



***Promoting the Oral Health
of People with Disabilities***

Proceedings of a forum

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***Published by the Dental Health Foundation in Association with The School of Dental
Science, University of Dublin, Trinity College, and the Centre for the Study of
Developmental Disabilities, National University of Ireland, Dublin***

November 2000.





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Preface

This forum was initiated by the Dental Health Foundation, Ireland as a response to the increased awareness of the oral health needs of people with disabilities. The Dental Health Foundation, the Centre for the Study of Developmental Disabilities in National University of Ireland, Dublin (NUI) and the Dental School & Hospital in Trinity College Dublin (TCD) were the partners involved in bringing the various interested groups together. Representatives of the key groups who attended the Forum included; carers groups, organisations representing specific special needs groups and disability services within the health boards, dental services in the health boards and academic centres in the Republic of Ireland and Northern Ireland. A range of speakers from the dental schools in Ireland and the United Kingdom as well as the service providers were invited to make short presentations on key topics. This report summarises the proceedings of the Forum and key issues that arose. It is hoped that this report will act as a stimulus towards addressing the many issues involved in providing oral health care to Special Needs Groups in the community.

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Opening Address

John Clarkson, Dean of the Dental School & Hospital,
Trinity College, Dublin

Professor Clarkson opened the Forum and welcomed representatives from the Irish Department of Health & Children; the Department of Health and Social Services in Northern Ireland; University College Cork; National University of Ireland, Dublin; the University of Newcastle upon Tyne; the Eastman Dental Institute London and the officers and staff of the health boards. He extended a warm welcome to representatives from the many agencies that provide services to people with disabilities. Professor Clarkson welcomed the opportunity to introduce these representatives to those in the dental profession who are providing dental services to people with disabilities. Professor Clarkson expressed the hope that the Forum would provide an opportunity to consider the views of the service providers and policy makers. The presentations by the various speakers were intended to generate discussion, which would help to identify the types of information, services, training and research necessary to make significant progress towards improving the oral health of people with disabilities.

PRESENTATIONS

PROMOTING HEALTH FOR PEOPLE WITH INTELLECTUAL DISABILITY.

Janette Tyrell, St Vincent's Hospital, Fairview, Dublin.

John Hillery, the Centre for the Study of Developmental Disabilities in National University of Ireland, Dublin (NUI)

When people with learning disabilities require primary health care, the question to be asked is whether this problem is of a medical, psychiatric or dental nature? In many cases the general medical practitioner (GP) is not the first port of call when people with learning disabilities seek access to health care, according to Dr Janette Tyrell, Senior Registrar in Psychiatric Learning Disabilities at St Vincent's Hospital, Fairview.

In 1994, The Commission on the Status of People with Disabilities reported that health professionals tend to see the disability first rather than the patient in need. Those with disabilities should be viewed as individuals who can access many of the same services as the rest of the population. The Strategy for Equality (1995) advocates delivery of health care as near as possible to the person within the community. It follows that access to specialist services for those who need them should be easy. It is increasingly recognised that we need to promote the concept of normalisation within health services delivery for people with disabilities.

For the general population general medical practitioners (GPs) provide acute 24-hour care, health promotion and health screening. People with disabilities require GPs for the very same reasons. In addition, they require care for needs specific to their conditions and also to address family needs regarding long-term prognosis, counselling and other such services. Dr Tyrell argued that while special needs specific to a condition may be monitored in institutionalised settings, GPs may be largely unaware of these needs.

Dr Tyrell reviewed research regarding primary care for people with disabilities. Howells (1986) reported that people with disabilities had an inadequate number of consultations or health checks with general practitioners. An easily treatable build-up of earwax went undetected in many cases resulting in severe hearing difficulties. A Welsh survey in 1995 showed that three

in ten people with learning disabilities had a psychiatric illness. Martin et al (1997) reported that 83% of people with disabilities have undetected health problems. Mencap (1997) reported on GPs' reluctance to tackle smoking, obesity and general screening for special needs patients.

Dr Tyrell recommended specific training for GPs and carers as well as the need for liaison officers. The *Care in Wales* strategy has developed a comprehensive policy on service delivery to people with disabilities. It advocates greater access to GPs and the promotion of annual health checks.

A project conducted by the Centre for the Study of Developmental Disabilities in NUI examined the health status of adults with intellectual disabilities in residential care. A large proportion had between one and four health problems that could lead to behavioural problems if undetected. A person with no verbal skills may portray pain through self-injurious behaviour. The medical problems reported were respiratory, gastrointestinal, musculo-skeletal and cardiac, while 20% of the sample had epilepsy. An examination of medication revealed high use of polypharmacy. Dr Tyrell reported that the increased use of behavioural therapies has lessened the requirement for some medication.

Dr Tyrell concluded with the recommendation that “*no person should be overlooked for treatment...because of a disability*”. She advocated primary health care as the gateway to specialist services. Standardised annual health checks and regular sensory checks should be provided for all with disabilities. People with disabilities should be encouraged to utilise GP services for primary health care and regular health screening.

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SPECIAL NEEDS: TRAINING PROGRAMMES

June Nunn

Newcastle upon Tyne Dental School

What has brought about the heightened awareness, in many countries, of the requirement for dental training in special needs? Dr June Nunn of Newcastle upon Tyne Dental School said this could be attributed to the increasing number of people who require specialist dental care. Medical advances have ensured that a higher proportion of those with disabilities survives to adulthood. Dr Nunn referred to a young patient she has been treating who suffers from osteogenesis imperfecta, who 10-20 years ago would not have survived childhood. The demography of the population is such that people with disabilities are living to an increasingly older age. Advocacy groups have called for specialist dental services and have forced service providers to modify special needs care.

