

Situations vacant: doctors required to provide care for people with learning disability

THE cost to the National Health Service of caring for the one and a half million people with learning disability in the United Kingdom is nearly equal to the combined costs of caring for people with senile dementia and schizophrenia.¹ Virtually all those with learning disability are on the lists of general practitioners, who are uncertain of their role and of the nature of learning disability itself. The condition is defined by using two sets of criteria — those based on social competence and those based on the presence of low intelligence. Both are difficult to interpret. Although intelligence tests are objective and measure an abstract ability (we can call it intelligence) we should remember the remark of Pierre Janet,² one of the founders of psychology, who said that the most important book ever written in his field of study was a dictionary because of the vocabulary that is necessary to express all the different facets of human personality, including intelligence.² This diversity is reflected in those who make up the group whom we label as having learning disability.

People with learning disability now feature more prominently in the work of general practitioners because patterns of care have changed. The publication of *Better services for the mentally handicapped* catalysed the move from institution-based care to flexible, locally available services.³ The structure of the population of people with learning disability has also changed, there being fewer children and more older people. As a group, people with learning disability have a greater number and a greater variety of health needs than the general population. There is evidence that these needs are not being met.⁴ Surprisingly, people with learning disability who survive beyond the age of 50 years are a healthy, even robust, group.⁵ This represents the effects of a differential mortality altering the group's medical characteristics to a greater extent than would be expected in the general population.

For the majority of people with learning disability the decision to seek medical advice is not autonomous but is devolved to a carer. Poor verbal skills restrict their ability to explain how they feel. For some, maladaptive behaviour may be the only means of communicating physical or emotional discomfort. They suffer because general practitioners are unfamiliar with their various clinical syndromes and do not have the time to examine or to listen to them. There is a good case for the provision of extra care to this group, which should include additional funding for the longer consulting time necessary and for carrying out procedures related to health gain targets.

The NHS and community care act 1993 defined general practitioners as the key identifiers of need, acting as a link between local authorities and health authorities. The emphasis shifted from services run by local authorities towards those purchased from the voluntary and private sectors.⁶ People with learning disability were no longer patients, not even clients, but consumers. This brought a risk that their identified needs would depend on the perspective of the professional or voluntary agency assessing them. However, this risk may have been reduced because professionals have learned about serving people better, by listening to consumers and offering more choice.

The community is now considered to be the appropriate environment in which people with learning disability should live and be supported. This presents a challenge to general practitioners who are faced by patients with, for example, dual diagnoses (learning disability and mental illness combined), conditions

about which they have had little training. For people with mild learning disability there are difficulties in relation to personality disorder and seriously irresponsible behaviour. Severe behavioural disorders, including self injury, occur in about 15% of people with severe learning disability.⁷ The Mansell report was commissioned to advise on this situation.⁸ It advocated small, community-based residential facilities and looked (perhaps naively) to generic psychiatric services for the management of patients with these complex problems. Specialist knowledge and services, including inpatient facilities, are essential for the effective management of this group of patients whose problems are difficult to manage.⁹ What matters is that community residential facilities are not seen simply as homes but as facilities which are open to scrutiny and in which the staff members are adequately trained. General practitioners carry a particular responsibility as they are the professionals who see the residents most frequently. It is essential that they are supported by specialist consultant-led teams.

Because of the small number of cases on any individual general practitioner's list, virtually no research into learning disability is carried out in general practice. For this reason, the Royal College of General Practitioners set up a working party in 1988 to study the interface between general practitioners and people with learning disability. The report recognized a gap between the expectations of people with learning disability and the attitudes of their general practitioners.¹⁰ At the same time, the Welsh health planning forum began work on a protocol of care, a part consensus and part meta-analysis document, for people with learning disability.¹¹ Both publications focus on improving health outcomes of care, not just on the process of caring. Both set targets for health gain.

General practitioners appreciate the importance of health promotion but our personal work satisfaction comes from treating people who are sick. This is reflected in the study by Kerr and colleagues reported in this month's *Journal*.¹² They explored the attitudes of general practitioners to people with learning disability and found that general practitioners were ready to provide primary health care but not health promotion to this patient group. Although there was opposition to health checks and the assessment of hearing and eyesight, other specific tests, for example thyroid function in people with Downs syndrome, were viewed favourably. The contrast between these positive attitudes and the negative approach to sensory tests may be underpinned not by a lack of interest but by a lack of knowledge of their importance.

