual need. Back-up services, within Primary Care Trusts, should be in community settings with the support of a predominantly, community-based Specialist. These figures do not take into account the time that Specialists will require in order to provide education, support for other workers such as General Practitioners with a Specialist interest.

If a whole time Specialist provides care for something in the region of 800 patients, this suggests a need for over 200 Specialists in Special Care Dentistry and result in the order of 6 per Strategic Health Authority. This recognises that the time required to provide care in a clinical setting; admit patients to, use, oversee patient recovery, and discharge from inpatient facilities; and to liaise with other members of the health and social care team may be significant. The number of patients per individual Specialist may be reduced but if they are supported by a wider team including Specialist Registrars on recognised training pathways, Staff Grade Dentists, perhaps Practitioners with a Specialist interest, and Professions Complementary to Dentistry, they may see a larger number of patients within a team. This begs the question - is 200 Specialists too many?

100 Specialists would result in about 2.5-3 whole time equivalents per Strategic Health Authority. Such numbers of Specialists actively working in the field of Special Care Dentistry should be easily achievable through mediation. Clearly

many more than 100 people would need to be mediated onto the Specialist list to take into consideration those people who would work part-time, and to achieve 100 whole time equivalents

Planning for the number of Specialists required in Special Care Dentistry is based on Consultant numbers in other Specialities. Planning can not be precise as the initial number of Specialists depends on the process of mediation with the GDC and the number of clinicians who can provide evidence that they meet the relevant criteria. However it can be said that, whereas, Specialists in Restorative Dentistry and the Mono-specialities of Periodontology, Prosthodontics and Endodontics are likely to be attracted to working in the private sector, this is less likely to happen with Special Care Dentistry.

Trainees

There would need to be approved training programmes in place to ensure that the workforce maintained an appropriate volume of Specialists and coverage across the UK.

Assuming there are 100 whole time Specialists and that a Specialist works for 20 years, then 5 Specialists will retire each year (assuming that the age span is even). To maintain the workforce, there will need to be at least 5 new trainees per year. Thus, with a three-year training programme, there will need to be 15 trainees at any one time.

If Specialists are working for a shorter time or are older when mediated onto the list, more trainees will be required, at least initially, to maintain a significant Specialist workforce.

Whilst, the cost to the NHS of recognising Specialist posts can be met through reconfiguration of the Salaried Dental Services, the price of training Specialists will be a cost pressure. There would also be support staff costs and other identified service and facility costs against the Specialty. However, legislation in inequality may throw the spotlight on the current NHS provision of care for people with a disability and the cost to the NHS of not meeting legislative requirements under the Disability Discrimination Act would be great.

Initial numbers

It is recommended that, based on the *'best fit calculation'* 100 to 200 Specialists are required. This workforce should be supported by 10 to 20 recognised Specialist training places in the first instance, followed by five training posts a year to maintain the workforce numbers.

7.2 Skill Mix and Facilities

Whereas Consultants and a large proportion of Specialists have until recently had a strong hospital focus, there is recognition that not all of them need to be based in hospitals or, if they are, they may only provide certain aspects of care in a hospital setting (Mouatt, 1995; Secretary of State, 2000). The legislation of increased Consultants and Specialist care outwith hospitals is already in place for Community and Personal Dental Services and is being formalised within the

current Health and Social Care Bill (UK Parliament, 2003). It is envisaged that many patients may receive routine care in a primary care setting whilst others will require a hospital base because of medical complications, the need for multidisciplinary care, or the need for care under general anaesthesia. The facilities for such individuals should provide good physical access for people with disabilities including appropriate transport.

The case mix of the Specialist in Special Care Dentistry caseload will vary depending on whether there is input to a regional centre for a disease or patient group, such as inherited bleeding disorders or oncology. It will include the complex end of the spectrum of medically, mentally and physically disabled patients and those with phobias and anxieties with referrals from other Specialist and Primary Care colleagues (encompassing medical, dental and social services).

There must be the opportunity for staff to work across settings with the equivalent of around one quarter of staff time provided in a secondary care setting. However, the initial balance will depend on who is mediated into the new Specialty. Ideally, Specialists in Special Care Dentistry should undertake the majority of care within a primary care setting where it may be provided more cost-effectively and more conveniently to the patient.

The dental team will include the need for Professionals Complementary to Dentistry (PCDs), particularly dental hygienists, and may involve liaison with oral health promotion services to ensure that a preventive approach is taken locally to support oral health care for people with learning disabilities (BSDH, 2001). Such an approach allows a pro-active move to reduce and prevent dental disease rather than sole continuation of the traditional re-active treatment of disease. Other routine care may be provided on a domiciliary basis for which there are established guidelines for care (BSDH, 2000a; 2000b).

7.3 Models of Good Practice

Models of good practice within the UK have been documented by the British Society for Disability and Oral Health (2000a; 2000b; 2000c); the BDA (2003) for dental services in particular; and by the Department of Health (2001a; 2001b), including the Secretary of State (2000) for health care in general. The NHS can learn from these models of care in developing Special Care as a recognised Dental Specialty.

