Improving primary care services for people with learning disability

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The health of people with a learning disability is significantly poorer than that of the general population. In this project, two senior nurses developed a programme of inclusive health care aimed at enabling people who have learning disabilities to lead healthier lives. The project demonstrated that a joined-up approach is required across agencies to tackle the exclusion of people with a learning disability from mainstream health care services.

The health of people with a learning disability is significantly poorer than that of the general population (Department of Health, 2003; 1998). Despite the many reports and policy recommendations about how to improve the situation, little has been done to address the social exclusion of this group, and their health and well-being continue to decline (Mencap, 2004).

Valuing People (DoH, 2001) provides the health service with key goals for engaging people with a learning disability in mainstream health services and ensuring they have equal access to high quality care. In a joint effort to challenge exclusion and address the agenda of Valuing People, Warrington Primary Care Trust and Five Boroughs Partnership NHS Trust joined forces. Two senior nurses developed a comprehensive programme of socially inclusive health care aimed at engaging people with learning disabilities more fully in their health care and their choices in leading healthy lives.

The project ‘Access All Areas’ was created in 2002 when the authors realised that the principles of Valuing People were perfectly suited to the principles of health visiting. The team developed a comprehensive programme in partnership with specialist services and service users, using a public health model of health care where people with learning disabilities are supported to make healthy choices and, often for the first time, given information in accessible formats to support their choices.

The focus of Access All Areas is to facilitate access to mainstream primary care services and avoid a two-tier system of health care that has been shown to be ineffective and often of poor quality (DoH, 2003; 2001, 1998; Mencap, 1998). The project requires staff to work in partnership with patients (DoH, 2001; Richardson, 1997).

Method

A total of 70 patients were identified through an audit of electronic patient record searches and the cross-referencing of people accessing the specialist learning disabilities team. The final patient group included in the audit was made up of 62 patients: 40 men and 22 women with a mean age of 38.4 years (range: 18–81). Each patient was considered individually and their specific needs – particularly with communication – were identified in a team approach with community learning disability nurses and specialist speech and language therapists. The health visitor and community staff nurse assessed the current health status of each patient, considering their current access to primary care services.

While some patients had relatively frequent access to primary care, several patients had lengthy gaps in accessing services, with one patient having not been seen by primary care services for 14 years.

Patients were contacted by a letter designed in collaboration with specialist speech and language therapists and were offered a choice of attending their GP surgery or having a community staff nurse or health visitor see them at home to complete a comprehensive health needs assessment (Barr et al, 1999).

Home visits can help health visitors build relationships with clients and provide practitioners and clients with a foundation for problem identification and solving (McNaughton, 2000). Clients are empowered as they control access to their home and the information they are willing to share with the professional. The goals of home visiting relate to empowering clients, supporting their inclusion, providing choices and fostering independence in decision-making (Harris, 2003; McNaughton, 2000).

Patient involvement

Patient-held health profiles are used as a further method of including clients in their own care. These packs are very similar to the personal child health record in that they contain the patient’s main health information and

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**BOX 1. KEY AREAS WHERE ‘ACCESS ALL AREAS’ REFLECTED NATIONAL STANDARDS**

- Oral health and treatment of dental caries
- Weight management and access to both healthy food choices and adequate levels of exercise
- Sexual/reproductive health and access to national screening programmes
- Self-examination and self-awareness of the body

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provide an active record for staff to make notes in. They are extremely useful at focusing patients and staff on health history and health needs and they also help to fully include the patient in identifying needs and planning to improve their health. The health action plan contained in the profile is explained to the patient in understandable terms and the patient is facilitated in identifying their health needs and formulating a simple plan to meet these needs, identifying people, such as friends or family, who can support their plan (DoH, 2002). The core of this process is providing patients with choices about their lifestyle and facilitating healthy choices where possible.

Where extra investigations were required, the health visitor discussed the patient’s expectations with the patient and their carer, what would occur in the investigation, and contacted the community learning disabilities team if it was determined that graded exposure was required to prepare the patient for intervention. This can greatly reduce the anxiety of clients and encourage future uptake of services (Lindsey, 1998). The importance of ensuring the patient is fully prepared for possible interventions can ensure they have some understanding of what is going to happen to them (Parish and Markwick, 1998).