Dental services in Britain are provided through the community dental service (CDS) and general dental practitioners (GDPs) at primary care level and through hospitals at secondary level. A dramatic change occurred in the delivery of primary dental care in the UK in 1990. A policy of continuing dental care for everyone through the general dental services (GDS) was introduced. Dental services for the normal school child were transferred to the GDS and thus the remit of the community dental service (CDS) changed. This service now collects epidemiological data on the oral health of the local population, offers preventive care and health promotion as well as a screening service in schools and other institutions. Lastly the service provides an essential 'safety net service' that delivers care to patients who are unable or unwilling to attend the general dental services.

This 'safety net' function entails looking after a complex patient spectrum. A lack of suitable training among community dental officers together with the changing patient profile highlighted the need for additional training and the development of a speciality. The need for this was illustrated by an example given by Dr Nunn: a colleague had recently referred a patient to her for secondary care. The patient was described to her as 'not the full shilling' and her colleague did not feel equipped to deal with the patient's special needs. Dr Nunn said the patient essentially required routine dental care and was only 'special needs' because of the requirement for sympathetic handling, some treatment under sedation and an awareness of the problems faced by both the patient and the carer in accessing dental care.



Having undergone the necessary basic general professional training and decided to specialise in the care of those with special needs, Dr Nunn outlined how one might undergo further training. Masters degree courses in special needs dentistry are available at Guys, Kings & St. Thomas' Dental School (GKT), the Eastman Dental Institute, London and at the Dental School in Newcastle upon Tyne. The MSc in Sedation & Special Care Dentistry at GKT includes basic sciences, treatment planning, behaviour management, general anaesthesia and local anaesthesia sedation, human diseases, medical emergencies, special needs groups, community skills, medico-legal issues and research techniques. Candidates attending the MSc in Special Needs Dentistry in the Eastman Dental Institute in London focus initially on critical reading, pain management and examination techniques with other postgraduate students. Aspects specific to special needs are delivered through lecture programmes covering general medicine and dental care for special needs patients, with an emphasis on medically compromised adults. The MSc in Disability & Oral Care offered in Newcastle upon Tyne is a modular system covering topics specific to disabilities, health service management, practical patient care and research.

Membership Diplomas are available for candidates having completed a masters qualification. The Royal College of Surgeons in Edinburgh offers a Diploma of Membership in Special Needs Dentistry, although this qualification is open to candidates who have not completed a formal training such as a MSc programme. The Royal College of Surgeons in England offers a Diploma of Member in Clinical Community Dentistry. Reflecting on the fundamental need for teamwork when providing services for people with disabilities, Dr Nunn identified the Diploma in Special Needs Dentistry as a further qualification for dental nurses seeking formal training in special needs. Dr Nunn said, "There is a recognition now of a need to formalise training, so that people are equipped with the necessary skills to provide such services. There is a need to deliver high quality, appropriate care for those people who are not in a position to voice their needs and demands. Please keep sight of that."

Contacts for further information regarding these courses include:

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PROVISION OF CARE: SPECIAL NEEDS - CHILDREN


Pádraig Fleming
Trinity College, Dublin

Dr Pádraig Fleming emphasised the importance of early referral of medically compromised children for dental treatment. Early Childhood Caries (ECC) poses a major problem for children with special needs. If ECC could be prevented, it would not only save money but also prevent considerable pain, infection and suffering in these children. Medically compromised children should attend a dentist by one year of age and be seen regularly thereafter. Dr Fleming agreed that although the dentist may not undertake treatment at this very young age the provision of preventive advice could be pivotal.

Many children with severe and profound learning disabilities have secondary medical complications, for example, 40-50% of children with Down's Syndrome have congenital heart conditions. Dr Fleming said that the presence of a physical disability in a child is often apparent but a medical problem in a child may often only be diagnosed by taking a careful history.

It is estimated that in Ireland approximately 600 babies are born each year with congenital heart disease. Approximately half of these children will not require treatment. Approximately two hundred children will require open-heart surgery, while the remaining 100 children may be treated using catheterisation procedures. After such surgical or catheterisation procedures approximately 50% require further intervention. Approximately 10% of children who are born with congenital heart disease will not survive infancy/childhood. Dr Fleming stressed the need for children with congenital heart disease to attend a dentist regularly. Approximately three to four children present in Our Lady's Hospital for Sick Children in Crumlin each year with infective endocarditis caused by oropharyngeal streptococci. These children are treated by cardiologists and infectious disease specialists. Although rare, the development of brain abscesses can occur in children with complex congenital heart disease. Children with inoperable heart conditions often pose major anaesthetic risks.

A system is currently being developed whereby parents will be given a card with their child's cardiac diagnosis - this card may then be presented by the parents of the child to the dentist.



This opens the lines of communication, as the dentist may now contact the cardiology team if any further advice or information is required about a child with congenital heart disease.

There are approximately 100-120 new cases of cancer diagnosed in children in Ireland each year. During treatment a central line is inserted and patients are therefore at risk of developing infective endocarditis. Oncology patients at Our Lady's Hospital for Sick Children in Crumlin undergo chemotherapy, radiotherapy, surgery, bone marrow transplantation or a combination of treatments. During therapy they are at risk of developing mucositis and ulceration of the mouth as well as being prone to infection and bleeding. A good diet and nutrition play an important role in preventing high decay rates in these children. Dr Fleming said that children with tumours in the head and neck region who undergo radiotherapy are at a high risk of developing decay due to the changes in quantity and quality of saliva, which results from the effects of radiotherapy on the salivary glands. Their treatment is managed on an acute needs basis: following discharge from hospital they are referred for regular care to their local dentist. Many children may be understandably needle-phobic following extensive treatment in hospital; this may pose dental behaviour management problems later on.

