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Survey of Dental Services to People with Learning Disabilities in Northern Ireland

Executive Summary

December 2005

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Foreword

The Review of the Community Dental Service (2003) prioritised the care of patients with special needs as a main concern, highlighting an integrated approach to providing oral health promotion and dental treatment to this population.

The main aim of the Oral Health Strategy (2004) Consultation Document was to improve the oral health of the Northern Ireland population and, in doing so, tackle health inequalities.

This study of people with learning disabilities was funded by the Department of Health, Social Services and Public Safety and took place during 2005. Research Evaluation Services were contracted to undertake the project and the dental consultant was Dr Ruth Gray. The Community Dental Service is thanked for their help and facilitation in providing much of the material for analysis in this study. Dr Gray is thanked for her comprehensive report, which formed the basis for this Executive Summary.

This study highlights the need to prioritise the dental services to, reduce inequalities in oral health, and improve access to general dental services and General Anaesthesia services. Initiatives for prevention of oral disease are essential including the implementation of a policy on water fluoridation, training of carers, oral health protocols in residential units and a skill-mix balance of staff to implement oral health programmes. Training of dental staff in special care dentistry is also essential. Community Trusts should co-ordinate dental initiatives and share oral health programmes. During the planning of dental services and the training of staff, a multidisciplinary approach should be taken with the aim of creating a supportive environment for good oral health. When planning dental care it is important to recognise the role of the carer and the person with the learning disability and in consultation, to encourage person centred planning of services.

Finally, it must be remembered that people with learning disabilities are not a homogenous group, they have many different needs and aspirations; but most of all it should be remembered that oral health and dental aesthetics are important to everyone and services should be planned and adapted to promote this.

Doreen Wilson

Chief Dental Officer

December 2005

Aims Of The Study

The study of dental services to people with learning disabilities was commissioned by the Chief Dental Officer (DHSSPS) and took place in 2005. It was a multifaceted research project with the following aims and methods:

1. To investigate the experience of service users (people with learning disabilities, their families and carers) on seeking and attending dental services.

Data was collected by a series of focus groups discussing the availability, acceptability and accessibility of dental treatment and oral health education.

2. To measure the baseline levels of oral health of people with learning disabilities (over 13 years old) in Northern Ireland.

Data was collected by an audit of dental screening examinations conducted by community dentists in two Trusts; Causeway and South and East Belfast; and totalled 269 subjects.

3. To assess the level of support and priority given to the oral healthcare in residential units for people with learning disabilities in Northern Ireland.

Data was collected by telephone interview with care unit managers and investigated the protocols for oral health, training and multidisciplinary nature of dental health promotion in the units.

4. To establish the nature of the dental service provided by the community dental service for people with learning disabilities.

Data was compiled from questionnaires to dentists and clinical directors in each Trust, and investigation of health promotion practices; the skill-mix of dental personnel; IV sedation and general anaesthetic protocols and practices and the training of community dental staff.

A detailed account of research methods, results, discussion and conclusions is available in the full report on the dental website at:

<http://www.dhsspsni.gov.uk/pgroups/dental/dental.asp>

Policy Background

'Reducing the inequalities of oral health within society.'

The main aim of the Oral Health Strategy (2004) Consultation Document was to improve the oral health of the population in Northern Ireland and in doing so tackle health inequalities.

At present, there are no available data on the oral health status of adults with a learning disability in Northern Ireland, but data is available from other countries. Previous studies investigating the dental health of people with learning disabilities revealed a high level of untreated dental decay with the main treatment experience being extractions instead of restorations. Oral hygiene was poor amongst people with learning disabilities and gum disease more prevalent than in the general population. (*Crowley et al., 2005, Cumella et al., 2000, Shapira et al., 1998.*)

A report by Mencap highlighted that people with a learning disability have a lower uptake of dental services than the general population (*Mencap 2004*). Health information has been shown to be largely inaccessible to people with a learning disability, resulting in an inequality of knowledge about health services and health promotion (*D'Eath et al. 2005*).

Studies have demonstrated the lack of knowledge, support and training about oral health that is available for parents and carers of people with learning disabilities (*Taylor-Dillon et al., 2003*).