Morris and Burke (2001a; 2001b) discussed the ideal interface between primary and secondary (ie Specialist) dental care. They concluded that the ideal qualities of such an interface could be summarised under the headings of equity, seamless care and efficiency & effectiveness (See Figure 3 in Section 2.5). According to them, “an equitable interface could be defined as one where all appropriate cases are referred regardless of other factors and there are no barriers to receiving Specialist care following referral. A seamless service could be defined as one where any treatment not available in primary dental care is available and accessible in secondary dental care and transition between different providers is easily arranged”. A completely efficient and effective interface is one where all referrals are appropriate and happen at the right time, patients are referred back to primary dental care once ‘specialised’ treatment is completed, they continue to see their

primary care dentist during lengthy courses of secondary dental care and referral and discharge to maintenance services are infallible.". They go on to discuss the factors that affect these ideal qualities. Within equity they discuss the problem of a large proportion of the population having no registration with a dentist; the scarcity of NHS secondary dental care, with most Consultant-led Dental Specialties only being available through dental hospitals; long waiting times; and the ability of affluent and articulate patients to negotiate the potentially complex process of working their way up a waiting list or accessing private treatment, essentially buying themselves off NHS waiting lists. All of these issues mitigate against access to Specialist dental care for people with disabilities and additional complex needs. Under the subheading of *Widening Access*, they conclude that "anything which improves access to primary dental care and secondary dental care is to be recommended. The development of outreach by consultant-led services is one possible solution, as is the development of NHS specialist care outside of. Consultant-led units".

Local models of good practice include meeting local needs in a seamless fashion through the implementation of a strategy document with Paediatric Dentistry and Community Dentistry so that there are agreed criteria for referral and discharge, and to promote clinical care pathways. Some CDS services have many staff, with a keen interest and identified roles for providing a Special Care Service, who have had training in the field of Special Care Dentistry. In other areas, some General Dental Practitioners (GDPs) have an interest in continuing care for long standing patients of their practices and discuss cases with Specialists. This shared care strategy with GDPs is to be applauded and encouraged.

As Primary Care Trusts implement the Health and Social Care Bill (2003), they may wish to address this issue within their service strategy. Models of Good Practice 1,2,3 and 4 are used to illustrate the practice of seamless and shared care that already exists.

Model of Good Practice 1: South Wales

Dental Hospital (DH)

⇒ The referral base is extensive serving a population of 1,797,000 people

⇒ The Dental Hospital provides a comprehensive service for Special Care patients and serves a large Medical School and Hospital with Specialities such as the Regional Haemophilia Centre, Genetic Centre, Cardiac Services, Renal Unit and Oncology Services

⇒ Patients are accepted for Specialist treatment within the Department or directed to CDS or GDS services following referral as appropriate

⇒ Some consenting patients will be suitable for the revised undergraduate Special Care Dentistry curriculum and will be channelled into care through the clinical teaching programme

⇒ With improvement of Trust and CDS facilities, more patients will be able to receive their treatment in a primary care setting with 'shared care' for particular aspects of their care.

Models of Good Practice 2: Lothian

Community Dental Service (CDS)

⇒ Patient referrals come from the Primary and Secondary Care sectors. Many of them come from colleagues in the Edinburgh Dental Institute who are Consultants and Specialists in Restorative Dentistry, Oral Surgery and Oral Medicine

⇒ There are a number of SDOs with different roles allowing cross referral as appropriate to provide a seamless provision of care between the District (non-teaching) General Hospital (DGH) and community setting

⇒ The CDS has access to dental surgeries in all three of the DGHs so that patients can be transferred to a hospital clinic for part or all of there treatment depending on its complexity and their medical history

⇒ The CDS is a regional centre for the South East of Scotland for the provision of dental care for people with haemophilia. It is also a regional centre for oncology

⇒ The CDS staff work with General Dental Practitioners at several levels
- Accepting referrals
- Providing advice and treatment plans
- Shared care of patients who are returned for continuing care with the practitioners having open door access to the CDS
- Provision of training courses

Models of Good Practice 3: North of England

General Hospital with Specialist Facilities

⇒ Referrals are received from General Medical and Dental Practitioners working in the Primary Care Sector

⇒ The limited resources mean that patients can not be accepted for continuing care but for single course of, or one-off, treatments

⇒ The Special Care Dentistry hospital-based service is required for
- People with complex medical status
- Provision of shared care within hospital Specialties
- Complex management of people that is beyond the scope of management in the Primary Dental Care setting eg those who can not cope with GA but can be treated with conscious sedation
- Comprehensive care and joint planning with other Dental Specialists (links with Maxillofacial surgeons and Specialists in Restorative Dentistry – including Prosthodontics) eg for patients with craniofacial abnormalities

Models of Good Practice 4: London

Dental Hospital (DH)

⇒ Patient referrals are received from the Primary and Secondary Medical and Dental Care Sectors including from Consultant and Specialist colleagues in Paediatric Dentistry, Restorative Dentistry, Oral Surgery and Oral Medicine within the hospital base and from other hospitals throughout the South East of England and other Regions

⇒ The Department acts as a regional centre for some groups of patients eg those with haemophilia, oncology, epidermolysis bullosa, positive HIV status and dental phobia

⇒ The Special Care Dentistry hospital-based is required for
- Advice and support for General Dental Practitioners
- Treatment for people with complex medical status, progressive medical conditions, severe learning disability, severe mental health problems, dental phobia, etc.
- Provision of shared care within hospital Specialties
- Complex management of people beyond the scope of management in the Primary Dental Care setting eg day-stay and in-patient GA facilities, and conscious sedation for both severely anxious people and for those who are classified as ASA III or over on medical grounds
- Comprehensive care and joint planning with other Dental Specialists

⇒ The high volume of referrals has led to the development of strict patient acceptance criteria and where possible patients are accepted for a single course of, or one-off, treatments only

⇒ Close links with the local and other regional CDS teams allows patients to be transferred seamlessly to another service for continuing care

⇒ Where patients are referred back to GDPs following treatment an open door approach for future patient care, or advice on such, is encouraged

7.4 Barriers to Accessing Care

It is important to think of barriers to access in broad terms rather than merely as access to premises. Following a review of the literature on "treatment accessibility for physically and mentally handicapped", Wilson (1992) concluded that it was difficult to find information on accessible dental care. Documented barriers to care for disability (Fiske *et al.*, 1990; Russell and Kinirons, 1992; Freeman, 1999 and 2002; Land, 2000; Edwards and Merry, 2002) include those items set out in Figure 7.