Children requiring treatment under general anaesthetic in Our Lady's Hospital for Sick Children in Crumlin, in 1999 were made up of the following groups: cardiac patients (44), oncology patients (17), cleft lip/palate patients, (8) special needs children from special schools and children with acute trauma or acute infection (129).

Dr Fleming suggested that there should be more dental consultations for special needs children in hospitals. Increased specialty training programmes in paediatric dentistry and increased remuneration for specialists in the health board dental services should improve the provision of future dental healthcare for medically compromised children.


PROVISION OF CARE: SPECIAL NEEDS - CHILDREN II

Tim Holland,
University Dental School, Cork.

Dr. Tim Holland in his presentation pointed out that numerous studies both in Ireland and abroad have established that dental caries prevalence among physically or intellectually disabled children is similar to groups without these disabilities. Levels of periodontal disease or gum disease on the other hand tend to be higher and oral cleanliness poorer in disabled groups. Unmet treatment need for special needs groups is universally high. Certain barriers exist which contribute to the lack of access to delivery of care; these include factors relating to the severity of the disabilities themselves, parental concerns about supervision and transport, and also access to buildings. In addition, a further important barrier exists within the profession itself, as dentists are sometimes reluctant to undertake responsibility for these patients because of concerns about behavioural problems. In order to develop a comprehensive service therefore, appropriate secondary care facilities must be put in place, so that general practitioners and health board dentists can refer patients who cannot be managed otherwise.

To this end, a unit was developed at the Cork University Hospital to provide a fully comprehensive secondary care service for patients with severe disabilities. This facility consists of a fully equipped and staffed operating theatre unit where treatment can be provided for referred patients under general anaesthesia. Access to other hospital services such as haematology, radiology and intensive care is also readily available. The service is provided generally on a day-stay basis, but patients can be admitted pre and post operatively as required.

In addition to providing the required facilities for treatment, adequate professional training is also essential. This should take place both at undergraduate and postgraduate level. A study completed in Cork in 1990 showed that 80% of physically or intellectually disabled patients treated were managed satisfactorily in a primary care setting, and only 20% required treatment in the secondary care unit described. Such units should also be used to provide continuing and postgraduate training.



The importance of a proper diagnosis of the need for primary and secondary care was stressed, as the cost of providing secondary care facilities for these patients is high. A study completed in Cork in 1998 showed that on the basis of such a unit being used for one day each week, fixed and variable costs resulted in a cost of approximately £700 per course of treatment. It was pointed out that increased usage of such a unit would reduce costs overall.

In conclusion it was suggested that the successful development of a comprehensive service for physically or intellectually disabled patients requires a combination of: appropriate training at both undergraduate and postgraduate level as well as the provision of appropriate secondary care facilities for those whose disabilities prevent them being treated in a general practice setting.

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PROVISION OF CARE: SPECIAL NEEDS - ADULTS

Roger Davies

Eastman Dental Institute, London

Dr Roger Davies of the Eastman Dental Institute in London discussed the services required when children with special needs grow up to become adults with special needs. He commended the discussion taking place in the Irish health services on the oral health care of special needs people. He stressed the need for planning such services and structures to support these services. Special needs clients fall into four categories, the elderly, the medically compromised, those with learning disabilities, and those with mental illness.

The Elderly


Dr Davies commented on the increased numbers of people over the age of 75 in the U.K. In the last century, longevity of human life increased by 30 years. This has implications for health care planning and provision. Significant numbers of people are presenting with musculo-skeletal (25%) and cardiovascular disease (13%). The findings of Overholser (1989) and Rosenborg et al (1989) are reinforced today: improvements in health care and greater acceptance of a healthy lifestyle are contributing to increased longevity as well as increases in the numbers of medically compromised people requiring dental care.

The Medically Compromised Patient

Dr Davies described the difficulties in obtaining accurate medical history records of those presenting with cardiac problems. In a WHO trial, 20% of 50-59 year old men with angina never recalled being told they had cardiovascular disease (Shaper, 1993). Patients in this category also include those with neurological and endocrine diseases, bleeding problems and malignant diseases. There is a considerable increase in the numbers of anticoagulated patients. Patients with more severe conditions may experience considerable difficulty in obtaining dental care.

Learning Disability

In the 1970s, it was said that the greatest unmet need of disabled people in the UK was for oral health care. There is a belief that in the UK that less than half of general dental practitioners are providing NHS dental care. This move towards private practice has ensured that the



“difficult cases” are less likely to be treated through the NHS. Intellectually disabled people are presenting with fewer filled teeth, poor oral hygiene, more severe gum disease and greater incidence of malocclusions. Although two to three per cent of the UK’s population have learning disabilities, only a small number of these are severe enough to warrant hospital care due to behavioural or concurrent medical problems. People with learning disabilities have the same dental treatment needs as everyone else, but they have poor access to services, transport, information and complain that professional attitudes are not sympathetic.

Mental Illness

Patients with mental illness are arguably the most difficult to treat. One in three general medical practitioner visits in the UK involves some form of mental illness. Patient problems relate to behaviour, compliance, and oral hygiene as well as drug side effects and interactions. Dental care is provided using behaviour modification, oral sedation, short appointments, education, or by simply waiting for the mental health condition to improve.

Hospital Role

A large dedicated multidisciplinary team is pivotal in caring for those special needs patients requiring in-patient hospital care and strict referral criteria are applied due to limited resources. Widening the criteria for this service would massively increase the numbers being referred.

Dr Davies commented on the pivotal role of carers. “All health care is directly proportional to the daily input,” so the most important people are relatives, carers, key workers and home help - “the person cleaning the teeth everyday”.

