ORAL HEALTH & DISABILITY:

The way forward

Trinity College Dublin

Dublin
Dental School
and Hospital

Dental Health Foundation
Ireland

NATIONAL DISABILITY AUTHORITY
ÚDARÁS NÁISIÚNTA MÍCHUMAIS

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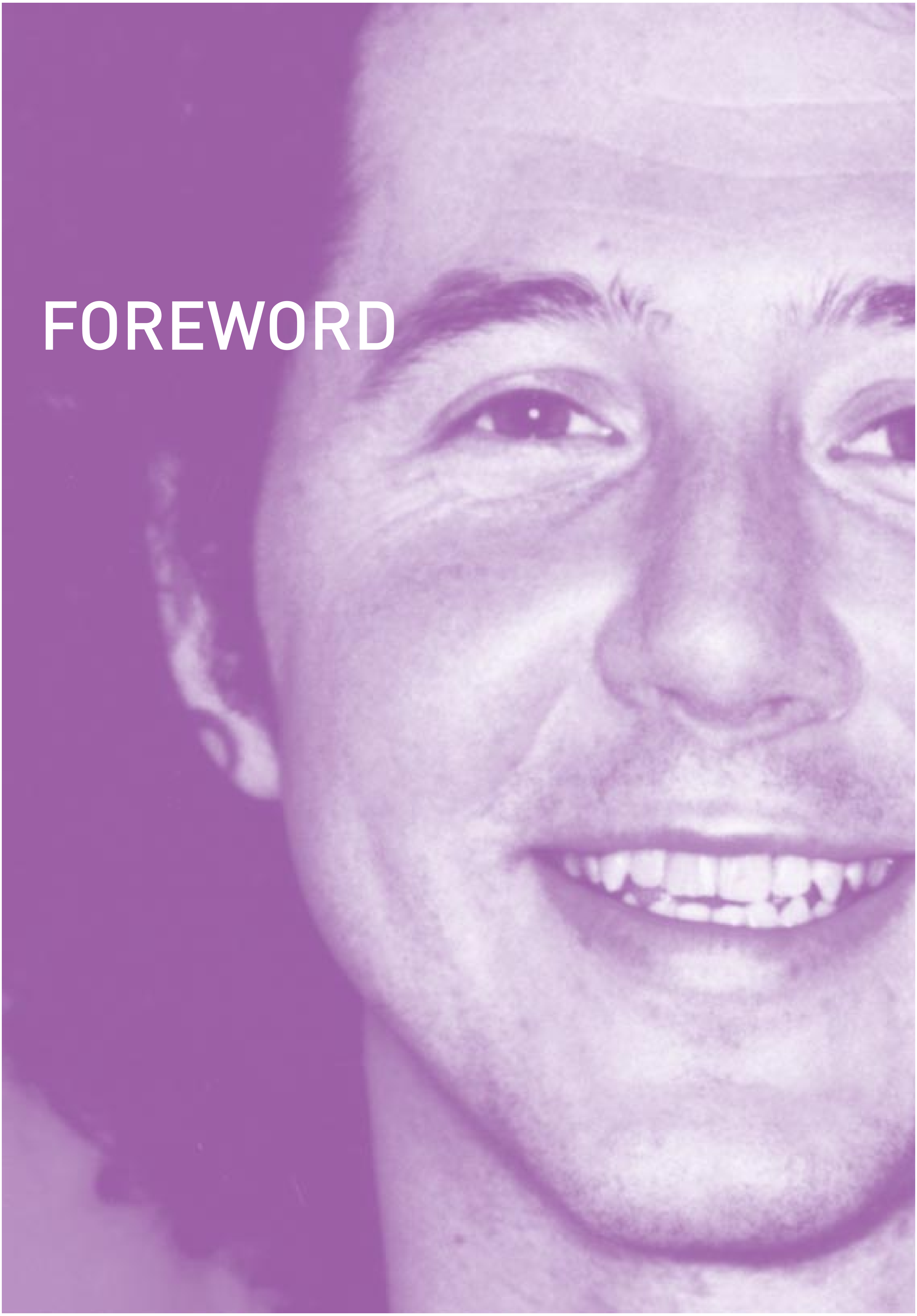
Contents

Appendices

FOREWORD



Foreword

"Oral Health and Disability: the way forward" is a significant initiative by the National Disability Authority, the Dental Health Foundation, and Trinity College Dublin, School of Dental Science.

The disability and health sectors are at a cross-road with the reform programme in health and the publication of the National Disability Strategy. Whilst a time of change throws up much uncertainty, it is also a time of opportunity. This publication is timely in informing the specific issues arising in the provision of oral health services to people with disabilities.