Figure 7. Barriers to Accessing Dental Care for People with Disability

Factors contributing to the inaccessibility of dental services include:

⇒ Poor information regarding available dental services

⇒ Access to services including transport

⇒ Physical access to the premises and the surgery

⇒ Access to appropriate oral health information

⇒ The need to be accompanied / reliance on a third party

⇒ Negative attitudes to the need to care – individuals and their carers

⇒ Anxiety and fear

⇒ Cost in emotional, psychological, social and financial terms

⇒ Professionals' attitudes to providing care

⇒ Professionals' lack of training

⇒ Access to appropriate Specialist care

⇒ Lack of equal opportunity compared with non-disabled peers

'Valuing People' (the Strategy for People with Learning Disabilities in the 21st Century) recommends mainstreaming care rather than providing Specialist services (Department of Health, 2001a). However, Baird *et al.* (2003) found that the ability to walk has a significant association on all aspects of attending the dentist and maintaining oral health, added to which, dental premises may not be accessible to all people with a disability. A review of the London Health Strategy (Greater London Authority *et al*, 2003) revealed that people with a disability were four times more likely than non-disabled people to find dental practices unsuitable or inaccessible. This means that people with physical disabilities are further disadvantaged in receiving dental care. Even where it is possible, it will take time for current dental premises to come up to a physical standard where access is equitable. Despite the imminent full implementation of the Disability Discrimination Act in relation to access to services that is due in October 2004, it is unlikely that all dental practices will have complied. Meanwhile, as a result of such barriers, people with a physical disability have lower levels of oral health and a higher level of untreated decay than the general population (Russell and Kinirons, 1992; Francis *et al.*, 1990). Some of the access issues relate to professionals' attitudes (See Case Scenario 5 – a recent case, currently under scrutiny by the Disability Rights Commission) and these can only be addressed through disability awareness training.

Case Scenario 5

⇒ Ms R is disabled through polio, she uses an electric wheelchair and an assistance dog to help her get around.

⇒ The local GDP refused her treatment because he would not allow the helping dog onto the premises

⇒ At the same time, the drive and three steps to the front door of the Practice prevented her using her chair. She had to try to cope by using sticks which was both painful and dangerous.

⇒ She is unable to find an alternative dentist and is left with a broken tooth.

⇒ She was not offered a home visit.

⇒ The Disability Rights Commission are currently investigating this case

Some General Dental Practitioners may have neither the experience nor the desire to provide care for people with disabilities (Fiske *et al.*, 2002)). For example, accessing NHS dental care remains a challenge for people with a positive HIV or Hepatitis C status (Fiske *et al.*, 2002) despite the fact that both the General Dental Council and the British Dental Association recommend that people with a positive viral status are treated in mainstream General Dental Practice. Although Gibson and Freeman (1996) point out that dentists with greater clinical experience and knowledge of treatment of HIV patients had more positive attitudes, clinical behaviours and interactions than others. In a recent study on the views of General Dental Practitioners providing care to people with a physical disability, Baird et al. (2003) found that, whilst most practitioners were providing some care for this group of people, they appeared to be limiting the treatment they offered and keeping it simple. The authors state that this could be interpreted as discriminating against patients with a physical disability. This type of discrimination is likely to occur for other groups of disabled people, for example those people with a learning disability or with mental illness (See Case Scenario 6 – a real event).

Case Scenario 6

⇒ A young man with a mild learning disability damaged his upper central incisors and required jacket crowns.

⇒ His mother was informed that there were 2 types of crowns and that he would be provided with the cheaper, less aesthetic, plastic type.

⇒ She was told that the more expensive porcelain crowns would be a waste of time, effort and money as he would very likely damage these teeth again.

⇒ Her son's appearance was important to both him and his mother, and she insisted that porcelain crowns were fitted.

⇒ They were fitted and remain undamaged a number of years later.

7.5 Care Pathways

It is well recognised that both the oral health care and the oral health of people with disabilities can be improved through the development and practice of integrated care pathways (BSDH, RCS, 2000; BSDH 2000a, 2000b, 2000c, 2000d, 2000e). They recognise the rights and needs of individuals. In the spectrum of health care, they move away from the '*Medical Model'* (that measures absence of disease as an indicator of health) at one pole of the spectrum towards the '*Social Model* (that measures well-being and emotion) at the other end. The result is to reach a reasonable mid-way path that brings together the medical and socio-environmental approach that considers quality of life, symptoms, well-being and function. This approach is integral to Special Care Dentistry where an individual with a disability can have a plethora of health and social personnel or agencies involved in their care. Care Pathway 1 provides an example of how this can work.

Care Pathway 1

⇒ Gwent Community Dental Service provides care for all people Requiring Special Care Dentistry who cannot access the GDS

⇒ Referrals are from GPs, Primary Care Dentists, the Hospital Dental Service and other health professionals eg Dieticians, Speech and Language Therapists. Referrals can be for 'one off' treatments but are mainly for continuing care

⇒ Adults with learning disabilities are referred through the Learning Disability teams as well as through outreach work by the dental team at day centres and residential homes.

⇒ Care programmes for specific groups are led by senior Special Care Dentists i.e. for older people, and adults with learning disabilities, mental illness and medically compromising conditions.

⇒ Each programme includes aims and objectives, targets and monitoring strategies. Approximately 1800 adult patients receive regular care within these service programmes. Others receive 'one-off' treatments.

⇒ The dental team carries out oral health promotion with carers in group residential homes and day centres, as well as on a 'one to one' basis with patients.

