Vulnerable people

– how can the primary health care needs of people with intellectual disabilities best be met?

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For thirty years he has worked as a consultant psychiatrist in Bristol. In 1975 he embarked on a series of research projects on the impact of the transition from institutional to community care. In 1988 he and his research colleagues established the Norah Fry Research Centre, which he directed until the end of 1999. From 1998 until 2001 he was seconded to the Department of Health as Senior Policy Adviser (Learning Disabilities). He co-authored 'Once a Day', good practice for primary health care teams working with people with learning disabilities. He was also heavily involved as a member of the Department of Health team who drafted the Government White Paper Valuing people: a new strategy for learning disability for the 21st Century.

For the last three years he has chaired the Learning Disability Advisory Group for the National Assembly for Wales. He chairs the Council of the British Institute of Learning Disabilities, is a trustee of Circles Network, a patron of the Home Farm Trust and a member of the board of the National Development Team. His textbook for psychiatrists in training, Mental Handicap, *was published in 1985. In 1997 he edited* The Psychiatry of Learning Disability, *an edited collection of papers for trainees in psychiatry published by the Royal College of Psychiatrists.*

Over the past twenty years there has been growing concern that the primary health needs of people with intellectual disabilities are being neglected. In most countries the role that general practitioners should play in meeting the health care needs of people with intellectual disabilities remains poorly defined. This may reflect a past when many people with an intellectual disability lived in long stay institutions outside the remit of family physicians. But today the situation is very different. It is estimated[1] that there are about 12 000 people in New Zealand with an intellectual disability, nearly all of them living in the community.

In the United Kingdom the number of people with intellectual disabilities is increasing by 1.1% per annum, in part because many more severely disabled children are surviving into adulthood, and in part because life expectancy has increased.[2] As life expectancy increases, so do age-related diseases such as stroke, heart disease, chronic respiratory disease and cancer. Recent surveys have shown increased and undetected morbidity in groups of people with intellectual disabilities and have highlighted inadequate diagnosis and treatment of specific medical conditions, including heart disease, hypothyroidism and osteoporosis.[3]

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In both New Zealand and the United Kingdom it is widely accepted that general practice is an efficient and cost effective way of delivering primary care. Family physicians trained in primary care provide the gateway through which people gain access to health care systems. They also provide much of the diagnosis, treatment and management of acute and chronic illness. General practitioners also play a key role in health promotion, health screening and counselling and support.[4]

Because general practitioners occupy the interface between individual patients and secondary care systems, they also play a crucial role in setting priorities and in rationing the delivery of health care.

A typical GP practising in the United Kingdom may expect to be consulted once a day about the health needs of a person with an intellectual disability. A call on the doctor may involve personal contact with a patient, or a discussion with a member of their family or perhaps a meeting with a paid carer. Few doctors have had adequate training to deal with the needs of this group of patients and

research has shown that some may be reluctant to engage with this group of patients.[5]

Meeting the health care needs of this population is both complex and difficult. Although most general practitioners see themselves as the appropriate people to provide health care for people with intellectual disabilities, a minority view them as an unwelcome burden.[6] Lennox and his colleagues have suggested that the main barriers faced by GPs are communication difficulties with patients and other health professionals and problems in obtaining satisfactory medical histories.[7]

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In the late 1970s, in a small local survey of GP attitudes in England, we found[8] that patients with intellectual disabilities caused the GPs so little trouble that they assumed that their primary health care needs were being catered for elsewhere. In a subsequent case control study[9] we found that GPs were more aware of the needs of their intellectually disabled patients but nevertheless the control subjects were more likely to be offered preventive health care when matched for age and gender.

A survey of 242 general practitioners in Wales[5] found that although GPs agreed that they were responsible for the medical care of people with an intellectual disability, they resisted assuming the responsibility for annual health checks and assessments of hearing and vision. They were also ambivalent about health promotion activities and thyroid testing in people with Down's syndrome.