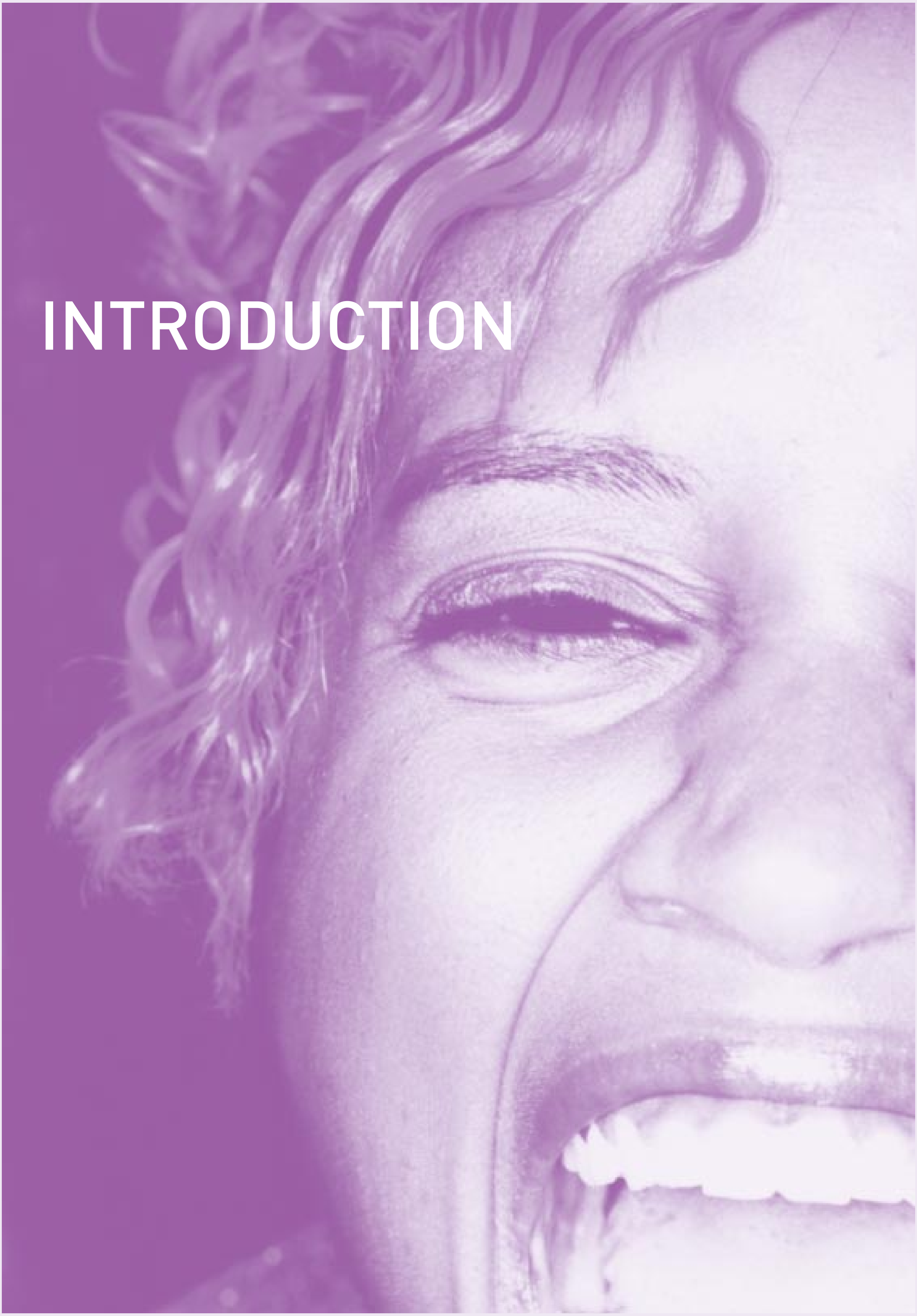
Drawing on the contributions of representatives of the oral health and disability sectors in the Republic of Ireland and Northern Ireland at an Oral Health and Disability Roundtable held on October 8th 2004, this document provides a series of recommendations that could change the current ad-hoc and unsatisfactory oral health care system for people with disabilities. It identifies ways forward in enhancing the oral health of people with disabilities through the development of inclusive, accessible and holistic service provision, appropriate education and training of the oral health team, targeted methods of service delivery, research and audit. The approach advocated is person-centred and the leadership of people with disabilities is promoted. As participants came from both jurisdictions on the island, it is hoped that recommendations outlined in this document can inform the development of an all-Ireland response to the oral heath needs of people with disabilities through partnership between all stakeholders, noting the existence of north-south oral health organisations and structures.

Oral health is central to the health and well being of people with disabilities. Investing in oral health should not only be calculated in monetary terms but also considered as an investment in empowering individuals through increased self-esteem, supporting communication, nutrition and improving quality of life.

The NDA welcomes the opportunity to work with our colleagues in oral health and looks forward to developing the oral health and disability agenda with all stakeholders into the future.

Angela Kerins
Chairperson, National Disability Authority

INTRODUCTION



Introduction

“… THE WAY WE THINK ABOUT THE NEEDS OF CHILDREN AND ADULTS WITH DISABILITIES IS NOT A SPECIAL DEPARTMENT OF LIFE…”

Martha Nussbaum, 2001

The United Nations Universal Declaration of Human Rights (1948) Article 25 states that : *“Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including…medical care and necessary social services.”*

In 1996, the Commission on the Status of People with Disabilities stated that people with disabilities have the right to a health service which is fair, accessible and which meets their needs. However, the Commission also reported that health professionals tend to see the disability first rather than the person in need. Although the Commission made no specific mention of oral health, it established the Government’s commitment to mainstreaming health provision.

People with disabilities have the same right to good general health as the general population. This right is realised in part through access to a good quality health service. The Government policy of mainstreaming service provision recognises that people with disabilities have the right to access the same oral health service as the wider population. This may require that additional supports are put in place by service providers to overcome environmental, communication, attitudinal and technical barriers. At the same time it is important to value and appropriately develop competence in specialist oral health care through research, professional training and provision.

Although this document primarily focuses on people with disabilities who are users of oral health services, it is noted that people with disabilities are also workers within these services who have a right to an inclusive working environment, which recognises and supports their valuable contribution. The NDA’s “Submission to the Working Group on Undergraduate Medical Education and Training” comments on the recruitment and retention of people with disabilities in health professions. Many of the messages contained within this document are relevant to the education and training of oral health practitioners for example with regard to the re-orientation of the curriculum or syllabus, teaching methods or delivery methods and other aspects of the organisation and delivery of education and training towards a social and human rights model of disability in order to promote inclusive, equitable, person-centred education and training, and practice.

Oral health is central to the health and well being of people with disabilities. Good oral health can promote communication, good nutrition, self-esteem and quality of life and lead to a reduction or elimination of pain. Poor oral health – bad breath, overcrowded teeth or unsightly decay – can reduce a person's ability to consume nutritious food, affect self image and confidence and cause significant pain, which a person with a disability might not be able to communicate. (This in turn can be the cause of further frustration or even damage such as self-harm.) The essential benefits arising from oral health cannot be underestimated. In short, good oral health empowers people with disabilities to face the world with more confidence, promoting their participation and contribution.

People with disabilities have a distinct oral health profile. Research has shown that people with disabilities are more likely to have oral health problems and require more treatment than the rest of the population. The first National Oral Health Surveys of children and adults with disabilities were carried out over 2002 and 2003. When compared with children who do not have disabilities, the survey showed that 30% more dental decay was untreated in children with disabilities. It also showed that the latter had more extractions and less preventive work, such as fissure sealants. Adults with disabilities had more missing teeth, needed more dental treatment and were 20% more likely to have no teeth at all if they were over 55, when compared with non-disabled adults. Research among a group of 153 older people with special needs in Northern Ireland showed that on average they each had 1.2 teeth. Of those teeth remaining, 56 needed to be removed (Campbell, Belfast City Hospital 2004) .

The oral health of people with disabilities can be compromised by general risk factors such as tobacco use and poor dietary practices, which also affect oral health. Research findings have pointed to possible associations between chronic oral infections and diabetes, health and lung diseases, stroke and low-birth weight premature births (US Surgeon General's Report, 2000). The recently published Northern Ireland consultation document "An Oral Health Strategy for Northern Ireland" (September 2004), includes a section on adults with mental health difficulties. It indicates that this group is at increased risk of dental decay, gum disease and mouth cancer due to poor oral hygiene, a diet high in sugars, prevalence of cigarette smoking and the effects of medication.