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INFORMATION CLEARINGHOUSE FOR SPECIAL NEEDS

Anne O'Connell
Trinity College, Dublin

A highway for the flow of information and communication between specialists, patients, support groups and rehabilitation services could prove to be the key in the provision of quality dental care to patients with special needs. Dr Anne O'Connell explained the US concept of an oral health information superhighway - the National Oral Health Information ClearingHouse (NOHIC).

“Special care” in oral health is required by many patients with a variety of medical, disabling or mental health conditions, where barriers exist to the provision of routine dental care. There is an ongoing trend to de-institutionalise patients with special needs and integrate them back into their local community. The term ‘special care’ covers a wide range of conditions: systemic disorders, genetic disorders, mental and physical disabilities and patients undergoing medical treatment, where either the underlying condition or the treatment may complicate oral health care. Lack of information, support and training for provision of dental care to this population were shown to be major obstacles at the local level. This deficit was recognised by the National Institute of Dental and Craniofacial Research (NIDCR) in the US, which sponsored the establishment of the National Oral Health Information ClearingHouse

The main aim of NOHIC is to provide a central resource for all healthcare professionals in the oral health care of special needs patients. Information is obtained from a variety of sources and is constantly updated by the staff of health information specialists. NOHIC can be accessed by phone, fax, email or via the website (see below). Specific questions will be answered following consultation with a national expert in that area. Fact-sheets, brochures and information packs are developed for both the patients and professionals in many frequently requested areas. Examples of this are for diabetes, cleft lip/palate. Details of organisations involved in special care are available (USA based). Customised searches on specific topics can also be performed. Ordering information is available on the web site. In the US this information is free, however international orders are possible by arrangement.

(NOHIC website address is <http://www.aerie.com/nohicweb/>).

Awareness of oral health issues is enhanced by information exchange and communication between the various medical specialities, dentists and the patient support organisations. To support this NOHIC are involved in health awareness campaigns. The recent Oncology project is an example of these efforts. A multidisciplinary team comprising the National Cancer Institute, National Institute for Nursing Research and the Centre for Disease Control and NIDCR formulated brochures aimed at encouraging communication between specialists, while the patient remains in control of his illness. 'Radiation Treatment and your Mouth' and 'Chemotherapy and Your Mouth' are two such brochures. Specific guidelines for care providers and slide programmes for training purposes have proved successful.

In 1985, the Combined Health Information Database (CHID) was established and is a consortium of 18 federally sponsored databases. Each component database relates to specific health care areas ranging from AIDS to obesity. The Oral Health Database is a reference tool that provides information on the topic from journals, newsletters, videotapes, CD ROMs and book lists. Health professionals, patients, parents and media/medical writers access this site. It is continually updated and available in multiple languages including Braille. CHID can be accessed at <http://chid.nih.gov>. A search generated via CHID is different to a Medline search in that more non-technical information is included in the CHID search.

The model of such a clearinghouse offers huge potential for providers of oral health care in Ireland, however there are a number of issues. The information provided is not copyrighted, so it can be modified, adapted and distributed to meet individual cultural/language requirements. NOHIC is based on American standards of care, so modifications may be required to comply for standards of care in Ireland. Linkage from the websites of various patient support groups and professional organisations to NOHIC would be invaluable. In addition, the existence of such a resource should guide development of new websites or information packs specific for the Irish population.

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POLICY ISSUES AND SPECIAL NEEDS

Gerard Gavin


Department of Health and Children

Dr Gerard Gavin, Chief Dental Officer in the Department of Health & Children, looks at special needs patients from a broader perspective. Barriers to oral health experienced by the medically compromised are associated with poverty, ethnicity and disability. Stigma and marginalisation from the mainstream are experienced by all of these groups.

Poverty is a dominating feature amongst the homeless, prisoners and intravenous drug users, while issues related to ethnicity impact most on the living experiences of the travelling community, refugees and asylum-seekers. The term disability is commonly applied to groups of people with intellectual, physical and sensory disabilities. In the case of intravenous drug use, a national epidemic is sweeping the country, concentrated in communities characterised by high unemployment, poverty, powerlessness and social exclusion. Manifestations of social exclusion are to be found in low participation in preventive health services e.g. low uptake of immunisation, dental screenings and treatment. A similar situation prevails in education and employment with poor participation and low attainment.

Government policies are increasingly focusing on the needs of these groups. Recent initiatives include the National Health Strategy and National Anti-Poverty Strategy (NAPS). Equality legislation was enacted in 1998 and this year saw the establishment of the Equality Authority. There have been initiatives also in education and with local drugs task forces.

The Dental Health Action Plan identified priorities and targets for the disadvantaged. One of the key objectives of the plan was the establishment of an oral health database to monitor changes in the oral health of the population including special needs groups. The other features of the plan were a dental treatment services scheme for low-income adults and the reorientation of health board services for the medically compromised and those with congenital facial abnormalities. The full implementation of the Dental Treatment Services Scheme from January 2000 will result in an annual commitment of over £40 million targeted at reducing the equity gap in health between medical card holders and the rest of the population.



NAPS is driven by the Department of Social, Community and Family Affairs. It was set up in response to a UN world summit in 1995, in which Ireland committed itself to eradicating poverty. It focuses on providing access to services, reducing inequality and guaranteeing the rights of minorities. It implies a partnership approach that incorporates consultations with service users. The strategy encourages self-reliance within special needs groups. The approaches advocated in NAPS are challenging to professionals but are essential for developing programmes for special needs groups.

Thirty special needs teams, comprising dental surgeons, dental nurses, dental hygienists and oral health promoters are being established in health boards. Academic centres in dentistry are essential for carrying out research and training in needs assessment and best practice approaches to special needs dentistry. Funding streams are likely to follow quality programmes that meet the evaluation criteria outlined in the Health Strategy and support the aims of the National Anti-Poverty Strategy.