A challenge to the dental services is the policy of deinstitutionalisation and integration into community settings. Research highlights that as individuals move from institutions to communities their dental attendance is less regular and there is a necessity to expand and develop community-based services (*Stanfield et al., 2003*).

If dental services are to respond in a local community setting, it is important that teams are trained and confident in care (*Wilson 1991*). A study with the community dental service in Northern Ireland in 1993 claimed that lack of experience and knowledge were the main barriers for dentists providing care for people with disabilities (*Russell and Kinirons, 1993*).

People Centred Research

The *North-South Forum on Oral Health and Disability 'The Way Forward'* recommended the initiation of person centred research (*Elliot et al., 2005*).

In pursuance of this principle, a series of focus groups comprising patients and carers were undertaken as part of this study. The main points arising from the focus groups were:

- The viewpoint of service users is fundamental to the planning of dental services to people with learning disabilities.
- Healthy teeth were an aspiration by all members of the focus groups. People did not want to undergo dental extractions. Dentures were desired when teeth were missing.
- Dental health is of major importance to the learning disabled and their families

Comment

People with learning disabilities are not a homogenous group; there are varying levels of oral disease and varying needs for accessing dental care and health promotion. The dental care must recognise the complexity and needs of each individual person, and adapt their service delivery as appropriate.

The main recommendations emanating from the user/carer research are captured in the subsequent sections.

Theme: 1

Prevention of Oral Disease

'A philosophy of lifelong prevention of dental disease should be adopted by all dentists' (Oral Health Strategy (2004) Consultation Document).

This research study has revealed that prevention of oral disease has been the main priority theme in the data collected.

Service providers, carers and the people with learning disabilities who participated all agreed that a greater emphasis should be placed on prevention. At present, oral health training for carers and people with learning disabilities is very limited and everyone agreed that training should be formalised and conducted in all Community Trusts.

Oral health programmes should be shared and adapted between Community Trusts, and should be evidence based through research and evaluation.

Positions within the community dental service should have the responsibility and remit to conduct such research and develop programmes. A skill-mix balance in each Trust to facilitate prevention is important including staff recruitment of oral health promoters and dental hygienists.

Early prevention of oral disease could be improved by involving health visitors and social workers in oral health education, as suggested by family carers. The community dental service could focus the priority of care of people with learning disabilities, by increasing targeted screening programmes. Care unit staff should be trained to recognise dental disease and to involve oral health in initial service user assessments.

The planning of oral health initiatives are led mainly by dentists, and this must be altered to a multidisciplinary approach; the input of carers and other health and social care providers and people with learning disabilities will result in resources that are appropriate and relevant. Collaboration in training of nursing and carer staff is essential.

Collaborative work should be conducted with care unit managers to improve oral health protocols in residential units, focusing on oral hygiene techniques, training of service users and staff, and creating a healthy eating policy.

Senior Dental Officers highlighted the concept of creating supportive environments, calling for DHSSPSNI to lobby for water fluoridation, legislation in confectionery advertising and healthy eating policies.

Recommendations

1. The community dental service should focus the priority of care of people with learning disabilities, by increasing targeted screening programmes.
2. Oral health promotion should be evidence-based and shared and adapted across Community Trusts.
3. All carers and people with learning disability should be offered a personalised oral health disease prevention and treatment plan.
4. There needs to be an appropriate multidisciplinary skill mix of personnel who are involved with care for the learning disabled.
5. The DHSSPS should continue to pursue water fluoridation, legislation in confectionery advertising and promotion of healthy eating policies.

Theme: 2

Training of Dental Teams

The training of dental teams was very limited, with the opportunities for training varying across Community Trusts. Care unit managers and family carers highlighted the need for disability awareness education. Some of the Community Trusts had conducted such courses, which had been reported favourably by staff.

People with learning disabilities highlighted the need for dentists to improve communication skills, and this was echoed by dentists' requests for training in communication and behaviour management.