⇒ Coordination of these services and treatment is carried out by experienced Special Care Dentists. They work in fixed clinics, mobile units and on a domiciliary basis. Dentists trained in sedation provide care for those patients unable to tolerate routine dentistry; and CDS dentists carry out care under GA in the local District General Hospital in collaboration with the Department of Oral and Maxillofacial surgery.

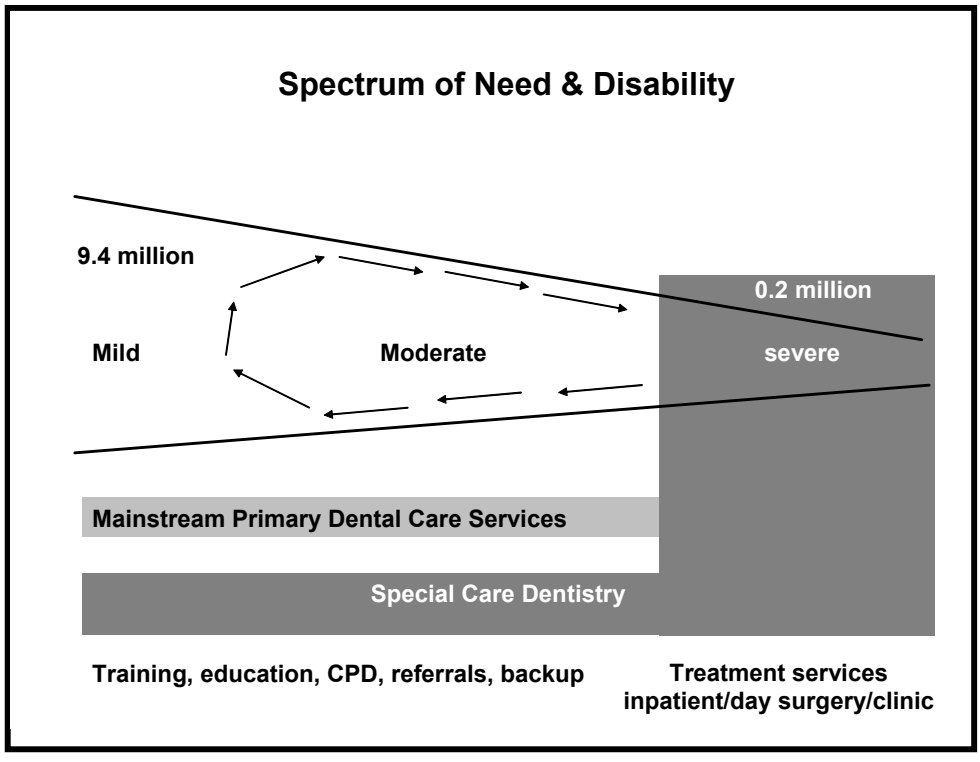
Care Pathway 1 illustrates the complexity of the skills required to manage these integrated care pathways. For this reason, it is essential that much of the training

in Special Care Dentistry and much of the delivery of Special Care Dentistry takes place in the community alongside and in communication with the other teams involved in the care of people with disabilities.

Within the dental profession, such an integrated care pathway provides both timely and appropriate patient care and timely and appropriate support for sectors of the dental profession. It also allows those members of the dental profession who wish to have advice and support in order to develop their skills in caring for people with disability to do so safely under the guidance of more experienced colleagues. In this way more Primary Care Dentists will feel confident to treat people with disabilities and some may go a step further to develop a Specialist Practitioner interest

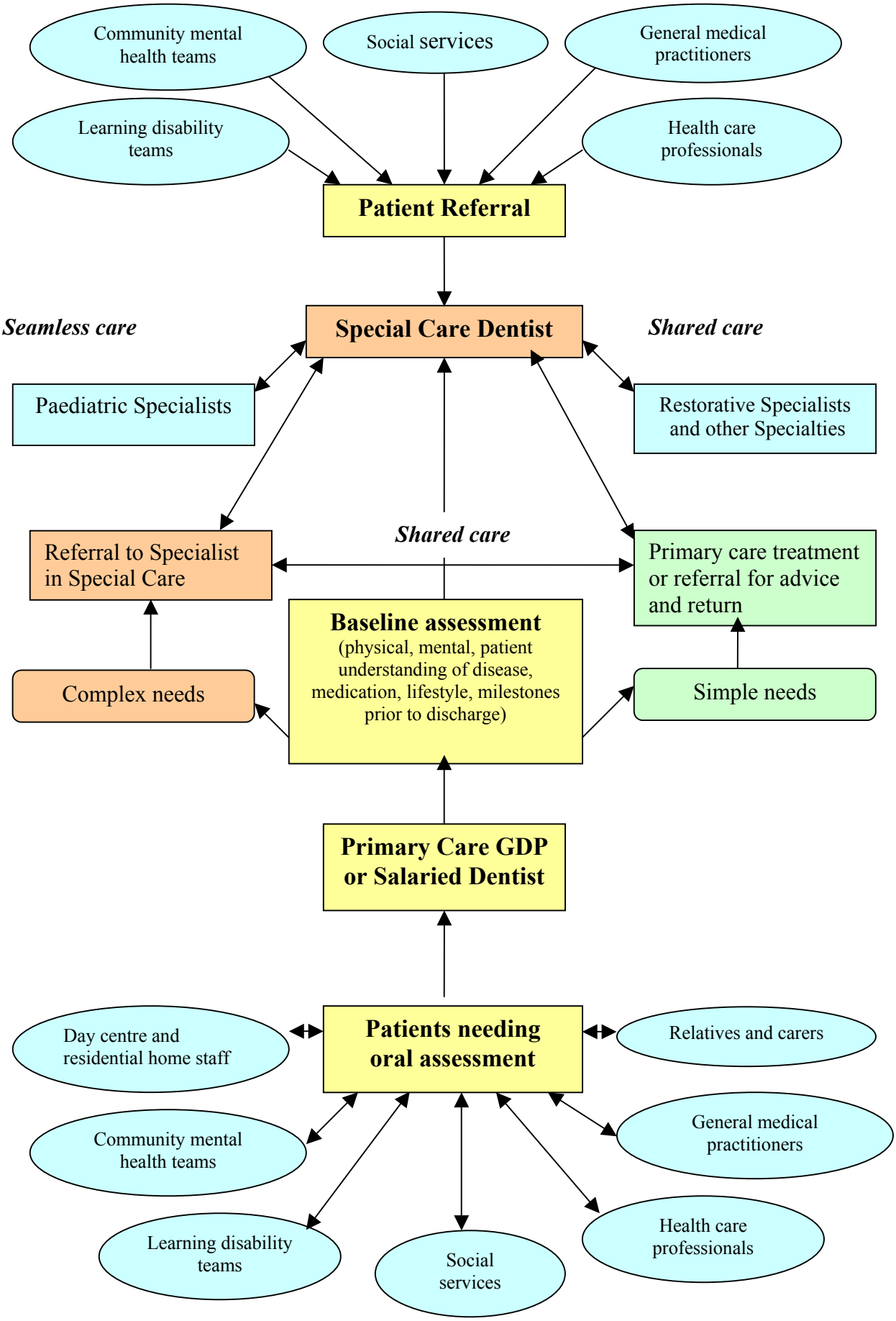
Those people who are at the severe end of the spectrum of disability and complex additional needs should have access to ongoing care from Specialists in Special Care Dentistry. Whilst bearing in mind that care pathways are not static, Figure 8 sets out how Specialists in Special Care Dentistry would integrate to support the Primary Care Dental Services, provide training programmes in Special Care Dentistry and provide oral health care for those people with Specialist needs.