Further people with disabilities, who present for oral health services, can challenge practitioners. These challenges include the delivery of a quality service to a person who may have poor understanding, uncontrolled movements, limited mouth opening, poor posture or limited mobility, who may experience tiredness during treatment or who may have medical problems.

People with disabilities may require more specific supports and re-orientation of practice and service provision in order to access mainstream provision. Critically, the issues go beyond the basic issue of physical access to treatment. Access also includes access to information provision, communication and attitudes. “An Oral Health Strategy for Northern Ireland” identifies specific barriers for people who experience mental heath difficulties: a lack of service knowledge, anxiety levels and oral health staff’s attitudes including a lack of empathy and understanding.

Oral health needs to become integrated into holistic health policy, service provision and professional training and development. However, oral health is, for the most part, divorced from general health. Doctors do not always think about the oral health implications of medication they might prescribe, for example, simply perhaps because of lack of training and understanding of oral health needs. When it comes to policy, oral health is often omitted or dealt with separately rather than as an integral part of general health policy and provision. Effective integration of oral health into the mainstream health agenda will contribute to a Value for Money (VFM) requirement in the Health Service (2001).

The Disability Legislation Consultation Group’s document “Equal Citizens: Proposals for Core Elements of Disability Legislation” (2003) includes a consideration of how mainstreaming can be realised whilst retaining a role for specialist provision when required. It recommends the following:

1. People with disabilities should be able to equally participate in mainstream service provision and receive adequate supports to enable them to do so. Any separate or targeted services should be limited to meeting specific needs of particular groups that are not met by mainstream service provision and to taking positive action to enhance outcomes for people with disabilities from mainstream provision. Mainstream services should in no way disadvantage or marginalise people with disabilities.
2. A statutory duty on public sector organisations to promote equality for people with disabilities. This requires all public bodies to establish clear equality objectives within their remit for people with disabilities and produce a strategy for the achievement of these objectives. This also requires them to disability proof or disability impact assess and monitor their policies, plans and programmes, in consultation with people with disabilities.

“Equal Citizens” also outlined a number of aspects of needs assessment, accessibility, advocacy and public service employment, which could promote a more inclusive oral health service.

An inclusive and holistic approach to the delivery of oral health care for people with disabilities will require research into:

- what it is people with disabilities require from an oral health service;
- support for people with disabilities and their family members and carers to be active participants in oral health care;
- development of a continuum of treatments by disability aware professionals ranging form health promotion interventions to surgical procedures.

In terms of practice, it is recognised that there is a need for more competence in special care dentistry. However, there is also a need for mainstreaming of good practice and awareness through improved oral health and disability awareness training at a regional and community level, where people generally go to see their dentists.

The building of competence involves the training of all oral health disciplines (dentists, nurses, hygienists, and health promotion practitioners) as well as administration personnel e.g. receptionists in order to deliver continuous, inclusive oral health care. Carers and family members, often responsible for ensuring the oral health of a person with a disability, also have to be educated and trained. In addition, other community and hospital based health professionals (e.g. general practitioners, public health nurses, nutritionists) should be informed about the importance of oral health and the impact their interventions might have on the oral health of people with disabilities.

With regard to oral health policy, “The Dental Health Action Plan” (1994) stated that “The services of health board dentists will largely be concentrated on providing oral health and treatment services to children and ‘special needs’ groups with an emphasis on preventive programmes”. However, a national survey of the “Practice and Perception of Dental Health Service Providers in Relation to Special Needs Groups”, commissioned by the Department of Health and Children (NUIG, 2002) concluded that, in general, oral health services in Ireland remain treatment focused. Current services are inadequately providing for the diversity of people in the population. Nationally co-ordinated policy and legislation addressing these factors is currently lacking. Added to this, the position of Chief Dental Officer in the Republic of Ireland has been vacant for some time with obvious implications for the ongoing development and communication of essential oral health policy at the highest level.

This differs from Northern Ireland, where a recently published consultation document “An Oral Health Strategy for Northern Ireland” (September 2004), includes comment and recommendations on children and adults with disabilities. It highlights issues of data, definition and the demographic context of an increasing prevalence of disability and the legislative context of equality requirements for access and standards of oral care. Recommendations focus on prevention, training, standards development, needs assessment and transport provision.

In recent years, significant progress has been made in disability and oral health in Ireland due to the commitment of specialist practitioners and disability organisations including the:

- Forum on Promoting the Oral Health of People with Disabilities (2000);
- Establishment of the Chair in Special Care Dentistry at Trinity College Dublin and the Chair in Disability Studies at University College Dublin;
- Establishment of the Irish Society for Disability and Oral Health;
- The first oral health surveys of children and adults with special needs were carried out in 2002 and 2003;
- Research into the service provision and quality of outcomes.

However, it is time for disability and oral health in particular to move away from “being something of concern to good hearted people” (participant at Oral Health and Disability Roundtable 2004) only, reflecting the broader shift within discourses around disability from charity to rights. As the new EU Health Strategy, “Enabling Health for All” states: “goodwill is not enough”.

In summary, accessing appropriate and good quality oral health care is a significant issue for both people with disabilities and their family members and carers. Oral health practitioners need support such as professional development as well as service resources to provide such care. Research, policy development and standards setting are central to ensuring good and innovative practice.

This position paper outlines emerging issues and how they should be addressed. It makes clear and realisable recommendations aimed at ensuring that oral health for people with disabilities in Ireland is of a world class standard. Ideally, person-centred oral health services should be delivered following on a holistic assessment of needs, by disability aware staff who are supported by advocates.

Policy, service and research are considered in the next sections, followed by ten key recommendations and concluding comments which reflect on the way forward.

POLICY

The Policy Context

> "on behalf of the State, promote and work to secure the rights of people with disabilities."
>
> **NDA Strategic Plan 2004-2006**

The publication of this report is timely in the context of significant policy change in the health, disability and wider equality sectors, nationally, trans-nationally and internationally. The current policy environment provides opportunities to initiate and influence change for people with disabilities.

