developing clinical guidelines on promoting oral health: an action research approach

A service providing day and residential care in Ireland has improved the general and oral health care of people with learning disability. Sheila Doyle and Caroline Dalton report

Over past decades the promotion of normalisation and socially inclusive policies has resulted in a move from institutional care to community living for people with a learning disability (Wolfensberger 1972). Service providers seek to ensure that people experience greater choice and control in their lives and are included within their communities (Jones 1999, Northway et al 2005). According to the National Intellectual Disability Database 2007, 8,262 individuals (or 32.3 per cent of people with learning disabilities in the Republic of Ireland) live in residential settings, mainly in the community (Kelly et al 2007). 'The numbers of people accommodated in community group homes and in residential centres have increased and decreased respectively, on an almost continuous basis, since data collection commenced in 1996,' Kelly et al note.

People with a learning disability have the right to be valued and supported as equal citizens, including the right to access equitable health care. As a result of community living, such people are accessing mainstream healthcare services more frequently
that such individuals experience health disparities (Mencap 2004), with studies linking this disparity to a lack of specialist knowledge and training of community healthcare workers on the needs of people with learning disabilities (Prasher and Janicki 2002). Although these people have the same rights to equal standards of health care as the general population, there is evidence that they generally experience poorer health, and oral health in particular, have unmet health needs and have lower uptake of screening services (Faculty of Dental Surgery 2001).

Importance of oral hygiene
Oral diseases have not always been given as much priority as other complex medical problems (Malmstrom et al. 2002). Yet the effect of oral problems on an individual's quality of life can be profound (Locker 1992). Oral disease has been linked with other systemic diseases, including cardiovascular disease, cerebrovascular disease, diabetes, respiratory infection, periodontal bone loss and osteoporosis (Malmstrom et al. 2002). Poor oral health can result in significant pain and an inability to consume nutritious food, and can damage a person's self-image and confidence (National Disability Authority 2005). Good oral health has many holistic benefits in that it can improve general health, dignity and self-esteem, social integration and quality of life (Fiske et al. 2000).

Up to 36 per cent of adults with learning disability and 80 per cent of adults with Down syndrome are believed to have unhealthy teeth and gums (Mencap 2004), with common oral conditions such as dental caries and periodontal disease featuring prominently.

A study carried out in 27 residential services in Ireland on the oral health of 281 adults with learning disabilities showed the residents had lower levels of treatment of dental caries and periodontal diseases in comparison to the general population (Crowley et al. 2003). The study identified that the residents had more extractions, fewer restorations, fewer natural teeth and were less likely to have dentures. These findings mirror those in a qualitative study of the oral health of 269 individuals with learning disabilities in Northern Ireland (Department of Health, Social Services and Public Safety 2005).

A Japanese study of 24 adults with Down syndrome found that all of them had advanced periodontal disease. In the worst cases, the disease had progressed to its maximum, while the lowest rate was 60 per cent (Yoshihara et al. 2005). The relevance of this finding is significant for people with Down syndrome because studies have identified that up to 40 per cent of people with Down syndrome suffer from congenital heart defects and immunosuppression (Griffiths 2000). Cardiovascular patients are at high risk of developing bacterial endocarditis during invasive dental procedures (Stiefel 2002).

Method
Given the importance of oral health care, the Kerry Parents and Friends Association undertook an action research approach to review the oral health of people with learning disability who make use of their services in southern Ireland. The association is committed to providing a professionally delivered, quality service to people with a learning disability and their families. Avison et al. (1999) say of action research: 'The emphasis is more on what practitioners do than on what they say they do', and, according to Coghlan and Brannick (2005), action research consists of five distinct areas:

- pre-step: identifying the necessity of undertaking the research project
- diagnosis: identifying the specific issue/problem involved

Pre-step
Initially, an oral assessment of those using the service was undertaken by the Health Service Executive (HSE) dental services (Southern Region). The HSE is responsible for providing health and personal social services for everyone living in the Republic of Ireland. The dental team examined 68 people with learning disability, 18 of whom lived in homes run by the association. The other 50 were day attendees who lived at home with their families.

Diagnosis
A total of 38 people needed some form of treatment after examination. Most of them could be treated in primary care settings, with only two assessed as requiring general anaesthesia for invasive dental treatment.

With more than half of those screened needing further treatment, staff identified oral health as an area that needed further intervention and wanted to promote oral health. Following this review, the Kerry Parents and Friends Association decided to develop clinical guidelines for promoting oral health.