The community dental service claimed to have received very little training in care of people with a learning disability, and called for the inclusion of training in the undergraduate curriculum and placements of students within community dental clinics. The dentists aspired to a formal training programme in special care dentistry and the establishment of a specialty. Greater emphasis should be placed on training and attendance at courses to improve the dental service's ability to provide acceptable care. Dental staff should be encouraged and facilitated to undertake postgraduate qualifications to promote specialist training.

Formal training for dental care professionals should be developed and should be accessible to community dental staff.

Senior Dental Officers felt that an integrated approach to training in service provision for people with disabilities would be of great benefit and should involve medical, nursing and care staff and people with learning disabilities.

Recommendations

1. All staff should have disability awareness and communication skills training.
2. Training programmes in Special Care dentistry for dentists and dental care professionals should be developed.
3. Training in the provision of dental care to people with learning disability should be included in the undergraduate curriculum.

Theme: 3

The Status of Oral Health and Disease

The audit screening exams have revealed that health inequalities exist. The prevalence of oral disease was higher, and the treatment provision lower, in the sample population of people with learning disabilities compared with the general population. People with learning disabilities experienced more extractions and fewer restorations. The number of natural teeth present was lower in the sample than in the general population.

Denture possession, in particular of partial dentures, was much lower than in the general population. Although the level of compliance and co-operation of a patient will be relevant to the treatment provided, there must be a recognition that people with learning disabilities would prefer to wear dentures if teeth are missing than not. If denture provision is low, the maintenance of natural teeth is essential. Dental aesthetics are important to this group.

The aim should be to reduce the number of extractions carried out and increase the range of treatment available for people with learning disabilities. Dental staff have highlighted the need for training in best practice protocols and treatment planning.

A small cross-sectional sample of 14-15 year old children revealed a high prevalence of disease and highlighted the need for further investigation into the dental health status of this population. A standardised method of data collection across Trusts will enable trends and treatments in oral health to be monitored.

Periodontal health was poor, with a high percentage of people examined requiring dental intervention. At present, only a small number of dental hygienists are available to provide a service for people with a learning disability. The distribution of dental hygienists between Community Trusts was inequitable. The valuable contribution of dental hygienists has been highlighted by community dentists, family carers and care unit managers. All these recommended that more dental hygienists are made available to work specifically with people with disabilities (see recommendation 1.4).

Recommendations

1. Core data sets and standardised collection procedures should be developed regionally.
2. Treatment of untreated dental disease should be a priority within the Community Dental Service
3. The aim of dental care should be to reduce the number of extractions experienced by people with learning disabilities, coupled with evidence-based preventive practices.

Theme: 4

General Anaesthetic

At present, the general anaesthetic services are inadequate, with long waiting lists unacceptable to both service providers and carers. Access to GA services is inequitable between Community Trusts. Service delivery has been reduced, due to changes in guidelines preventing GA sessions in Muckamore Abbey Hospital, and cancellations in other centres due to staff shortages, lack of anaesthetic cover, renovations and patient illness. This has resulted in waiting lists over 2 years in the School of Dentistry. Meanwhile, Causeway Trust with new facilities have a much shorter waiting list. Low numbers of people have been treated under GA in 2004 by the CDS due to the many interruptions and cancellations of the service and a greater priority of GA sessions for dental treatment in hospital scheduling.

The number of available sessions should be increased and the pool of dentists and anaesthetists trained and willing to work in GA clinics should be increased. Investigation of integrated care pathways, with the efficiency of the co-ordination of joint anaesthetic services and a greater multidisciplinary approach to care of people needing treatment under GA should be examined.

The Senior Dental Officers suggested the development of a centre of excellence for dental and medical care of people with learning disabilities. In addition, that facilities, support and care for people with learning disabilities staying overnight in hospital should be improved.

People with learning disabilities and their carers asked that the process of GA administration be made less traumatic for the patient, and that medical and dental staff have better communication about the procedure.

Recommendations

1. Across Trusts, there should be equitable access to dental care for all patient groups, including treatment provided under General Anaesthetic to those with a learning disability.
2. Community Trusts should work towards a standard referral pathway for any person requiring general anaesthesia for dental treatment.
3. The patient experience of GA could be improved with better planning and communication.
4. Further research into the role IV sedation could play in reducing GA waiting lists should be carried out.
5. An effective care and pain relief service is required for those patients on long GA waiting lists.
6. Work should be undertaken in all Trusts to contribute to the reduction in waiting lists.