The NDA's publication "Disability Agenda: Legal Systems of Redress" (2004) summarises selected legal instruments such as the Equality Act 2004, Equal Status Act 2000 and Employment Equality Act 1998. It also indicates current international activity such as the preparation of the UN Convention on the Protection and Rights and Dignity of Persons with Disabilities and advocacy for a European Directive on Disability. Trans-nationally, the provisions of the Good Friday Agreement and the early focus on health as an area for co-operation between the two jurisdictions provide opportunities.

From a late start and poor historical record Ireland is viewed positively internationally for its equality legislation and policy. The Report of the Commission on the Status of People with Disabilities in 1996 marked a watershed in Irish disability policy. The Report sets out a legislative, policy and service framework aimed at realising the economic, social and cultural rights of people with disabilities. Following the Commission's report Government policy has been committed to:

- a social model of disability;
- a focus on the realisation of people with disabilities' rights;
- the mainstreaming of provision for people with disabilities;
- the building of an inclusive society.

Delivering on a recommendation of the Commission on the Status of People with Disabilities, the "National Disability Authority Act 1999" led to the establishment of the National Disability Authority.

The NDA has statutory remits in the areas of policy, research and standards. The Mission of the NDA is to:

> *"on behalf of the State, promote and work to secure the rights of people with disabilities."*

Disability is one of the nine grounds under equality legislation. As noted above the NDA's publication "Disability Agenda: Legal Systems of Redress" outlines the provisions under current equality legislation. This legislation has promoted the rights of people with disabilities to equal treatment and participation in Irish society, including access to goods and services and employment. Disability specific legislation includes the enactment of the Mental Health Act 2001 and the Education for Persons with Special Needs Act 2004 (see also Legal Systems of Redress 2004).

In 2004, the Government published the National Disability Strategy, which has four components:

- The Disability Bill;
- The Comhairle Amendment Bill;
- The draft sectoral plans from six Government departments including the Department of Health and Children;
- The budget estimates.

Current key national policy initiatives include the:

- Health reform programme;
- Expert Group on Mental Health Policy, reporting in 2005;
- Review of the National Health Promotion Strategy;
- Review of disability services, completing in 2005.

Successive social partnership agreements (Programmes for Prosperity and Fairness and Sustaining Progress) have included commitments to promote inclusion and participation, for example, in areas of public service accessibility.

The National Disability Authority is charged with supporting their implementation through its Public Services Accessibility Team, which is focusing on the areas of the built environment, ICT and quality customer services.

Oral health and disability legislation and policy require an update and development. The Health Act (1970), for example, defines the community health service as a school service. There is a gap in benefit provision and therefore a limitation on access to oral health care if a person with a disability is over 16 but has no medical card. The Dental Health Action Plan (1994) does not contain any substantial reference to special needs.

In Northern Ireland, the "Mental Health and Learning Disability Review of Legislation, Policy and Practice" will report in 2005. As discussed above, Northern Ireland has published a consultation document on oral health "An Oral Health Strategy for Northern Ireland".

Current themes in disability policy are the promotion of:

- Human rights and social model of disability;
- Leadership of people with disabilities;
- Partnership with all key stakeholders including people with disabilities and their families and carers;
- Mainstreaming of provision;
- Quality and standards;
- Disability or equality awareness and attitudinal change;
- Access, including physical, information, communication and attitudinal access;
- Co-ordination and integration of services;
- Disability or equality proofing of services.

Justified and widespread expectations of equal access to high quality services, including access to high quality oral health services exceed the less than perfect reality, however. Progressive disability, equality and human rights legislation and policy need to be developed and fully implemented. These need to be supported by adequate resources and a system for ongoing monitoring and review so that these expectations can be met.

SERVICES

Delivering the Right Service - Getting the Right Balance

A Routine Trip to the Dentist

The following case study examples were shared at the Oral Health and Disability Roundtable to illustrate the experiences of people with disabilities and their family members and carers.

A child, who has an intellectual disability, is so anxious during a trip to the dentist that she has to be strapped to a chair in order to receive basic oral health treatment.

A parent whose son has to receive a general anaesthetic every time he visits his dentist.

A parent who had to drive around the country on Christmas Eve to find a dentist with appropriate special needs training and facilities so that his son could enjoy a pain-free Christmas.

A child who can't express when he or she is in pain.

A parent whose child won't let her brush his teeth; a parent unable to brush his child's teeth adequately because of an impairment or condition.

A parent who had to respond to a dentist's suggestion that her daughter's front tooth should be extracted.

A parent unable to get up the stairs to the local dentist's surgery with his son's wheelchair; a disabled person who cannot get into the dentist's chair; a parent supporting a child who is frightened of a receptionist's loud voice.

People with disabilities, their family members and carers often face extraordinary dilemmas in very ordinary circumstances on what should be routine trips to the dentist. These experiences were shared at the Oral Health and Disability Roundtable 2004.

Whether the issue is availability, accessibility, accommodation of needs, affordability or even acceptability, the oral heath system as it stands fails to answer the needs of many people with disabilities, their family members and carers in many areas of the country. The service issues raised at the Oral Health and Disability Roundtable were diverse, ranging from:

- Access (physical to and within facilities; communication including sign language interpretation, the use of visual aids and actions to support lip-reading);
- Stress reducing practice including tone of voice, mannerisms and easy to understand explanation;
- Equity and equality, particularly in relation to rural location and age (children at transition to adulthood);
- Governance, particularly in relation to capacity and consent, the use of general anaesthesia.

This section also considers the balance between mainstreaming and specialism, the skill mix in the oral health team and the service model recommended by the Hanley report.

Many service improvements do not involve huge changes for the oral health team. In fact, simple changes can often make significant differences for a person with a disability and a family member or carer. For example, being given the last appointment of the day means that the knock-on stress associated with the possibility of affecting other service users because of loud protests on the dental chair might be lessened. Critically, it also means that the dentist will have more time to spend with the person.

The current health structure poses many challenges to the delivery of an equitable oral health service. In common with other health areas, the inverse law operates whereby where there is most need there is often the least provision of services. For example, in Roscommon, a rural county with an aging population, older people often have to travel over 60 miles to their nearest public health dentist. In addition to this, while they may be eligible for free travel, that provision is not much use to them if there is no bus service in operation. There are also the hidden costs of making the trip for free dental care. The cost of paying for a personal assistant to travel with one or the cost of paying somebody to drive one to the dentist or the cost of time off work for an escort.

In addition to these equality issues of rural location and income, the experiences of children moving into adulthood were raised. Recognition of the needs of young people making the transition from child to adult services is paramount to not only ensuring a seamless delivery of care but also that valuable resources invested in the paediatric services are not wasted. Many young people appear to fall out of services. Resources need to be targeted as part of a wider transitional planning with people with disabilities so that this does not continue to happen. There are also issues of governance that need to be addressed; most urgently those relating to capacity and consent, and the use of general anaesthetic.