Figure 8. The Integrated Role of Special Care Dentists



A model of best practice for the integration of Specialist and Generalist care to provide Special Care Dentistry is presented schematically in Figure 9. It also involves many other partners who may be involved in a care pathway

Figure 9. An Integrated Model of Best Practice



8.0 Future Developments

8.1 Undergraduate Teaching

Currently there is limited input to undergraduate curricula, and the GDC requirements for this type of educational experience are minimal (GDC, 2002). The Specialist Society for Special Care Dentistry, The British Society for Disability and Oral Health (BSDH), has highlighted its concern to the General Dental Council (GDC) that, without a critical level of experience in the discipline of Special Care Dentistry, new graduates will lack the confidence and the ability to provide care for people with disabilities in mainstream general dental practice. The GDC replied, assuring BSDH that this would be considered in the next curriculum review. Without changes to the undergraduate curricula, the situation of people at the mild end of the spectrum of disability being unable to access appropriate care within the Primary Dental Care Services will be perpetuated.

Meanwhile, BSDH is reviewing current undergraduate training in Special Care Dentistry and, in due course, will be making curricula recommendations. The future Specialist will need to contribute to the teaching of undergraduates, postgraduates and the wider dental team including PCDs, with several teaching sessions per week. In the long term, this will enable more care to be mainstreamed in line with the learning disabilities strategy (Department of Health, 2001a).

8.2 Training in Special Care Dentistry

In the past there has been a piecemeal approach to training in the provision of dental care for individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability. The majority of individuals who currently provide such care do so as Generalists who have developed their special interests in this field to a range of levels. A small number of people have developed this interest to an academic or Consultant level by following a range of *ad hoc* educational and training experiences as well as learning on the job. Despite this situation, Special Care Dentistry has developed to the point where it is supported by two well established and respected Specialist Societies (namely the British Society for Disability and Oral Health and the British Society of Gerodontology) and their scientific journals (The Journal of Disability and Oral Health and Gerodontology, respectively). Additionally, both Societies hold two scientific study days each year with attendance ranging from 80 to 220 people.

It is envisaged that there will be a need for services and thus training programmes for Specialists working across primary and secondary care settings, which would involve liaison with other dental and medical Specialties and agencies. The volume of trainees should commence at about ten percent of the number of Specialists, with the necessary adjustments made, depending on the profile of dentists mediated onto the Specialist list who are likely to come from across the age spectrum.

The discrete and distinct body of knowledge, skills and competencies required of a three-year training programme in Special Care Dentistry is outlined in the JACSCD document (2003) “Training in Special Care Dentistry”. This programme meets the criteria required by the EU directive and is comparable in structure and duration to other Specialties that already meet these criteria. In developing the

training document, JASCD drew on the equivalent documents of other Specialties, in particular those of Paediatric and Restorative Dentistry. The training programme set out in the document also embraces the *"7 Pillars of Competency"* in Specialist training set out in the recent document Modernising Medical Careers (department of Health, 2003), namely that training should be competency assessed, service-based, patient centred, flexible, structured and streamlined, coached and quality assured.

Although there is as yet no Specialty in Special Care Dentistry there have been at least two training posts established in Special Care Dentistry within the CDS in areas of England in recent months. JACSCD has encouraged the adoption of their document "Training in Special Care Dentistry" as a basis for these training posts in an effort to lend some structure and commonality to current training. The recognition of a Specialty would automatically bring structure, commonality, competency assessment and quality assurance to future training pathways in Special Care Dentistry.

8.3 Training and Education

All health professionals, whatever their sphere, are required to participate in continuing professional education Therefore, clinicians providing Special Care Dentistry for people with disability should have access to further education in this field at the appropriate level – be it Specialist or Generalist. Recognised Specialists, either mediated under transitional arrangements or via higher Specialist training would subsequently establish formal mechanisms for addressing clinical governance including professional development, peer review, audit, etc. across organisational boundaries (Department of Health, 1999b).