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ASSESSING THE NEED IN IRELAND - MODELS FOR ASSESSING SPECIAL NEEDS


Helen Whelton
University College, Cork

The Inverse Care Law (Tudor Hart 1971) states that the availability of good medical care tends to vary inversely with the need for it in the population served. Those who need it the most use it the least. This principle is generally found to apply in oral health services. Health promotion has its greatest impact on socially and economically advantaged groups. Dr Helen Whelton turned her attention to assessing the dental service needs of disadvantaged groups, such as medical card holders, disabled people, travellers, homeless people and those in long-term care within the health boards.

There is a complex relationship between supply, demand and the need for services. If one has a need for a service, but has no access to its supply, one could be termed 'special need'. The need may be total or marginal. Dr Whelton presented three approaches to assessment: comparative, corporate and epidemiological. Comparative assessment considers the relative level of standard of services provided, for example, in different health boards. It assumes similar levels of need and demand in different areas. Corporate assessment is based on the demands, wishes and perspectives of interested parties. If properly constructed, it can provide a fair representation of special needs groups. Epidemiological assessment has been used extensively to ascertain the needs of the normal population and is now being applied to special needs groups.

Dr Whelton presented this socio-environmental method. To identify target groups, the co-ordination of data held at various levels is required. The current political climate may have an impact on this assessment. To determine the burden of disease and the quantity and characteristics of services available, dedicated surveys on prevalence and incidence among special needs groups are required. Services need to be continually monitored and evaluated.

Dr Whelton suggested drawing on past studies to examine how services should be provided to disadvantaged groups. One such study is Holland's (1988) examination of the need for referral of persons with intellectual and physical disabilities in residential and day care. He found that 80% of patients could be treated in primary care. Thirty one per cent of participants required



secondary care treatment, with 20% of these needing treatment under general anaesthetic, such a study provides valuable 'needs assessment' information.

Does epidemiological assessment work? Nuttall and Davies (1988) were critical of it because in follow-up studies, teeth that had been defined as decayed in U.K. national surveys remained untreated. Needs were assessed in the UK on the basis of tooth condition. However, in Irish national surveys, treatment need is assessed separately, based on the clinical opinion of the examining dentist and is, therefore, arguably more valid.

Dr Whelton suggested that services be examined in terms of facilities, cost-effectiveness, accessibility and effects on quality of life. The latter has never been measured before. Models of care may take the form of health promotion, or restorative treatment, or may be based on Sheiham's holistic approach (Wilson & Cleary, 1995).

Epidemiological assessment can be used to estimate special needs, but requires a consultative approach to assess the subjective perception of needs. The take-home message can be summed up by a quotation from a report by the Commission of the Status of People with Disabilities, 'We must be asked what we think and what we need.'

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SERVICES AND STRATEGIES IN THE EASTERN REGIONAL HEALTH AUTHORITY

Conac Bradley

Special need services within the Eastern Regional Health Authority (ERHA) date back to the 1960s. Services comprised a one-woman mobile unit travelling to special national schools in every remote spot of Co. Dublin. It was not until 1984 that a Senior Clinical Dental Surgeon (Paediatric) was appointed to take charge of the special needs service and in 1989 another dentist joined the team. The special needs remit was widened six years later and seven additional Senior Clinical Dental Surgeons were appointed in 1996.

Dr Conac Bradley, Senior Clinical Special Needs, ERHA, outlined how currently the eight special needs team care for patients experiencing difficulties in accessing care. A list of defined Special Needs Groups has been agreed, however this list is not definitive and is regularly reviewed. The ERHA's services are both 'need-led' and 'demand-led'. The former pertains to screening in special national schools, adult training centres, day centres, sheltered workshops and residential centres. The service involves a comprehensive recall system and also a register of those who do not fall into screening programmes, such as, medically compromised children. Demand-led services refer to situations where it is not feasible or appropriate to offer a need-led service.

The dental care provided is both primary and secondary. Dedicated secondary care facilities are offered to special needs children in Our Lady's Hospital in Crumlin and the ERHA is currently appointing a Senior Clinical Dental Surgeon in Paedodontics. Special needs patients in ERHA also have access to services in St James' Hospital, St Columcille's Hospital, Temple Street Hospital, Tallaght Hospital and the Dublin Dental Hospital. Special needs adults can access dedicated secondary care services in James Connolly Memorial Hospital in Blanchardstown where restorative dentistry is provided under general anaesthesia.

The ERHA is actively involved in health promotion, dental health education as well as formal and informal data gathering, with particular emphasis being placed on special needs patients. Dr Bradley said the ERHA is striving to increase need-led services and to expand pilot projects that are currently running. Increased health promotion will lend itself to disease prevention



among special needs patients. Dr Bradley outlined the importance of training and valuing staff in order to retain them within special needs services.

Although the ERHA still encounters some problems with waiting lists for secondary care and a lack of intermediate care such as treatment under sedation; Dr Bradley believes the health authority has come a long way. Research, education and training will prove to be the keys to a successful future.

STRATEGIES AND SERVICES IN THE NORTH WESTERN HEALTH BOARD & NORTH EASTERN HEALTH BOARD


Daniel Thompson

The geographical locations of the North Western Health Board (NWHB) and the North Eastern Health Board (NEHB) necessitates self sufficiency in the provision of special needs services. Dr Daniel Thompson is the acting Senior Clinical Dental Surgeon at Letterkenny Hospital in Donegal. He was fortunate when he joined the dental service two years ago, that there was already a considerable interest in special needs groups. This provided the flexibility to plan and structure special needs services.