Managing patient anxiety

Graded exposure is a method that can be used with anxious patients. It is a way of identifying a hierarchy of fears so that the community learning disability nurses or the specialist team clinical psychologist can work on the least feared situation first, using relaxation and confidence building. A gradual exposure is then built up to the more feared concepts and events as the patient’s confidence increases and their anxiety reduces. It differs from desensitisation in that desensitisation has no hierarchy of exposure or cognitive elements and uses only behavioural techniques. However, both these methods are useful for reducing anxiety about health procedures for people with learning disabilities (Reber, 2004).

Results

At the start of the project, the team found that only 14 patients out of the patient group of 62 had accessed a ‘well person’ health check within the previous 12 months. On completion of the project, 60 patients were offered and received a health needs assessment. Of these, 46 were provided with a health action plan. There were also key areas of health where health action plans, advice and support were reflective of national standards (Mencap, 2004) (Box 1).

Identifying the needs of carers became an important issue for staff in this project. Many patients living at home with a learning disability are cared for by increasingly older carers, most often parents, who have their own health needs that they often do not prioritise as they are focused on the needs of their child (Barr et al, 1999). In several cases, the health visitor needed to spend some time addressing these needs as part of the holistic home health assessment of these families, and referrals were generated for both GPs and carers’ organisations to provide extra support.

In two cases, quite serious health problems were identified in carers and these were addressed by both the GP and the community health team.

Discussion

The team found home visits were helpful for some patients with learning disabilities. Patients tend to feel more comfortable having blood pressure measurements, weight checks and health discussions in the security of their own home as they can find a medical setting threatening. This has highlighted important training issues for primary care staff about the adaptation of mainstream services to meet individual needs and the importance of preparatory, non-treatment visits to primary care facilities before care is carried out.

Challenging negative attitudes towards people with a learning disability was a central part of the project. It was found that primary care staff including receptionists, practice nurses and GPs often did not have the necessary training and skills to deal sensitively with those of a dif-
References


Different intellectual ability, or have the equipment and motivation to organise their services to ensure people with learning disabilities are fully included (McConkey and Truesdale, 2000; Fitzsimmons and Barr, 1997).

Primary care colleagues cited time constraints of conducting a complex assessment or tailoring care as a reason for not fully engaging with the project. With the increased pressures of meeting national service framework targets and the increased involvement of practice nurses in chronic disease management, the danger exists that those with learning disabilities will continue to suffer from exclusion and difficulty in accessing primary care.

Research has shown that GPs have been reluctant to fully engage in the health screening of their patients who have learning disabilities (McConkey et al, 2002). Locally in the project area, however, all of the GPs expressed considerable interest in the project and were keen for their practices to be involved and for skills and awareness to be raised.

Limitations

The project has some limitations. The results relate to only one particular primary care area and one particular health visiting service. It may be that staff working in other areas hold different views about the role of the health visiting team. Likewise, the patient group, while reasonably large, was limited.

Conclusion

The success of primary care providers in delivering the health care guidelines of *Valuing People* (DoH, 2001) is dependent on both the motivation of primary care staff and the ability of primary care and specialist learning disability teams to work collaboratively towards the common goal of improving access to mainstream health care services.

The Access All Areas project has demonstrated that, in order for social exclusion to be tackled fully, a joined-up approach is required across agencies that recognise how current practices may inadvertently assist exclusion.

Specialist learning disability teams, who themselves are under pressure to justify their role (Powell, 2004), have been an essential resource in supporting patients and primary care staff throughout the health action planning process, and have also been a central part of delivering health promotion messages within specialist services (Beacock, 2002; Coyle and Northway, 1999).

Involvement in this project has allowed staff to practice the public health role they feel they were trained to deliver and has supported the public health role of health visitors. Health visitors are often best placed for the provision of health action planning for people with a learning disability (Elkan, 2000; Cody, 1999). Grassroots knowledge of local communities, nurse-prescribing skills, the ability to refer to a wide range of leisure and health activities and other professionals, and the philosophy that all people are to be valued, make the involvement of health visitors in such projects invaluable.