The work being currently undertaken by the Law Reform Commission on capacity and consent and people with disabilities is welcome. It could clarify the legal situation and inform the development of good practice guidance and protocols in this area.

Because of the particular challenges outlined above regarding the treatment of people with disabilities, oral health practitioners frequently use General Anaesthetic (GA) as a way of carrying out necessary, but often routine, procedures. In a study carried out over a 12-year period of 410 long-stay residents with a learning disability it was found that 75% of them needed a general anaesthetic for the purposes of providing their dental treatment. (Campbell 2003).

The use of GA raises a number of practice issues. Firstly, is GA used too frequently among people with disabilities, given the inherent general risk in its use? Should GA be administered if there is no intensive care unit (ICU) available? Critically, high-risk patients (ASA III) need to be treated in a hospital and may need to be monitored overnight if they are treated under GA. However, if an overnight bed is unavailable access to the oral health care in an appropriate setting is reduced.

Two key questions of governance emerge. Firstly, where should people with disabilities requiring general anaesthetic be treated, in a general or specialist facility? Secondly, what type of dentist should carry out the work, given that the treatment required could be either surgical or restorative?

It is generally agreed that the skill-mix within the oral health team should be adjusted so that there is more emphasis on continuous oral health and the prevention of decay and gum disease. There is an urgent need for more dental hygienists and more oral health promoters. However, these professionals need to be recruited and retained in services. The potential role of lay oral health promoters, persons with disabilities, family members or carers, should be explored also.

It is also recognised that there is a need to work within interdisciplinary teams so that oral health is seen as part of general health. This means that professionals such as general practitioners, public health nurses, or nutritionists, for example, also need to be involved as members of the wider oral health team.

A dilemma exists in the evolution of all services for people with disabilities: to promote mainstreaming whilst at the same time not losing sight of the need to develop and consolidate specialist services where these are needed. In relation to oral health services across Ireland, there is the added dimension of a variation in which groups are targeted in the different regional health services, depending on the profile of the ‘special needs’ groups within that locality and the area’s perceived priorities.

There is merit in moving towards a model of service delivery as envisaged in the Hanley Report (Report of the National Task Force on Medical Staffing) of a ‘hub and spoke’ arrangement whereby high cost specialist services (for example general anaesthesia in hospitals) are provided safely and effectively in dedicated centres. Routine and supporting oral health care would then be offered to people in locally accessible clinics, by staff with training in Special Care Dentistry as well as dental practitioners with a special interest. A model for ensuring competence in the latter group is already being developed by the British Society for Disability and Oral Health, funded by the UK Department of Health. Similar policy initiatives for cost-effective oral health service development cannot move forward in Ireland in the absence of dental leadership within the Department of Health and Children to inform and steer strategic planning.

Central to the Hanley model for oral health services will be the availability of education and training to ensure competence amongst those members of the oral health team, largely employed in the publicly funded service, who have an interest in Special Care Dentistry. The approval of such education and training programmes needs to be considered urgently by the Dental Council, the Department of Health and Children and the relevant training bodies in partnership with persons with disabilities and their family members and carers.

RESEARCH

Research - Promoting Evidence Based Policy and Practice

Research should form the basis for policy and practice that will respond to the needs of both the service user and the service provider. This section considers the research activity in the disability and oral heath sectors and identifies future directions for oral health and disability research including:

- Health status and outcomes;
- Effectiveness of treatments;
- Use of general anaesthesia;
- Targeting of professional and service resources;
- Identification of the experiences, needs, priorities and preferences of people with disabilities, their family members and carers;
- Needs of different groups of people with disabilities.

The National Disability Authority, under its statutory remit, has been developing the disability research agenda since its establishment. The Commission on the Status of People with Disabilities recommended a national disability study. To realise this recommendation, the NDA has developed a research instrument based on the World Health Organisation's "International Classification of Functioning" and has worked closely with the Central Statistics Office (CSO) to include disability questions in the census to deliver demographic data on people with disabilities. In 2004, the Department of Justice, Equality and Reform announced that the first post-centile study on disability would be conducted following the next Census.

The NDA has conducted a review "Disability Related Research in Ireland 1996 – 2001", produced "Guidelines for Including People with Disabilities in Research" and guidance on research with children with disabilities and ethical guidelines. It has promoted emancipatory approaches in disability research i.e. research that promotes the leadership of people with disabilities. The first annual NDA research conference was entitled "Using Emancipatory Methodologies in Disability Research".

To date, most research on oral health and disability carried out in Ireland has concentrated on oral health needs as well as the activities of oral health providers. Research that has been carried out on specific populations has generally been under the wider category of 'special needs', including research on the oral health of Traveller children (Graham, 1986), homeless people (O'Neill, 1999) and on children in special national schools (McAlister and Bradley, 2003).

Milestones in disability research include the work of Tim Holland and Denis O'Mullane in 1986, which identified a backlog of dental disease needs amongst people with disabilities. It concluded that the dental needs of the majority of these people could be met by final year dental students or house officers, with the remainder of people requiring consultant care.

In a research project published in 1990, the same team examined and compared the oral health of this group of adults with disabilities over two years. When first examined (1985), the group had a high prevalence of untreated dental disease. When examined two years later (1987), dental decay was less of an issue but continuing care and gum disease was still a problem.

This raises an important point in the dental treatment of people with disabilities. It shows that dentists can provide appropriate acute treatment but cannot as easily provide continuous care under the present system in some parts of Ireland. Any strategic development in policy, research and standards needs to work towards the provision of a continuum in care that will include maintenance programmes and result in prevention of dental decay and gum disease.

As discussed above, there is also the question about the use of general anaesthesia (GA) in the provision of oral care for people with disabilities. Apart from the cost element, the issues surrounding consent for the use of GA on a regular basis to treat people with disabilities has to be questioned. Strategies around the use of GA require an evidence base. There needs to be research and debate on the use of GA, amongst all stakeholders in order to develop consensus around good practice on its use.

Research carried out to date also raises serious questions about the effective use of professional and service resources to treat people with disabilities. Areas for investigation could include the use of Paediatric Dentists to treat adults, and the infrastructure at undergraduate level including curriculum focus and training.