People with special care requirements in these health boards fall into the following categories: medically compromised patients, mental/physical/sensory disability patients, travellers, refugees, phobic patients, the elderly and psychiatric patients. Referrals come from a variety of sources including acute hospitals, general medical practitioners, general dental practitioners, public health nurses, social workers, psychiatric hospitals, geriatric units and special needs institutions. Barriers to care for these groups include anxiety, cost, mobility and a lack of perceived need for dental care.

The NWHB covers counties Donegal, Sligo, Leitrim and some of west Cavan. It has a population of 211,000, of which 14% are over the age of 65. The total number of special needs patients is not accurately known. The NEHB, which covers counties Louth, Meath, Cavan and Monaghan, has a total population of 306,155. This figure includes 2,321 people with special needs and 15 centres for the elderly. In the NWHB there are two Senior Clinical Dental Surgeons and one dental hygienist, whereas in the NEHB there is one Senior Clinical Dental Surgeon and no dental hygienist.

In Donegal those patients with learning disabilities receive an annual visit for dental examination with follow-up treatment if required. Treatment is carried out at the local health board clinic if possible. Facilities to provide a full range of dental treatments under general anaesthetic are available at the local general hospitals. Dr Thompson highlighted the importance of a full general anaesthetic service. He noted the excellent service provided by the general anaesthetic team in Donegal and their valuable contribution to patient treatment. Some



patients are referred to general dental practitioners. The hygienist travels to institutions and schools in the area and talks to patients, parents, carers and teachers.

Both health boards offer an open-door service to the travelling community. Medically compromised adults have a walk-in service, while there is a treatment, prevention and recall system in place for medically compromised children. Those with learning disabilities receive an annual visit, a domiciliary service is provided for the aged. Dr Thompson stressed the importance of special needs oral health services being available, accessible, appropriate and acceptable. He called for increased skills in communication, teamwork, behaviour management, diagnosis and problem solving.

Problems encountered by these two health boards relate to the further training of dentists as well as their recruitment and retention. Needs assessment has not been carried out and the database for persons with disabilities remains incomplete. Dr Thompson expressed the opinion that many more patients could be treated at primary care level (either general dental practice or health board service) with appropriate training. He called for an oral health promotion strategy and adequate facilities, particularly general anaesthetic services.

SERVICES AND STRATEGIES IN THE SOUTHERN HEALTH BOARD & SOUTH EASTERN HEALTH BOARD


Niall O'Neill

Integral to the provision of special needs oral health care is appropriate training. The focus of Dr Niall O'Neill's presentation was interim training needs, particularly in light of the 30 additional teams that are about to be employed in special needs areas. Representing the Southern Health Board and the South Eastern Health Board, Dr O'Neill observed that the job description of health board dental surgeons encompasses paediatric dentistry, care of those mental and physical disabilities and the care of medically compromised patients.

Dr O'Neill recommended that existing and new Senior Clinical Dental Surgeons should have an attachment to a Dental Hospital for induction training, consisting of theoretical and practical aspects of special needs dentistry. The didactic component should be provided in different formats and should include training in use of the library and Internet. Best use should be made of information technology for improved patient care and professional development. The European Computer Driver's Licence (ECDL) was suggested as a good starting point. Cross-infection control, blood-borne diseases, cardiac conditions, behaviour management and consent issues would need to be included. Behaviour modification courses are required to deal with challenging behaviour. The Department of Applied Psychology in University College Cork, the University of St Andrew's and the Cope Foundation in Cork are offering such courses.

Clinical training should involve hands-on treatment of special needs patients using different modalities of anaesthesia. The patients treated should cover all age groups and disabilities. Dr O'Neill recommended attendance at multi-disciplinary clinics and stressed the importance of hospital-based training to forge contacts between senior clinicians on the medical and dental staff.

Dr O'Neill suggested that the duration of attachment training should be a minimum of three weeks. Three weeks of training based in a centre for people with disabilities should follow. This is necessary for treating large numbers of mentally and physically disabled people in residential care.



After induction, these clinicians should be able to plan treatment and provide dental care for the majority of special needs patients. There will remain a need to refer a small number of special needs patients for secondary care, with the referring Senior Clinical Dental Surgeon being responsible for maintaining good oral health.

Dr O'Neill recommended that such training be eligible for accreditation with the Postgraduate Medical and Dental Board.

SERVICES AND STRATEGIES IN THE MID WESTERN HEALTH BOARD MIDLAND HEALTH BOARD & WESTERN HEALTH BOARD


Joe Green

“We need to give the carers of special needs patients a better deal. They deliver more oral health care than we dentists can ever do,” said Dr Joe Green, representative of the Mid Western Health Board (MWHB), Midland Health Board (MHB) and Western Health Board (WHB). Dr Green highlighted the carers’ pivotal role in service provision. They exercise considerable influence on diet and oral hygiene as well as being instrumental in facilitating the attendance of special needs patients for dental care. The carer should be the target for oral health promotion. Carers may even satisfy the criteria for being a special needs group in themselves. Dr Green expressed the opinion that if it were easier for carers to access dental services at the same time as the individuals they care for, there would be an improved service uptake for those with special needs. An active health promotion strategy to get the message across would benefit those with special needs.

The MWHB, MHB and WHB cater for a total of approximately 900,000 people. Dental services for special needs patients are provided primarily through the health board dental service and some general dental practitioners. There is some targeting of services through the special schools, otherwise services respond to demand. It is through organisations providing care, that many adults with special needs access dental care. The provision of dental care under general anaesthetic is restricted by limited availability of facilities with resulting long waiting lists.

Dr Green listed several factors which influence service delivery to people with disabilities. These were information; needs assessment; response of service providers; multi-sectorial approach, infrastructure, access, communication, external supports and carers.