Planning action
While treatment for most dental diseases is available, preventive programmes must be modified according to the needs and abilities of each individual (Stiefel 2002). Continuous, systematic and individualised oral care can inhibit the progression of oral disease (Yoshihara et al. 2005).

While it is clear that clinical guidelines on oral health care should be included in practice settings, a study in Ireland identified that only 12 per cent of service areas had written oral healthcare guidelines in place (Crowley et al. 2003). Despite the importance
of oral health promotion. Crowley et al.’s (2003) study found that 66 per cent of staff reported that they had received no training in oral care, while 80 per cent recognised a need for such training. Carers (family and professionals) should be offered, and should take up, advice on oral health education. Improvements in the oral health of adults with learning disabilities have been demonstrated through training and education of front-line staff (Nicolai and Tesini 1982). Nurses and care staff are key agents in the delivery of care to people across services in Ireland. Delegates attending the 2005 National Association for the Mentally Handicapped of Ireland conference were told that although many professionals have an important role to play, it is those on the front line who have the most detailed knowledge of the person and his or her behaviours. Interventions designed by front-line staff may be more suitable than those designed by visiting specialists.

The registered intellectual disability nurse (RNID) plays a pivotal role in preventing oral disease, a principal aim of oral health promotion and oral health education, through the development of oral health programmes (Stiefel 2002). In light of this, the development of the guidelines was undertaken by the community RNID within the Kerry Parents and Friends Association.

Taking action

Initially the community RNID (SD) contacted nine service providers to ask whether they had oral healthcare guidelines. Only two of the nine services had such guidelines in place. The others identified the need for guidelines and expressed an interest in their development.

Contact was made with the HSE dental services (Southern Region), informing them of the decision of the Kerry Parents and Friends Association to develop guidelines relating to oral health. The response of the dental health team, comprised of a dental nurse, a dental hygienist and two dentists, was very positive. Practical support in the form of literature and information leaflets on oral health, though not specific to learning disability, proved to be beneficial in the development of the guidelines. Subsequent meetings with the dental hygienist and dental nurse aided the development of oral care assessments and oral care plans for service users. The dental team offered to provide additional support by reviewing the guidelines on completion. According to Waldman and Perlman (2007), developing professional relationships between nurses and dentists should improve the availability of accessible dental services for people with learning disabilities.

A comprehensive review of the available national and international research in this area
was also undertaken by the community nurse (SD) to ensure an evidence-based approach to the development of the guidelines. Information provided by the HSE dental team was incorporated with research specific to LD in the development of the guidelines.

The clinical guidelines for the oral health care of adults with an intellectual disability were completed last May and focused on the improvement of oral health care within an integrated care approach. They were aimed at all those involved with the health and welfare of people with a learning disability and provided information on nine specific aspects of oral health care (see Table 1). The guidelines offer information on the care of dentures, oral care of service users who are edentulous and the oral care of the unconscious service user. Specific charts for recording aspects of oral health practice were also developed, including screening assessments, oral health care plans and oral hygiene practices.

Evaluating action
Since the clinical guidelines were completed, the response has been positive. After they were endorsed by a management meeting of the Kerry Parents and Friends Association, a decision was taken to implement the guidelines. Feedback from front-line staff within the association has also been positive.

Two organisations that were originally contacted to ascertain whether services had guidance in place have subsequently requested a copy of the completed guidelines. One of these provided feedback, saying that the guidelines were practical and easy to follow. They had been shown to the dental services for the organisation and it was recommended that the guidelines be adopted.

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Positive feedback from the HSE dental services indicated that the guidelines will improve the general and oral health of individuals attending the service. The dental team also said that they would like to see such guidelines developed by all organisations providing services to people with learning disability.

In identifying best practice in this area, education on oral health was considered to be vital for service users, staff and carers. This has been addressed with the HSE dental care team, who offered to attend training sessions to support the use of the clinical guidelines.

An evaluation of the effect of the guidelines and the education of service users, staff and carers will establish whether the measures undertaken to promote oral health are fit for purpose. It is envisaged that such an evaluation will follow the implementation of the training programme.

Conclusion
The importance of oral health for people with a learning disability has been emphasised in the literature, as have the health disparities that can blight lives (Mencap 2004). Learning disability services should encourage front-line staff to develop knowledge in relation to oral health and offer guidelines to promote oral health (Crowley et al 2003).

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References