Psychiatrists in the specialty of learning disability accept that their role goes beyond the diagnosis and management of mental illness. They accept responsibility for the promotion of mental health and for ensuring that the emotional needs of people with learning disability are recognized and respected. Missing in the care of this vulnerable group of patients is the professional equivalent of the paediatrician or the geriatrician to cope with their multiple needs. A tide of opinion favours the creation of a new specialty.¹³ Yet general practitioners, adept as they are at dealing with ill-defined symptoms and problem complexes, should be capable of filling this service gap. People with learning disability do not need a new specialty but closer cooperation between general practitioners and consultants. The importance of this is illustrated, for example, in the area of abuse. Almost

everyone with learning disability has suffered some form of abuse, for example a lack of respect by the general public, or physical, sexual or emotional abuse. Serious abuse is experienced by a considerable number of children and adults with learning disability.¹⁴ The climate of the market economy, with its purchaser-provider split, makes interagency cooperation difficult, thus the likelihood of a coherent response to disclosed or suspected abuse is diminished.¹⁵ Matters concerning the protection of children who, like people with learning disability, are vulnerable to exploitation, have moved on since the introduction of the 1989 children act. Why, we might ask, did the NHS and community care act 1993 not encompass the principles of *Working together*¹⁶ which has streamlined child protection?

An era in the history of learning disability is gradually coming to an end. It is now entrenched as a specific area of disability. Its survival as a distinct field of clinical care will depend on consultants and general practitioners listening to one another and agreeing a policy which will meet all the medical and psychological needs of this group. General practitioners must grasp the opportunity to raise the profile of this group of patients. The topic fits in well with general practitioners' ordinary clinical practice. We are poor at communicating to others not only the health care needs of people with learning disability but also the contribution to their care that we can make.

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Complementary medicine — doing more good than harm?

IN answer to the question 'Do you believe complementary therapies have a place in mainstream medicine?' 65% of a sample of hospital doctors in the United Kingdom answered 'yes'.¹ There is no doubt that complementary medicine is becoming widely acceptable. That so many doctors replied positively implies that the evidence for the efficacy and safety of complementary medicine and for its cost effectiveness is available and conclusive. But is this the case?

Let us look first at efficacy. If one adopts the well-known and generally accepted hierarchy of evidence, ranging from anecdotal data at the lower end, uncontrolled and audit studies somewhere in the middle and randomized controlled trials or meta-analyses of such trials at the top end, and applies this to complementary medicine, one finds mostly inconclusive evidence. Case reports in support of complementary treatments abound — if any therapy has been in use for a while there are bound to be positive cases. Similarly there is no shortage of observational, uncontrolled or audit studies to suggest that complementary medicine is effective. This type of evidence shows that the perceived effectiveness of complementary evidence is well documented.² But is its effectiveness superior to placebo, standard treatment or other controlled interventions? Only randomized controlled trials (which minimize bias) are capable of answering such questions.

Several well-conducted randomized controlled trials have demonstrated the effectiveness of various complementary therapies over placebo for given indications. However, a systematic search will usually also identify trials that suggest the opposite. Thus, as in most other fields of medicine, the answer is not clear cut. Unfortunately, discussions about complementary medicine are often handicapped by lack of objectivity; 'selective citation'³ describes authors' tendencies to report the evidence that corresponds with their preconceived ideas, while discarding contradictory results.

Selective citation should become obsolete as the move towards systematic reviews and meta-analyses ensures that the true picture is presented. Meta-analyses have been undertaken for acupuncture,⁴ homoeopathy⁵ and spinal manipulation.⁶ The first two reviews conclude that the evidence in support of the effectiveness of acupuncture and homoeopathy is insufficient at present.^{4,5} The third review shows that manipulation is effective for acute, uncomplicated low back pain, but the evidence does not support its use for other indications.⁶ This does not mean that a remedy has been proven not to work for a specific condition; just that the 'jury is out' and that more data are required. In other words, well-conducted randomized controlled trials are urgently needed, and before the results of these are available it is impos-