Service delivery is influenced by a lack of information; databases are not up-to-date, as many clients are reluctant to have their details stored in such systems. Different needs assessment surveys influence service provision. Dr Green believes the balance between clinical assessments and non-clinical elements should improve. Local dental services are often reflective of services from other sources that are available to those with special needs. If there is a strong voluntary group locally there tends to be a strong response from the health board.



Services providers believe staff shortages, time pressures and non-availability of medical management close to the patients' homes are impacting adversely on special needs services. The exchange of information and co-operation between disciplines is vital in overcoming this difficulty.

Dr Green recommended improved availability of equipment, training and accessibility to dental clinics. Dental surgeons in private practice should also be encouraged to improve access for those with disabilities. For many patients within these health board jurisdictions a general anaesthetic facility could be as much as 50 miles away. Government policy is gearing towards equity in treatment; therefore, the response has to be timelier for groups with greater needs.

Communication problems are inherent in the service. The availability of interpreters for those using sign language and refugees is limited. It can be difficult to explain complex dental treatment details to such patients. Consent issues pose another communication problem.

An extensive support network is available for dental surgeons within schools, residential facilities, health boards, voluntary organisations, the dental schools, the Dental Health Foundation and the Department of Health and Children. Dr Green recognised that although difficulties exist, there is a substantial service present for people with special needs.

DISCUSSION

A broad discussion took place following the presentations. It covered the many points raised by the speakers concerning the provision of oral health care to people with special needs. Dr Patricia Noonan Walsh invited suggestions as to ways that this initiative could move forward. The following is a summary of the main issues raised in the discussion.

The Special Need Patient


The definition of 'special needs' as used by the Department of Health & Children is so broad that it is difficult to interpret. Dental personnel find it daunting to tackle all of the special needs areas included in the definition. It was suggested that clearer definitions of special need categories and the role of primary and secondary care for each one were required.

The dental treatment required by the majority of special needs patients is routine primary care and is not specialist treatment. However some of these groups may need additional facilities such as larger dental surgeries to improve wheelchair or buggy access, or facilitate provision of dental care while in the wheelchair or buggy.

The Multidisciplinary Approach

Problems exist in the provision of in-patient dental care for medically compromised patients. Hospital consultants managing patients with medical conditions may require that their patients be admitted under their care while the dental treatment is being provided. If there is no facility to provide the dental treatment in a consultant's hospital but there is a dental service available in another hospital it may be extremely difficult to get the patient admitted under another consultant. It is difficult to obtain beds for in-patient or day-case care for those patients with chronic chest disease and cerebral palsy.

The interaction between disciplines affects the ability of patients with special needs to access services. The efficiency with which professionals interact is seen as a measure of the interest in the client. There is evidence to show that the way parents are informed about their child's special needs will influence their ability to access services. To improve service accessibility, it is vital that all health care undergraduate students are trained to function in a multidisciplinary team approach to the provision of oral health care for people with special needs.



Special needs patients require more time for treatment, this may prove to be an economic barrier for general dental practitioners.

Special needs groups and their carers need to be given a voice and to have input into the organisation and delivery of services. Interpreters and sign language are important requirements for some groups. Services should focus on the organisation and management of services to facilitate special needs patients.

If user involvement is encouraged, this may mean the incorporation of travellers and or carers onto planning committees. The question posed was - “Are we open to that?”

The barriers to care for people by virtue of their deprivation or poverty need to be examined. There is a need to improve the uptake of the existing services within these groups. More flexibility is required to offer needy patients emergency care.

Special needs dental consultants should be based in the Dental Hospitals, in order to have a strong input into undergraduate, continuing and postgraduate educational programmes. Such consultants should also develop strong links with the community-based services so as to provide advice and consultation for dentists at primary care level. The Dental Schools play central roles in the education of future dental personnel, provision of consultant services and provision of advice as well as secondary care services. Oral health care for special needs groups should not be the preserve of one group or grade of dental personnel. Other team members, for example, hygienists are equally important, particularly as their input pertains to prevention of oral health problems. A team approach is essential.

Education/Training

It is vital that appropriate education in oral health is provided in all nurse education programmes. All categories of nurses (general, public health, learning disability and mental health) were identified as fulfilling a key role in identifying special needs patients and facilitating access to oral healthcare. General and public health nurses are often not aware of the implications of poor oral health for their patients. Improved appreciation among nurses of patient problems is required. Improved liaison with public health nurses would ensure more referrals. A flow of information between these professionals should exist. Most specialist-training programmes for nurses in psychiatric institutions afford a very low profile to education about oral health needs of patients.

Primary care dentists (general dental practitioners or health board dentists) rather than specialists should treat the majority of children with special needs. In order to do so, training for dental personnel should be formulated on a modular basis for short training periods for general staff. Continuing dental education courses with specialists should be available in the Dental Schools.

A training programme over a six-week period was discussed. Concern was expressed about this proposal in that it may be perceived as adequate training for special needs posts. However it was agreed that the duration of the proposed training pathway was purely an interim measure, to prepare dentists who are coming on stream and applying for senior clinical positions in special needs. The proposed course would be introductory and would not claim to be a thorough training pathway. It was also agreed that there was a need for formal postgraduate training in Special needs.


Many medical consultants/specialists lack an understanding of the impact of disabilities on oral health and on the provision of oral health services. Some of the current problems in the provision of services for special needs patients within the hospitals might be solved by improving the awareness within the medical profession about the relationship between oral and general health.

There is also a deficit of education and information for the public. To correct this, the use of effective resources should be developed, for example, a National Oral Health Information Clearinghouse (NOHIC).

Improving Special Needs Services

Service provision should be based on the requirements of people with special needs and not merely on the needs of the service providers. Much of the forum discussion related to services and general anaesthetic facilities. One speaker stressed the need for priority for a health care system based on prevention rather than treatment.