Individuals recognised as Specialists will have the approved experience and skills to train and educate both new Specialists in Special Care Dentistry, and interested Generalists who wish to provide evidence-based care for patients for people with less severe disability. Generalists require the advice and back-up of Specialists when they face situations beyond their scope. At the moment do not always have a clear route to access such support.

Special Care Dentistry should be a separately recognised NHS Specialty with its individual Specialist code. This will enable service activity to be monitored nationally. Whilst Wales has now acknowledged the value of Special Care Dentistry through the allocation of an individual Specialist code, England is still considering the situation.

9.0 Career Flexibility

As a broad-based Specialty, Special Care Dentistry has an inherent flexibility as a result of the diversity of the patient base and because of the easily transferable skills associated with this field of dentistry. The development of a Specialty would provide a viable career pathway with the opportunity for career progression and job satisfaction. Appropriate training (as laid out by JACSCD, 2003) would lead to a career in a Specialty with a sustainable need and demand (See Section 4 of this document).

It is envisaged that the Specialty would work across primary and secondary care settings, recognising the importance of seamless care and providing Specialist care in the community, and outwith Hospital Dental Services where appropriate and possible. In order to achieve a sustainable supporting infra-structure it would need to be managed within the NHS through Hospital Trusts and salaried Primary Care Services.

10.0 The International Picture

A number of countries are moving towards the establishment of a Specialty in Special Care Dentistry. Inevitably, terminology varies slightly from one country to another. However, New Zealand and Brazil already recognise this area of dentistry as a Specialty. The Royal College of Australasia has developed a Fellowship examination in the subject and America has affiliated itself with the Royal College of Surgeons of Edinburgh (through their Membership in Special Needs Dentistry) to formalise its training programme in Hospital Dentistry. To some extent, the USA has already formalised training in Special Care Dentistry through the establishment of dental training programmes within its hospitals managed by the Department of Veterans Affairs.

Scandinavian countries are looking to the UK to lead the way in the development of a Specialty in Special Care Dentistry. Within the UK it looks likely that Scotland will take the lead. NHS Education for Scotland is currently looking to develop a framework for a training pathway in Special Care Dentistry. Whilst, they recognise that there is, as yet, no Specialty in Special Care Dentistry, they recognise that there is a specific need for training in this clinical area that is currently not well served. The pathway they plan to develop will be similar to the Specialist Registrar training in Paedodontics and Orthodontics. As such, entry will be post-MFDS and the training will involve a three-year programme followed by an exit examination. The pathway will be primarily a community-based training with appropriate Hospital Dental Service links. It is anticipated that two training places a year will be created in the first instance. It is likely that this will come to fruition within the next twelve to eighteen months.

11.0 Support for a Specialty

Support for a Specialty in Special Care Dentistry has grown both within and without the dental profession. Over the last eight years, the Dental Faculty Board of the Royal College of Surgeons has supported the Faculty Development Group for Community Dental Practice; established a Working Group to provide an expert view on training in Special Care Dentistry; and supported that group's recommendation to set up the Joint Advisory Committee for Special Care Dentistry (JACSCD) as a free-standing committee, to promote and oversee the introduction of training programmes, the development of curricula and training standards and formative assessment processes.

A survey exploring the views of Specialists in both Paediatric and Restorative Dentistry is underway. Data is still being analysed. With response rates of over 70% so far, early findings indicate that the majority of Specialists in Paediatric Dentistry support the development of a Specialty in Special Care Dentistry

(Hunter *et al.*, 2003). At the time of writing the data related to the Specialists in Restorative dentistry has not been analysed. However, anecdotal evidence from the current President-elect of the British Society for Restorative Dentistry suggests that, in his opinion, the majority of Specialists in Restorative dentistry also look favourably on the development of a Specialty in Special Care Dentistry (King, 2003).

Without the dental profession, unsolicited support has been forthcoming from RADAR – the disability network (Stead,2003), from MENCAP (Holland, 2003), form the Health Council (incorporating the Disability Partnership of the Prince of Wales) (Health Council, 2002) and from the Disability Rights Commission (Fiske, 2003a).

12.0 Further Research

Further research is always required. It is requisite to monitor values, opinions, need, service delivery and effectiveness, and the delivery and appropriateness of training. It is also required to inform appropriate change. This report highlights the need for a Specialty in Special Care Dentistry and further research should occur in parallel to, and following on from, the creation of the Specialty of Special Care Dentistry. This is something that should be an integral part of the re-evaluation of all Dental Specialties.

Within Special Care Dentistry areas of research could explore issues of service delivery and organisation from the perspective of clinicians, patients and their carers. Qualitative research using staff and patient focus groups would be a valuable method of doing this.

Questionnaire surveys of various groups could be used to explore the level of Special Care Dentistry provided, aspired to, future interests and developments, models of good practice, etc.. Such surveys could target Consultants in Dental Public Health at Primary Care Trust or Strategic Health Authority level; directors and senior staff of Personal and Community Dental Services; Paediatric Dentistry consultants and Specialists regarding the seamless transition of children with disability from Paediatric Dental services to adult Special Care Dental services; and Restorative Dentistry consultants, Specialists and trainees regarding their future role and how they view their role related to Special Care Dentistry.

Comparisons of urban with rural areas and of teaching with non-teaching districts will be expected to reveal differences. Facilities and staffing are likely to differ considerably. Patients may be offered different treatment plans according to where they reside, local policies, and local treatment philosophies. Continuing research is required to identify areas of inequality of treatment options and provision that may occur as a result of such differences so that they can be appropriately addressed.

