In her article, O’Hara (2003, this issue) has concisely addressed the multitude of complex issues relating to ethnicity in people with learning disabilities, to their carers and to provision for services. The article brings out the interplay between culture, race, ethnicity and learning disability, using an interactional model.

Learning disability and ethnicity have hitherto been neglected areas of service delivery, audit and research, with only a few exceptions. The White
paper Valuing People: A New Strategy for Learning Disability for the 21st Century (Department of Health, 2001a) puts ethnicity in the context of learning disability on the map and urges service providers to take appropriate steps to offer culturally sensitive and effective services which incorporate the four key principles of rights, independence, choice and inclusion. The National Health Service is required to promote health equality for people with learning disabilities from minority ethnic communities, in accordance with its new general duty under the Race Relations (Amendment) Act 2000, which came into force on 2 April 2001.

However, to provide appropriate services which include prevention, early detection and health promotion, it is necessary to ascertain prevalence patterns of mental and physical health problems in people with learning disabilities from minority ethnic groups and examine variations compared with the indigenous population. Further, evidence is needed that shows how the uptake of available services is influenced by the attitudes, beliefs and perceptions of service users, carers and the community regarding mental illness and epilepsy in people with learning disabilities.

There have been very few studies of this group which have looked at patterns and presentation of mental illness. In one of these, Chaplin et al (1996) concluded that Asians were significantly more likely than White Caucasians to receive a psychiatric diagnosis, particularly that of psychosis. Morbidity and mortality in people with learning disabilities from ethnic minorities are influenced by a complex interplay of factors, including emigration, culture shock and difficulties with acculturation. Moreover, problems with language and communication, stigma within society in general and within the community or subculture in particular, also have an impact. Other stressors that impinge on health outcomes include provisions for appropriate educational opportunities, paid or sheltered employment and voluntary work. Outcome is also influenced by awareness of the availability of services and support and by ease of access, which determines their uptake.

The meaningful participation of service users in order to incorporate their views is far more complex, often because of issues relating to impairment of communication and overall cognitive function. However, speech and language therapists with the necessary cultural competence can help to understand, acknowledge and address the core views of service users as closely as possible.

From a service provider’s point of view, a way forward may be to delegate specific responsibility for service users with learning disabilities from ethnic minorities to a senior manager who has the necessary cultural competence. This would allow the nature and adequacy of service provision to be identified and help in establishing training opportunities for staff. Service usage would need to be monitored, along with regular consultation with local ethnic minority groups. It would be important to ensure that audit standards are achieved.

Focus groups can be established to facilitate consultation with service providers, particularly in areas with substantial minority ethnic populations. The groups may include service users, representatives of carers from ethnic minority groups, community leaders, general practitioners, health purchasers/providers and representatives from social services.

Generic services have highlighted that the ethnic dimension in the Health of the Nation targets (Department of Health, 1999) should be emphasised and, in particular, there should be an explicit acknowledgement that the social outcome of people from ethnic minorities who have mental health problems should be improved (Department of Health, 2001b). This would apply equally, if not more so, to individuals with learning disabilities.

All staff should receive basic training in the principles of community-based care and alternative service models that are culturally sensitive and competent. Particular provision is required for training on culture, learning disability and mental health, the impact of racism on the perceptions of staff, the common stereotypes and discriminatory attitudes and behaviour of staff and how they affect uptake of services and health outcomes.

There should be a seamless integration of services into a network of social and health care available locally, including culturally appropriate day care, respite care and supported-living schemes. Partnership boards have been formed for learning disability services within the department of social services and these are expected to facilitate dialogue and cooperation towards better social and health outcomes for this and other groups.

The health needs of carers of people with learning disabilities from ethnic minorities need to be investigated. The document Family Matters, Counting Families In (Ward, 2001) acknowledges the difficulties faced by carers from minority ethnic communities, including insensitivity to issues of culture and language and false assumptions about communities wishing to provide care within their own family environment or erecting barriers against statutory agencies. It emphasises that all services provided for carers should be responsive to the needs of people from ethnic minorities.

Every attempt should be made to avoid assumptions about cultural stereotypes and every effort should be made to provide a truly culturally
sensitive service based on the views of service users and carers. In many places, progress to date has been limited to the development of leaflets in minority languages and recruitment of a few members of staff from ethnic minority backgrounds. There must be a significant departure from tokenism, as real approaches generally fail to address the issues.

It is important to ensure that service-user and carer groups represent the ethnic mix found in the health district that they represent and that they acknowledge the heterogeneity of the ethnic minority population, thereby including smaller ethnic minority groups, new arrivals and refugees. It is equally important to have a delicate balance, facilitating integration and acculturation in the mainstream of society while acknowledging and providing for cultural diversity and needs. Without this, there is a real danger of social isolation.

References

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