Much discussion referred to models of good practice, for example, in general anaesthetic facilities. The publication of guidelines or evidence-based standards would benefit those professionals who do not have such facilities, providing uniformity among services across Ireland from a quality and ethical perspective.



Many speakers identified a need for secondary care/specialist services for special needs patients. The necessity to put a structure in place for the recruitment and maintenance of such special needs professionals was highlighted. This would include an appropriate career and salary structure.

It was suggested that it would be beneficial if the complex issue of consent were to be addressed at a higher level.

Oral Health Promotion

It is vital to develop formal and informal health promotion programmes for parents and carers of people with special needs. Programmes should give priority to the prevention of oral health problems and should be specifically tailored to special needs groups.

The merits of 'Dental Health Month' in the US were discussed; whereby dentists attend schools in the community and undergraduate students provide community outreach programmes.

General suggestions were made about the need for oral health education for pregnant women and in maternity hospitals/units. A consultant working with special needs patients stressed the importance of recognising the need for the parents of new-born babies with disabilities to have time to come to terms with other issues associated with the disability, before embarking on intensive oral health education.

Key Issues to be Addressed

Definition of Special Needs

A clearer understanding of the term “Special Needs” in relation to oral health care services is required. The role of primary and secondary care services for the various categories of special needs patients should be determined in the light of this understanding.

Services

The remit of the Health Board Dental Services in planning, organising and providing care for special needs groups should be outlined.

The majority of special needs patients require routine primary care, which should be provided in a primary care setting.

Secondary care services should be developed through a team approach within the Health Board Dental Services, with appropriate support from consultants in the dental schools. A multidisciplinary approach to the provision of care, in particular for patients who have a medical and or intellectual disability is required. Oral health promotion should take into account the requirements of special needs patients.

Access to Care

Service providers should focus on developing strategies to ensure access to care for the various categories of special needs patients. Barriers to care such as access to facilities, interpreters, sign language and availability of domiciliary care should be addressed.

Facilities

A review of existing facilities for the provision of oral health care of special needs patients is recommended.

The availability of relative analgesia and general anaesthetic services will form an important part of the review in order to ensure uniformity of facilities throughout the country. The development of a centre of excellence for special needs patients has commenced in the Dublin Dental School and Hospital.



Training

Undergraduate dental students and dental auxiliaries should be trained in the provision of primary care for special needs patients.

Continuing education programmes should be available to dental personnel involved in providing care to special needs groups. Appropriate courses for all health care personnel should be developed in consultation with the Centre for the Study of Developmental Disabilities.

Formal postgraduate training in “Special Needs” should be made available by the dental schools for Senior Clinical “Special Needs” dentists in the Health Boards. In addition regular rotation with consultants in special needs in the Dental Hospitals should be available. The structure within the Health Boards should be attractive enough to recruit and retain staff involved in this field.

Communication

The involvement of the users of services and the organisations representing special needs groups should be fully taken into account in the planning of services. The formation of an association for the provision of Oral Care for Special Needs Groups should be considered. This should include the providers and the recipients of care and be linked to similar societies in other countries.

The formation of a National Oral Health Information ClearingHouse (NOHIC) should be considered, through the auspices of the Dental Health Foundation. NOHIC could provide an important service to parents, carers, patients and providers.

Research

A database of the various categories of special needs patients should be set up.

Ongoing evaluation of the oral health services to special needs patients should be carried out.

Basic and applied research should be initiated, linked to the academic centres, into the various conditions affecting special needs patients.

Acknowledgements

We would like to express our appreciation to the Department of Health & Children and in particular Dr Gerard Gavin, Chief Dental Officer for providing the support which made this Forum possible.

The success of the Forum was due in large measure to the enthusiastic participation of representatives of the various interested groups involved in providing care for those with disabilities. We are very grateful to all these groups.

Finally, we would like to thank Ms Breeda Hyland of the Dental Health Foundation and Ms Marie O'Connor of the Centre for the Study of Developmental Disabilities in National University College of Ireland, Dublin for their assistance in organising the Forum.

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Forum Programme

Time	Schedule	Speakers
08.30 a.m.	Registration	
09.15 a.m.	Opening of Meeting	John Clarkson Dean, Dental School, Trinity College Dublin
09.20 a.m.	<u>Session 1</u>	Chair John Clarkson
09.20 a.m.	Promoting Health for People with Intellectual Disability	Janette Tyrrell St. Vincent's Hospital Fairview, Dublin.
09.50 a.m.	Special Needs: Training Programmes	June Nunn Newcastle
10.30 a.m.	Provision of Care: 'Special Needs - Children'	Pádraig Fleming Trinity College Dublin Tim Holland University College Cork
11.15 a.m.	Coffee	
11.30 a.m.	Provision of Care: 'Special Needs - Adults'	Roger Davies Eastman Centre, London
12.10 p.m.	Information Clearinghouse for Special Needs	Anne O'Connell Trinity College
12.30 p.m.	Lunch	
01.15 p.m.	<u>Session II</u>	Chair Patricia Noonan Walsh Centre for the Study of Developmental Disabilities, NUI, Dublin
01.15 p.m.	Policy Issues and Special Needs	Gerard Gavin Dept. of Health & Children
01.35 p.m.	Assessing the need in Ireland - Models for Assessing Special Needs	Helen Whelton University College Cork
02.00 p.m.	Reports from health boards in 4 Regions of Ireland	Health Board Dentists
03.15 p.m.	<u>Discussion</u> 'Future of Special Needs in Ireland' Service Needs, Training Needs; Resources	Joint Chair Patricia Noonan Walsh John Clarkson