

Editorial

On not valuing people

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Raising a child is an exercise in anticipation; the first smile, the first steps, the first word all eagerly sought after. Each small sign of progress is noted and discussed as a sign of more marvellous things to come. The first day at school arrives in what seems like no time at all; the first book, trip away from home, move to secondary school, bank account. All these treasured moments are steps towards an independent, adult life that is viewed by parents with a mixture of pride, a mild astonishment and some incomprehension of the brave new world that their grown up children inhabit with ease. These children are the lucky ones. In England alone there are between 55 000 and 75 000 children who have some form of moderate or severe learning disability and who will, thus, never achieve the many steps required to live and function independently (Foundation for People with Learning Disabilities, 2007a).

The resulting social, economic and emotional burdens on parents and families are huge. Children with learning disabilities have difficulty in forming and maintaining social relationships with their peer group which means that many of the usual childhood events may not take place: friends for tea, shopping trips for music or make up, nights out on the town. Difficult or challenging behaviour patterns can reinforce social isolation for both the individual and the family. Going for a pizza or a trip to the wildlife park is simply not possible if your child cannot cope with it. Providing 24-hour care has economic consequences, especially as parents age. Adult children with learning disabilities do not leave home in the same way as their counterparts. They remain with their parents for longer or move into some form of sheltered or supported living arrangement. Thus parents have to support their learning-disabled children throughout their lives, even if they do not actually live with them.

This picture may seem bleak, and indeed for some it is, but the point is that the consequences of learning disability create a long-term relationship which is

quite different, in many ways, to those between other parents and children. The parents, and indeed other family members and carers, become experts on looking after the person with learning disabilities. They understand that individual's communication style, needs, behaviours and preferences. They develop strategies for coping with the demands of everyday life and the daily struggle to ensure that the individual with learning disabilities receives the services and support to which he or she is entitled, even at the cost of their own well being (Foundation for People with Learning Disabilities, 2007b). According to a recent report, this is a never-ending and thankless task as far as healthcare is concerned (DH, 2008a). Despite legislation to promote equality, and numerous reports and enquiries, people with learning difficulties in England do not receive the healthcare to which they are entitled; their parents, relatives and carers have to constantly struggle to make sense of the system and fight for even the most basic provision, often in the face of the most appalling professional ignorance.

There are approximately 796 000 adults with learning disabilities in England and it is estimated that their number will increase to around 900 000 by 2021, especially in the older age groups (Emerson and Hatton, 2004; Foundation for People with Learning Disabilities, 2007a). They form a sizeable minority which, in any other context, would be sufficient to create powerful and vocal pressure groups that demanded equality with other health service users. Yet, people with learning disabilities remain invisible. They find it much harder than others to obtain treatment for illnesses and conditions that are not related to their disabilities. Health service providers have taken few steps to improve access or to ensure that services are fit for purpose (DH, 2008a). Monitoring for compliance with this aspect of disability rights is poor and commitment to changing this situation seems to be weak.

Coupled with this institutional discrimination is what the report politely terms '*limited knowledge about*

learning disability' (DH, 2008a, p.7). Health service 'staff are not familiar with what help they should provide or from whom to get expert advice' (DH, 2008a, p.7). The expert help that is under their noses, parents, family, carers, is routinely spurned 'even though they often have the best information about, and understanding of, the people they support' (DH, 2008a, p.7). Parents, families and carers struggle to be heard, constantly having to balance advocacy against the risk of alienating staff who think they know better. This is immensely time consuming, demanding and stressful. At the back of parents', family's and carers' minds is fear about what may happen when they are not able to be with the person they look after. This is no idle worry. People with learning disabilities die because health professionals do not take them seriously or do not know how to treat them (Mencap, 2007; DH, 2007). Putting it bluntly, this is a disgrace. Emma, for example, was a young woman with severe learning disabilities who had difficulty in communicating. She was admitted to hospital for investigations for pain but discharged because the staff couldn't cope with her behaviour. The investigations revealed the presence of a cancer which doctors then refused to treat because Emma could not, in their opinion, give consent. None of the professionals in this account provided Emma with any analgesia despite the fact that her initial hospital admission was for pain and they knew that her cancer would be painful. Her mother had to go to the high court to challenge the doctors' decision but, by the time this had been achieved, it was too late and Emma died (Mencap, 2007).

Accounts like this reflect a level of professional ignorance, complacency and even downright neglect that would not be tolerated in any other sphere. It is to be hoped that recommendations of this most recent report will be carefully addressed by service providers and that those responsible for inspections and monitoring will ensure that people with learning disabilities are afforded the treatment and care to which they are entitled (DH, 2008a).

Inherent in bringing about such change is the need for leadership at all levels and in all parts of the health service in order to promote a positive attitude towards people with learning disabilities and to make clear that neglect and discrimination against them is unacceptable, just as it is against members of other minority groups. Leaders should ensure that services get things 'right, first time, every time' (DH, 2008b, p.3). They could begin by collecting locally-generated data about the numbers and needs of people with learning disabilities. Alongside this should be a system for engaging directly with them, their families and carers so that service providers and professionals can learn first-hand about what is required to ensure equity in service provision and personalised care.