Theme: 5

Access to Dental Services

Access to health information for people with learning disabilities and their carers is poor. During the focus group, the service users suggested better communication from the dental team, and a more creative approach to conveying information, such as on the appointment cards. Care unit managers also suggested the use of visual aids in explaining dental disease and treatment; the importance of this was recognised by family carers.

Senior Dental Officers and family carers commented on the inequity of accessing 'out-of-hours' dental care for people with learning disabilities. Reasons for inequity given included the lack of information about the patient's medical history and lack of experience in special care dentistry of the dentist on call. A wider training base to include general dentists in the provision of dental care of people with learning disabilities is necessary, and better information technology systems need to be put in place for the sharing of dental and medical histories.

Accessing regular dental care for all is a priority of the Oral Health Strategy (2004) Consultation Document. Due to the many pressures of supporting a person with a learning disability, carers claimed that it was often difficult to prioritise dental appointments. A targeted recall appointment system would facilitate better access. As many people with learning disabilities living in the community are unaccounted for, due to a lack of comprehensive registers, a system should be put in place at the transition period of school leaving.

Screening of day centres and residential units was reported as being positive by carers and should be continued. In Community Trusts, where a targeted approach was not in place, staff should be made available to take part in screening and oral health programmes.

Recommendations

1. On-line access to dental records between community dental clinics & hospitals should be facilitated in future planning.
2. Clear information on how to access 'out-of-hours' emergency dental care should be provided to all patients.
3. Greater use of mobile units and more targeted screening should be considered
4. Appropriate and effective follow-up screening procedures for learning disabled patients after leaving school need to be developed.

Summary of Recommendations

1. Prevention of Oral Disease

- 1.1. The community dental service should focus the priority of care of people with learning disabilities, by increasing targeted screening programmes.
- 1.2. Oral health promotion should be evidence-based and shared and adapted across Community Trusts.
- 1.3. All carers and people with learning disability should be offered a personalised oral health disease prevention and treatment plan.
- 1.4. There needs to be an appropriate multidisciplinary skill mix of personnel who are involved with care for the learning disabled.
- 1.5. The DHSSPS should continue to pursue water fluoridation, legislation in confectionery advertising and promotion of healthy eating policies.

2. Training of Dental Teams

- 2.1. All staff should have disability awareness and communication skills training.
- 2.2. Training programmes in Special Care dentistry for dentists and dental care professionals should be developed.
- 2.3. Training in the provision of dental care to people with learning disability should be included in the undergraduate curriculum.

3. The Status of Oral Health and Disease

- 3.1. Core data sets and standardised collection procedures should be developed regionally.
- 3.2. Treatment of untreated dental disease should be a priority within the Community Dental Service
- 3.3. The aim of dental care should be to reduce the number of extractions experienced by people with learning disabilities, coupled with evidence-based preventive practices.

4. General Anaesthetic

- 4.1. Across Trusts, there should be equitable access to dental care for all patient groups, including treatment provided under General Anaesthetic to those with a learning disability.
- 4.2. Community Trusts should work towards a standard referral pathway for any person requiring general anaesthesia for dental treatment.
- 4.3. The patient experience of GA could be improved with better planning and communication.
- 4.4. Further research into the role IV sedation could play in reducing GA waiting lists should be carried out.
- 4.5. An effective care and pain relief service is required for those patients on long GA waiting lists.
- 4.6. Work should be undertaken in all Trusts to contribute to the reduction in waiting lists.

5. Access to Dental Services

- 5.1. On-line access to dental records between community dental clinics & hospitals should be facilitated in future planning.
- 5.2. Clear information on how to access 'out-of-hours' emergency dental care should be provided to all patients.
- 5.3. Greater use of mobile units and more targeted screening should be considered
- 5.4. Appropriate and effective follow-up screening procedures for learning disabled patients after leaving school need to be developed.

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