McAlister and Bradley's work in 2003 on targeted services in the Eastern Regional Health Area (children in special national schools referred to above), showed that children with special needs had much better oral health outcomes when provided with targeted resources (Bradley 2003). In the research project, eight Senior Dentists treated 3,280 children with special needs, including those with disabilities. When compared with children in mainstream schools, they had more decay-free teeth and they had comparable levels of dental treatment. They continued, however, to have higher levels of gum disease. Further research is required to identify the reasons for such results including investigation into the skill-mix in oral health teams.

The former North Eastern Health Board is currently carrying out research on the results of early intervention in the oral healthcare of children with disabilities, which will be reported in 2005. Preliminary results point to the benefits of interim intervention as the best means of preventing dental decay and gum disease. This might mean something as simple as educating parents about the benefits of a sugar-free diet from birth or teaching parents how to brush their infant's gums and teeth from as early an age as possible. Earlier intervention is also important in adults who may become disabled through acquired illness, injury or disease, to prevent the often rapid deterioration in oral health that may be the consequence.

Within all research and subsequent service development programmes, there must be constant evaluation to ensure, firstly, that they actually deliver for people with disabilities and secondly, that they make the most cost-effective use of valuable resources. Evaluation needs to include an assessment of whether services realise the implementation of Government disability and health policy discussed above by asking whether services promote:

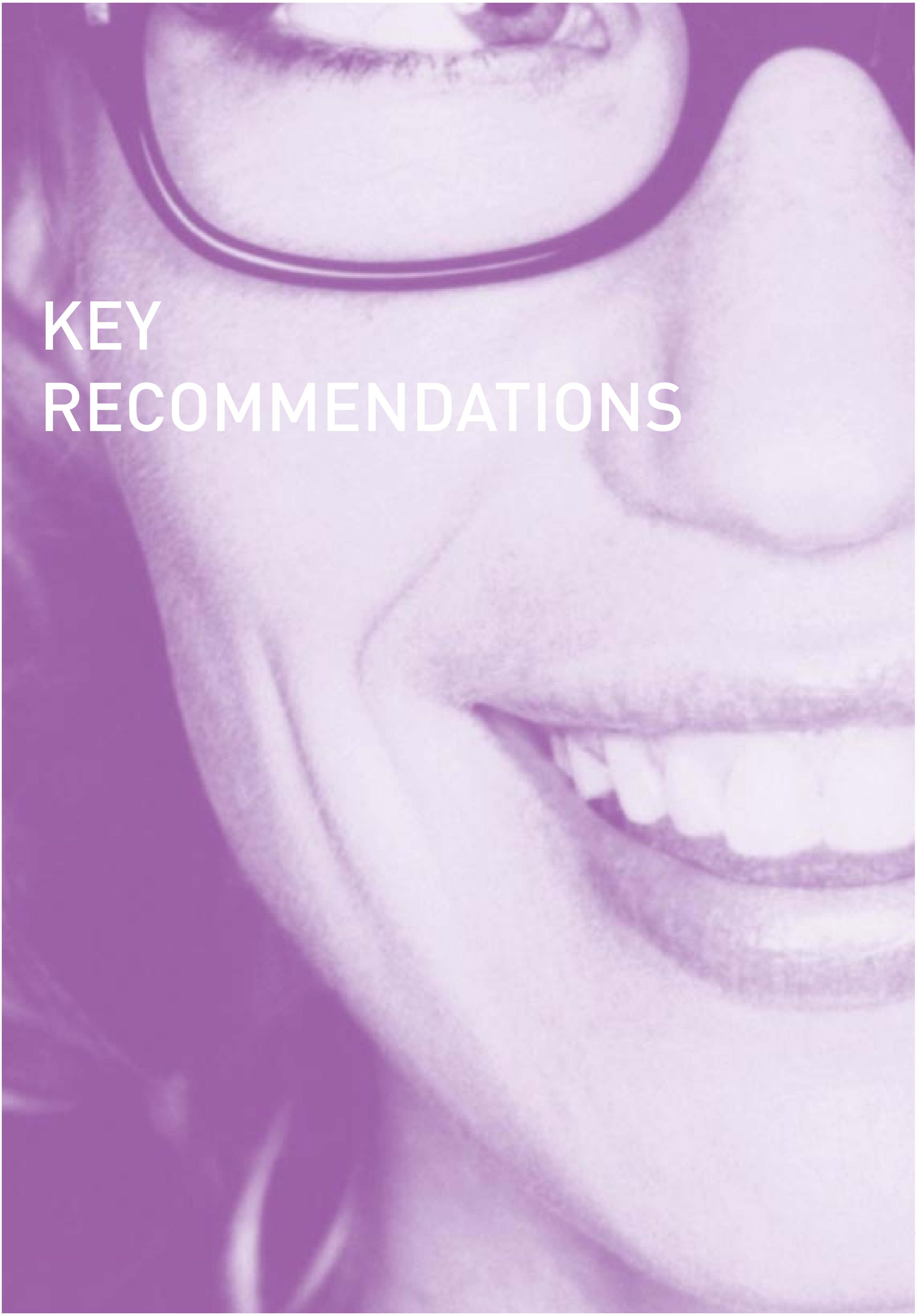
- Human rights and social model of disability;
- Leadership of people with disabilities;
- Partnership with all key stakeholders including people with disabilities and their families and carers;
- Mainstreaming of provision;
- Quality and standards;
- Disability or equality awareness and attitudinal change;
- Access, including physical, information, communication and attitudinal access;
- Co-ordination and integration of services;
- Disability / equality proofing of services.

It is valuable to ask other questions. Do teeth actually matter to people other than the oral health team? Do people with disabilities mind if they have missing or even no teeth, if they have tooth decay or overcrowding? From anecdotal evidence and feedback from disability representative groups, the answer seems to be a resounding yes. The research based evidence for this remains elusive. It is widely accepted that asking the service users - people with disabilities, their families and carers – what it is they want from an oral health service is long overdue.

A person-centred approach to research will focus on what makes a service work for people with disabilities, how different treatments affect them, and how they expect to be treated, for example. Armed with such evidence, oral health services can, for the first time, be properly developed and designed to address needs adequately. However as a pre-requisite for such research there has to be an agreed, more specific definition of ‘special needs’ groups and disability services. At present, this varies between health service regions.

Good quality research includes, who the researcher questions and how s/he asks the questions. Critical design issues include: How are people with disabilities going to be reached? How are they going to be communicated with? Additionally, while it might be easier to elicit information from family members and carers the views of people with disabilities must also be accessed. While it may make sense to work through representative organisations and service providers, it is also important to remember people with disabilities who are living in their family or own home and who are not in direct contact with services.