13.0 Conclusion

The dental profession has a responsibility to ensure that the needs of the most vulnerable sections of society are addressed and that access to services and service outcomes are equitable across societal groups. It is very clear that high overall standards of clinical care, reduced variations in access to and outcome of services, and clinical decisions based on the most up-to-date evidence of what is known to be effective are key to the future delivery of NHS care for people with disabilities.

People with disability and additional complex needs are currently receiving care in a non-uniform, and often piece-meal manner, from various sections of the profession. They must clearly benefit from improved access to good primary dental care and the services of designated Specialists where the needs and demands of patients' are beyond the experience and scope of a generalist. This is one of the greatest current challenges to the dental profession, but it is a silent challenge as many of these patients do not have a public voice. This option is appropriate for the majority of people with mild and moderate special care requirements. However, for people with complex needs, their interests would be best served by the establishment of a dedicated Specialty of Special Care Dentistry.

The creation of 200 Specialists in Special Care Dentistry would provide:

⇒ People with multiple disabilities and complex needs with equitable access to Specialist dental care and an on-going dental service

⇒ Dental practitioners working in Primary Care Services with advice and support (as required) to give them information and confidence to treat people at the less severe end of the spectrum of disability

⇒ A back-up service for General Dental Practitioners

⇒ Training for Specialist Practitioners and safety-net services for their patients as required

⇒ Continuing professional development for Generalist and Specialist Dental Practitioners

⇒ Appropriate support for other Dental Specialties

Quality services will therefore be developed and maintained through the provision of Specialist-led dental services, working in partnership with other agencies to care for people with disability and complex additional needs.

The model of care of a Specialist in Special Care Dentistry who is involved in treatment planning, and then either providing care or being involved in shared care with other Specialists, Specialist Practitioners or interested Generalists is the way forward to ensure quality care for people with severe disabilities.

14.0 Recommendations

The Joint Advisory Committee in Special Care Dentistry makes the following recommendations as a result of the information set out in this document:

1. ***Mechanisms should be put in place forthwith to recognise the Specialty of Special Care Dentistry*** within the NHS, Royal Colleges and to create a Specialist Register at the GDC. The latter move will enable existing dentists with the requisite skills and experience to be mediated into the Specialty.
2. ***JASCD should become a Specialist Advisory Committee for Higher Training in Special Care Dentistry*** to oversee training to provide quality care in line with health policy to meet identified health needs.
3. ***There should initially be 10-20 training posts in the Specialty*** with a minimum of one per Strategic Health Authority.
4. ***Specialists in Special Care Dentistry should be predominantly community based.***

Demography of Disability **Annex 1**

	Volume of need	**Source**	**Reference**	**Predicted change**
Physical impairment or disability	8 million have affected by diseases related to arthritis 73% of people with osteoarthritis have difficulty in carrying out usual daily activities	Disability Partnership	DCMS Towards 2004 seminar, 18/07/00	
Sensory impairment or disability	5.8 million have a hearing loss 1.7 million have a serious sight problem	Disability Partnership	DCMS Towards 2004 seminar, 18/07/00	
Intellectual impairment or disability	1.2 million people are registered with a learning disability in England of which 210,000 (children and adults) have severe or profound learning disabilities which are uniformly distributed geographically and across socio-economic groups 1-2% of the population have a mild learning disability which amounts to about 1.2 million in England 0.2-0.3 million have a severe disability in the UK 10,000 with a disability live in NHS facilities and 53,400 in residential care	Valuing people: a new strategy for Learning Disabilities in the 21st century Disability Partnership	Department of Health, 2001a Disability Partnership, 2000b	Increase in the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years as a result of inc life expectancy, inc in autism and prevalence in minority ethnic populations
Mental impairment or disability	7.2 million cases of mental health problems	Disability Partnership	DCMS Towards 2004 seminar, 18/07/00	
Medical impairment or disability	Musculoskeletal disorders (e.g. Osteoarthritis) Cardio-respiratory and neurological disorders	Disability Partnership	Disability Partnership (2000b)	Increases with ageing population

Emotional impairment or disability	Dental phobics? Agoraphobics?			
Social impairment or disability	250,000 have a severe facial disfigurement	Disability Partnership	DCMS Towards 2004 seminar, 18/07/00	
Developmental impairment or disability	Genetic or congenital disorders, eg Downs syndrome: incidence of 1.5 per 1000 births Edwards syndrome: incidence of 0.3 per 1000 births with only 10% of children surviving the first year Cerebral palsy develops in 2-3 per 1000 live births	Disability Partnership	Disability Partnership (2000a)	Longer life span 1/3 of people with cerebral palsy will have an IQ of <50
Combination of a number of impairments and/or disabilities	People with a learning disability have a higher risk of epilepsy than the rest of the population 15% of people with spina bifida will have learning difficulties The majority of people with Downs syndrome have IQs in the range 33-55 and a higher average incidence of epilepsy and other medical problems			
Older people	9.4 million (16% of UK population)	Govt Actuary's Department, 2002	Tinkle *et al*2003	Increase to 12 million (19% of population)
Total Disability	9.4 million disabled adults in the country and 0.4 disabled children	Disability Partnership	People with disabilities and Holiday Taking	