Ironically, such ideas are to be found not in any documents about people with learning disabilities but in the latest report on the NHS as a whole (DH, 2008b). This focuses on the provision of high-quality, personalised care based around helping everyone to stay healthy. Personalising in this context 'means making services fit for everyone's needs, not just those of the people who make the loudest demands ... that include people traditionally less likely to seek help or who find themselves discriminated against in some way' (DH, 2008b, p.3). The report goes on to propose a draft NHS constitution that offers all patients a pledge to provide accessible services, high-quality care and environment and nationally-approved treatments. Further pledges to patients concern informed choice and consent, being treated with respect and confidentiality. The NHS belongs to everyone and, consequently, patient and public involvement in all aspects of the service is essential in ensuring that it continues to provide equitable treatment and care for all patients, irrespective of any distinguishing characteristics, including learning disabilities (DH, 2008c).

Moving on, we are pleased to present in this issue a number of papers that will contribute to the improved provision of health and social care for members of several different social groups. We begin with an editorial about a new report on Irish people and mental health. There are over half a million Irish people in England and Wales alone. They experience high levels of morbidity and mortality that exceed that of both other immigrant groups and the host population (Abbotts *et al*, 2001). Despite this, the Irish were not, until recently, included in ethnic monitoring in any systematic way and, consequently, mental health service providers were unlikely to have a very clear picture of the needs of this population group. The report discussed in this editorial highlights the many factors that affect the health of Irish people and presents a number of recommendations for improvements in service provision.

Our first research paper addresses another minority group that has received little heed in the UK. Chinese people have been living here for at least 200 years but with little attention paid to their health and social care needs. The 2001 census indicated that Chinese people made up approximately 4% of the black and minority ethnic population, although recent projections suggest that numbers have increased due to migration from China (www.statistics.gov.uk). Chinese people are likely to be self-employed and to marry within their ethnic group, factors which may, in part, explain why they have been overlooked (www.statistics.gov.uk). However, China has been much in the news this year. The Olympics have raised the profile of the peoples, languages and cultures that make up this huge country. Juping Yu's study of the views of Chinese British

young people about sexual behaviour opens a window on the views and experiences of young Chinese people who have grown up in Britain, and their parents. In many respects the findings presented here reflect those identified in other migrant groups but they offer a fresh perspective in relation to Chinese people.

Our debate paper continues the theme of sexual issues in a very different context. Trish Hafford-Letchfield and Anna Nelson raise some important points about the ways in which current approaches to the management of substance abuse ignore, or even seek to suppress, the individual's need for intimate relationships. They argue that, rather than seek to discourage service users from engaging in intimate relationships, practitioners need to recognise that these can be a source of strength and support in reducing substance abuse. We hope that the ideas put forward in this paper will promote debate on this issue and look forward to receiving your thoughts.

Our next two research papers are concerned principally with research methodology. Tapash Roy and Cathy Lloyd discuss the use of audio methods of data collection in a country in which literacy levels are low and in which many languages, such as Sylheti, have no written form (*Multicultural Matters*, 2005). In such circumstances it is easy for researchers to make assumptions about the suitability of certain methods. This paper challenges such thinking with an imaginative and effective approach to quantitative data collection. This paper is complemented by Margaret Stone and her team who demonstrate the usefulness of an action research approach to the adaptation of patient education programmes. This is a low-cost, sustainable approach that challenges the idea that change inevitably costs money.

Our last research paper continues the focus on educational issues. Darren Mays and his colleagues discuss the role of public health professionals in promoting and improving the health of populations, both locally and nationally. They highlight a number of anticipated changes in the US population over the next few years: an increase in the numbers of Black and Hispanic people and a corresponding decrease in white populations. What this means is that populations that already experience health inequalities with high levels of morbidity and mortality will increase. It is the public health professional's role to address this situation and enable people to stay healthy for as long as possible. It is, therefore, a matter of concern that schools of public health are not recruiting more students from Black and Hispanic minority groups. Hispanics in particular appear to be under-represented among the student cohorts. As Mays and his colleagues point out, this situation requires urgent attention. Moreover, it is not a matter solely for the US. Other countries

experiencing immigration will have to face up to the implications of changes in their populations and ensure that their own schools of public health produce practitioners from diverse backgrounds who are equipped to provide culturally-competent services.

Finally, we wish to thank Nisha Dogra (nd13@leicester.ac.uk) for her column on papers that readers may have missed. In this issue Raghuram Shivram presents a discussion about a recent research paper. We also thank Lorraine Culley (lac@dmu.ac.uk) for the Knowledgeshare section which, as usual, contains a range of useful information about resources and events. If you would like to contribute to either, or indeed both of these features, please contact Nisha or Lorraine at the email addresses shown. We are currently collecting material for Volume 6 and look forward to hearing from you.

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