Within the disability community itself, people with various disabilities have very different needs and challenges. Accordingly, a one-size-fits-all approach to oral health services will not work. The oral health community needs to understand, for example, that issues such as emotional tone, dress, gender or use of technology might mean the difference between a positive experience at the dentist and a traumatic one.



KEY RECOMMENDATIONS

Key Recommendations
Small Changes – Big Differences

1. Define 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 persons with disabilities should be determined in light of this understanding. Legislative definitions of disability could usefully inform the redefinition of ‘special needs’ previously defined by the Department of Health and Children in 1997.

2. Establish Definitive Training Pathways

Disability / equality awareness, including in-service work in the community, needs to be a central part of training of the oral health team. Continuing education programmes should be available to oral health personnel involved in providing care to persons with disabilities.

In addition, a clearly defined and flexible training pathway needs to be developed for people who wish to specialise in Special Care Dentistry that is centrally funded by Government.

3. Adjust the Skill-mix within the Oral Health Team

There needs to be adjustment in the skill-mix in oral health care provision with greater emphasis on the role of, and investment in the training of, dental hygienists and oral health promoters within the oral health care team. A comprehensive “train the trainers” programme should be initiated to train people with disabilities and family members and carers as oral health promoters.

4. Deliver Mainstreaming, Value Specialism

Good quality oral health services should be integrated into the general health care plan, as envisaged in the Hanley Report. Further discussion needs to take place about how the Government’s commitment to the mainstreaming of health provision for people with disabilities can be delivered whilst ensuring the development of specialist knowledge and competence.

5. Promote Accessibility and Equity

Appropriate, quality oral health care should be equitably and accessibly delivered across the country and to all groups of people with disabilities. Public oral health providers should be encouraged to apply for the NDA's Public Services Accessibility Award. The good practice guidance on quality customer service, built environment and ICT included in the PSA Award should be used as a benchmark for primary care. Service providers should be encouraged to develop service plans that will deliver accessible provision over time. Information about supports and incentives to promote service accessibility and employment of people with disabilities should be disseminated to oral health care service providers.

6. Focus on Early Intervention

There has to be greater investment in early intervention in not only promoting and sustaining the oral health of children with disabilities but also that of adults who may develop a disability in later life, because of illness, disease or injury.

7. Acknowledge Competence Appropriately

Specialisation in the oral heath care of people with disabilities should be acknowledged by way of a seal or quality mark. The structure within the public health services should be attractive enough to recruit and retain staff involved in this field.

8. Establish an Information Clearing House

A "highway" or clearing house for the flow of information and communication between specialists, service users, support groups and rehabilitation services should be established to provide information on quality oral health care to persons with disabilities and their families and carers.

9. Initiate Person Centred Research

Research needs to be adequately funded and co-ordinated so that it can move from being largely professional and medically-led activity to being person led, informed by emancipatory research approaches. Researchers should explore what it is that people with disabilities, their families and carers, need and prefer in order to inform the development of services that meet those needs adequately. Research needs to identify barriers to service use and how these can be addressed.

10. Address the Issues of Capacity and Consent

The work being undertaken by the Law Reform Commission should be used to inform the development of policy and protocols regarding people with disabilities' capacity to consent to treatment. This needs to be addressed as a matter of urgency given the significant use of General Anaesthesia for oral care.

CONCLUDING COMMENTS

Concluding Comments

The partners who have produced "Oral Health: the way forward", the National Disability Authority, Dental Health Foundation and the Trinity College Dublin School of Dental Science, consider this publication to be timely in the context of significant legislative, policy and service activity in the health and disability sectors in Ireland and Northern Ireland. Building on the recent research and organisational progress in the area of disability and oral health since the "Forum on Promoting the Oral Health of People with Disabilities" (2000), a way forward is proposed to address issues raised by stakeholders who attended the "Oral Health and Disability Roundtable" event. These include people with disabilities, the family members and carers, oral health professionals, service providers, policy makers and academics from both jurisdictions on the island of Ireland.

This way forward is informed by the thrust of Government health and disability policy since the "Report of the Commission on the Status of People with Disabilities" (1996) which has promoted:

- human rights and social model of disability;
- leadership of people with disabilities;
- partnership with all key stakeholders including people with disabilities and their families and carers;
- mainstreaming of provision;
- quality and standards;
- disability or equality awareness and attitudinal change;
- access, including physical, information, communication and attitudinal access;
- co-ordination and integration of services;
- disability or equality proofing of services.

Central to the notion of the "European Health Strategy" is the premise that good will is no longer enough to ensure good health. Up to now, most work on oral health and disability has been carried out by 'good hearted people' who have an interest in ensuring that people with disabilities receive proper health care. The acknowledgement of professionalism and properly remunerated competence at all levels if oral health care is required to move beyond charity to a rights based approach.