Citation	Special care groups	Research design	Key findings	Oral condition/disease
Carr et al, 1997	Mental retardation and developmental disabilities	Repeated measures: two groups both received instruction, one provided manual toothbrush, the other Interplak; n=56 adults all with MR, of differing dependence for oral hygiene	Individual tooth brushing instructions provided to participant staff prior to receiving assigned plaque-removing instrument; measures taken at baseline and every 3 months for 1 year; Interplak toothbrush significantly improved gingival health (minor differences notes in debris and calculus)	Dental hygiene
Mojon et al, 1998	Elderly long-term care residents	Pre-post experimental/control; n= 116 elderly long-term care residents, primarily dependent all cognitively able to give consent	Preventive oral health programme provided to providers (interactive lecture, slides and practical demonstration) residents assessed prior and at 18 months; no decrease in plaque index measured, however, bacterial counts and active root caries decreased.	
Lewis *et al,* 2002	Adults with developmental disabilities residing in community settings	353 adults in LA,	Need for preventive dental services identified	
O'Donnell *et al*, 2002	People with handicapping conditions	General dental practitioners in Hong Kong to treat patients with handicaps. A questionnaire and practitioner scale were developed and circulated to 400 general dental practitioners of whom 250 responded giving a response rate of 62.5%.	59.6% of practitioners saw between one and five patients with handicaps per year; 15.6% saw none at all. The mean score was 33.68 (SD=9.19) on a scale with a range from 0 to 60. General dental practitioners were relatively enthusiastic about treating people with handicaps but felt it was not economically viable and that the Government should play a more prominent role in provision of dental care for this group	

Friedlander AH & Marder SR, 2002	Schizophrenia	Review article	Advanced dental disease associated with inability to plan and perform oral hygiene procedures, medication which results in xerostomia, limited access to care associated with paucity of financial resources and adequate number of dentists comfortable with providing care	
Tiller *et al*, 2001	Oral health status and dental service use of adults with learning disabilities living in residential care and in the community	Cross-sectional study: clinical survey and face to face interview questionnaire	Both groups of adults had similar levels of dental caries experience (DMFT scores). However adults living in the community had significantly more untreated decay (1.6 cf 0.7) and poorer oral hygiene. Adults in residential care had significantly more missing teeth (10.1 cf 7.5). Adults with learning disabilities living in the community had greater unmet oral health needs than their residential counterparts. They were less likely to report a regular pattern of dental attendance than their residential counterparts (55% cf 85%) and more likely to attend when in trouble (30% cf 10%) A significantly lower proportion of community living subjects used the CDS than residential subjects (23% cf 47%)	
Turk *et al*, 1997	Women with cerebral palsy: mental retardation 934%0 learning disabilities (26%) and seizure history (40%)	Telephone questionnaire of 63 women residing in the community	43% reported poor dental health (secondary health conditions) poor dental health was associated with a history of seizures	
Taylor et al, 1994	Pre- and post-retirement oral health assessment (perceived and normative)	Perceived and normative dental needs were assessed for people for pre-retirement (55-64 years) and retirement age (65-74 years) in	Of the pre-retirement group, 77% were dentate compared with 65% in the older cohort. The younger age-group was more likely to believe teeth were more important and to perceive a need for dental care. People who attended for the examination were more likely to perceive a need for	

		Camberwell, London, using a postal questionnaire and dental examination.	(64% and 15% respectively) and want treatment (39% and 17%) than non-examines. Also, they were more likely to be unhappy with their appearance (43% and 20%) and to be in pain (42% and 21%). Treatment need was similar for both groups with regard to restorative and extraction needs. However, the retirement group were more likely to have deep periodontal pockets (33% and 8%) and a greater normative need for denture	
Daly, 2002	Homeless people		Problems with mainstreaming clients Lack of support for clients who are housed may reduce access to dental care	
Coulter *et al* (2002)	People with HIV	This is a longitudinal study of interview data collected in a probability sample of adults with HIV receiving health care in the US	Oral health is strongly associated with physical and mental health but provides noteworthy unique information in persons with HIV infection.	Major issue in the late 1980's and 1990's but the need for special services is reducing as treatment improves the length and quality of life. This facilitate the use of routine dental care services by people with HIV infection.
Shaw *et al*, 2000	People with head and neck cancer	Review	The outlook following treatment for head and neck cancer continues to improve and, as people keep their teeth into later life, dentists will increasingly be expected to address the oral problems that patients experience after radiotherapy	

Steele *et al* 1998	Older people living in the community matched with older people in residential care	Cross-sectional study including dental examination and questionnaire as part of National Diet and Nutrition Survey with matched subjects (free-living and institutionalised)	Institutionalised adults were more likely to be edentulous (79% cf 50%), higher levels of unsound teeth (3.3 cf 1.7) and a higher prevalence of root caries (RCI of 46% cf 26%).	
Stiefel *et al*, 1990	Chronic mental illness	37 patients with chronic mental illness in UK	Higher D and M; lower F component	
Waplington et al, 2000	Homeless people with mental health problems	study investigated the **dental** needs, demands and attitudes of a group of homeless people living in a hostel in Birmingham, many of whom had mental health problems. **dental** examination. Five of the subjects were selected to take part in semi structured interviews.	Thirty-one per cent of the subjects were found to be edentulous, with only 32% wearing dentures. The dentate subjects had a mean DMFT (+/-SE) of 15.9 (+/-7.8). High levels of **dental** need were found amongst the dentate subjects who had an average of 3.6 (+/-3.9) decayed teeth and 54% had one or more teeth with obvious pulpal involvement. Eighty-five percent of the dentate subjects had some **dental** wear leading to exposed dentine. The periodontal condition was generally poor, 50% of dentate subjects having excessively mobile teeth. The interviews revealed a low level of perceived need and indicated that difficulties would be encountered in tailoring services to meet this client group's requirements.	
Lewis *et al, 2001*	Hospitalised psychiatric patients in Cardiff		63% edentulous	
Kelly *et al*, 2000 and Nunn *et al*, 2000	Older people surveyed within the Adult Dental Health Survey of 1998		Root caries becoming a public health problem in older people. Nearly 2/3 of root surfaces were vulnerable	
Turk *et al*, 1997	Women with Cerebral Palsy	Cross sectional telephone survey of women living in the community	Secondary conditions were common; 43% reported poor dental health	

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