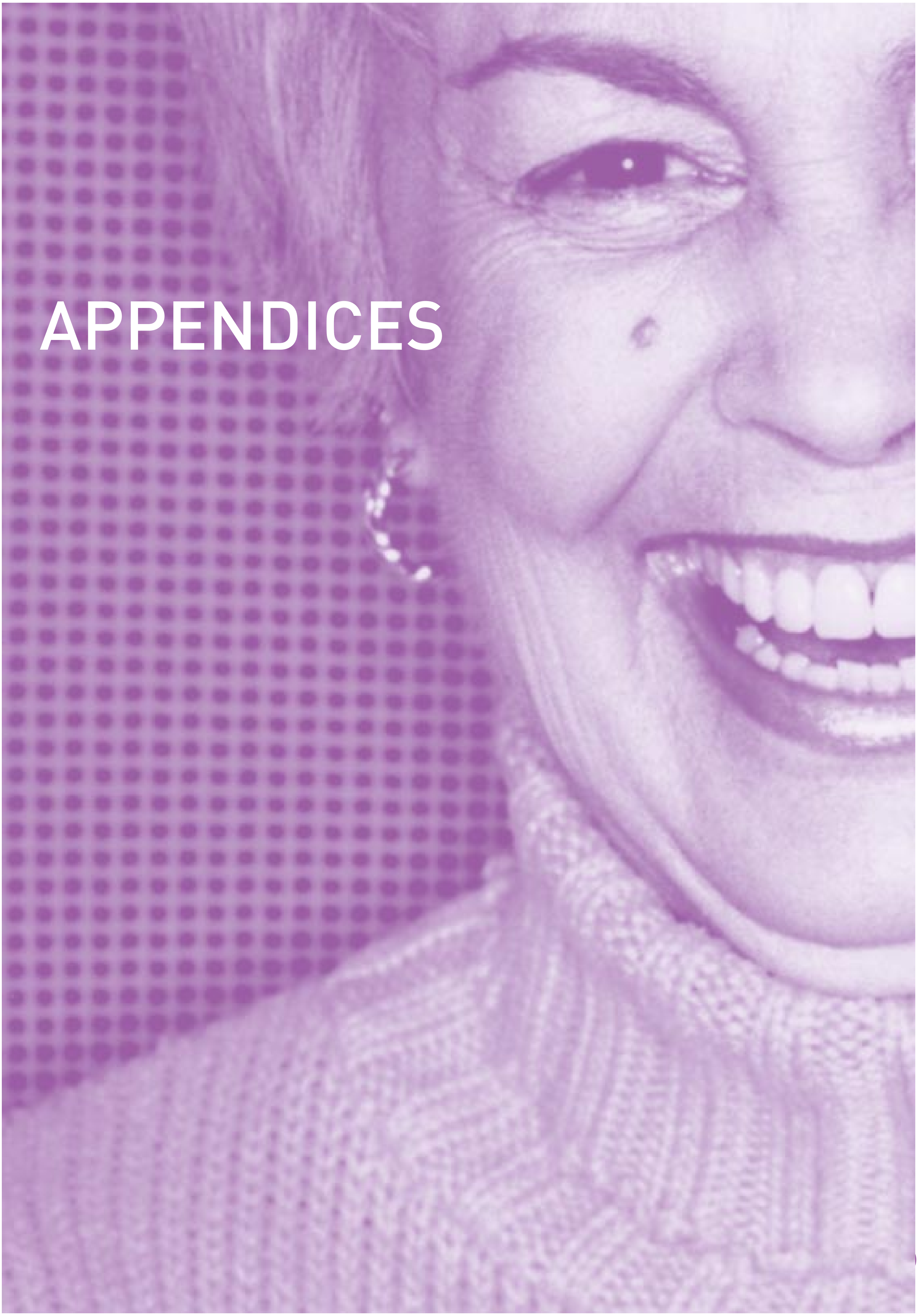
In order to ensure that the recommendations within this document are progressed and the issues continue to be discussed, it is essential that there is a framework for the promotion of oral health for people with disabilities.

Following the ten key recommendations in the previous section, “Oral Health: the way forward” concludes with five steps that provide a road map for taking this agenda forward:

- Conduct research into the needs and preferences of people with disabilities, their family members and carers regarding oral health service provision;
- Conduct research and develop practice on the building of competence in oral health care for people with disabilities;
- Promote debate on progressing the mainstreaming of provision whilst ensuring the development of specalist knowledge and skills;
- Develop a framework for action grounded in this evidence base;
- Develop a communication strategy to embed this framework into policy making and service development processes in order to place disability onto oral health agendas and oral health onto disability agendas.

Delivering such a change agenda requires a partnership approach with clearly defined roles for each participant. The National Disability Authority, Dental Health Foundation and Trinity College Dublin School of Dental Science look forward to continuing to work on this issue with people with disabilities, their families and carers, representative disability and oral health bodies, researchers, policy makers and service providers in Ireland and Northern Ireland.

APPENDICES



Appendix I

Oral Health and Disability Roundtable Invited Delegates

Ms Conac Bradley	Irish Society for Oral Health and Disability
Mr Norman Campbell	City Hospital Belfast, Northern Ireland
Dr Evelyn Connolly	North Eastern Health Board
Dr Edward Cotter	Irish Dental Association
Mr Padraig Creedon	Society of Chief and Principal Dental Surgeons, Ireland
Mr John Dolan	Disability Federation of Ireland
Ms Antoinette Doocey	Primary Care Task Force, Department of Health and Children
Ms Iris Elliott	National Disability Authority
Dr Brid Farrell	Wraparound Project, Northern Ireland
Professor Ruth Freeman	Queen’s University Belfast
Ms Finula Garraghy	NAMHI
Ms Patricia Gilheaney	Mental Health Commission
Ms Patricia Gilsenan	Dental Health Foundation
Ms Tina Gorman	Dublin Dental School & Hospital, Special Care Dental Nursing
Mr Seamus Greene	National Parents and Siblings Alliance
Dr Sinead Hanafin	National Children’s Office
Ms Anna-May Harkin	Evaluation and Planning Division, Department of Health and Children
Mr Richard Hensen	Schizophrenia Ireland
Dr Owen Hensey	Central Remedial Clinic, Clontarf
Ms Joan Hinchy	People with Disabilities in Ireland
Mr Brian Howard	Mental Health Ireland
Mr Brendan Ingoldsby	Disability Division, Department of Health and Children
Professor Martin Kinirons	Dental School & Hospital University College Cork
Mr Shay Mc Govern	Health Promotion Unit, Department of Health and Children
Mr Paddy McGowan	Irish Advocacy Network
Ms Maureen McInerney	North Eastern Health Board
Mr Owen Metcalfe	Public Health Alliance Ireland
Mr David Moloney	Department of Health & Children
Dr Barney Murphy	South Western Area Health Board
Ms Bairbre Nic Aongusa	Mental Health Division, Department of Health and Children
Professor Patricia Noonan-Walsh	University College Dublin
Professor June Nunn	Dublin Dental School & Hospital Trinity College Dublin

Mr Brian O’Donnell	National Federation of Voluntary Bodies
Dr Mary O’Farrell	Oral Health Promotion Research Group Irish Link
Ms Michelle Oliver	Community Dental Service
Dr Colleen O’Neill	Society of Chief & Principal Dental Surgeons in Ireland
Mr Declan Quinn	North Eastern Health Board
Ms Deirdre Sadlier	Dental Health Foundation
Mr Matt Walsh	Western Health Board
Mrs Doreen Wilson	Department of Health, Social Services and Public Safety Northern Ireland
Ms Ann O’Neill	Health Board Dental Surgeons
Dr Margaret Shannon	Department of Health and Children
Ms Helen Whelton	Oral Health Service Research Centre, University College Cork
Ms Monica Wilson	Disability Action, Northern Ireland
Working Groups	CAWT

Directors of Disability Group Health Boards

Directors of Mental Health Group Health Boards

Disability Equality Unit, Department of Justice, Equality and Law Reform

Joint Chairpersons, Oral Health Managers Society of Ireland

Appendix II

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