The same questionnaire was subsequently used in a survey in New Zealand.[1] Of the 250 general practitioners who were sent the questionnaire, 65% responded. Interestingly the New Zealand GPs also showed a lack of enthusiasm for health checks – only 23% of respondents agreed that it was the GP's responsibility to perform a yearly health check on people with intellectual disability. On the other hand an Australian study[10] found that the majority of the 912 GPs in their Australia-wide sample were enthusiastic about health checks. Virtually all the doctors in this sample agreed that it was their responsibility to facilitate or ensure that health screening was undertaken. Lennox and his colleagues found the results of their study 'compelling'. They argued that the results demonstrated the growth of a more positive attitude concerning GP roles and responsibilities in providing health care to people with intellectual disabilities.

Ten years ago the Welsh Office published their *Protocol for Investment in Health Gain: Learning Disabilities*.[11] This suggested that initiatives, such as health checks, could lead to worthwhile health gains for people with intellectual disabilities, but the concept of 'health gain' was slow to take off. In 1995 the Department of Health, in London, published *The Health of the Nation – a strategy for people with Learning Disabilities*.[12] This highlighted areas such as cancer, mental health, coronary heart disease and stroke, where more effective targeting of health input would produce health gains. A research study based in Birmingham, England, used the *Health of the Nation* material to devise a health check protocol. The researchers set out to demonstrate the health gain benefits from health screening.[14,15] The team found that ongoing consultation with users and carers was vital to the success of the project.[16] The study identified a significant number of people with intellectual disabilities who were overweight. A fifth of the intellectually disabled group were clinically hypertensive and there was a high prevalence of physical inactivity. Although the authors found that intervention could be acceptable to people with intellectual disabilities and that tangible benefits could be observed, they were less sure whether the interventions could be successfully administered to a larger number of people and whether the health gains could be maintained over a long period of time.[15]

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A much larger study of health screening was subsequently carried out in New Zealand.[16] Using the Cardiff Health Check,[17] 2 500 residents of IHC New Zealand Inc. (previously known as the New Zealand Society for the Intellectually Handicapped) were screened. The screening revealed that 73% of screened people required some follow-up health intervention. The authors concluded that the health screening process showed that there was substantial evidence of 'health gain' *(see article by Webb and Rogers in this journal)*.

By 1998 Welsh Health Authorities were convinced that the concept of 'health gain' was of fundamental importance for all client groups. The publication in 2001 of *Health Evidence Bulletin: Learning Disability*[18] marked a major step forward. This 75-page document has a specific focus on the health care needs of people with intellectual disabilities. It provides a series of statements about specific interventions, each with a precise indication of the strength of the evidence and the sources for each statement. The evidence has been critically appraised, compiled under the direction of a public health physician in an ac-

cessible document and reviewed by a multi-disciplinary team. Although the bulletin is primarily designed to help health authorities develop local strategies and commission high quality health care, it is likely to be very useful for general practitioners everywhere. The evidence, which is organised in ten topic areas, includes chapters on epidemiology, the management of behavioural disturbance, the role of drug therapy, and a substantial section on medical conditions in people with an intellectual disability.

A similar approach has been followed in Australia in pursuit of 'health targets'. Health screening of a sample of 200 people with intellectual disabilities in Sydney[3] had found an average of five disorders per person, of which half had not previously been detected. Based on their Australian experience, Beange and her colleagues[19] promoted the notion of health targets with a view to reaching an international agreement on the minimum health interventions that should inform primary health carers. The fifteen targets selected drew upon conditions that were highly prevalent, easily detected, and amenable to treatments that were available. This list of targets provides valuable common ground for setting an international standard.

In England, the Department of Health has led discussions on how more effective primary health care can be delivered to people with intellectual disabilities. Following extensive consultation, *Once a Day*[20] was published. This guidance on good practice was written for members of primary health care teams who were unfamiliar with the needs of people with intellectual disabilities. The guide sets out the main issues likely to be faced by the primary care team and offers advice about how those needs might best be met. Twenty-five thousand copies of the guide were distributed free. It was well received and stimulated further interest in the best ways to provide primary health care to this vulnerable group of citizens.

In England, two years later and following a further eighteen months of consultation, the Government published *Valuing People – a new cross departmental strategy for people with intellectual disabilities for the 21st Century.*[21] Although the remit of *Valuing People* went far beyond the health needs of people with intellectual disabilities, the changes which were proposed in the methods of health care delivery are likely to be of interest to family physicians and health care providers elsewhere.

People with intellectual disabilities may be vulnerable people – but they are also valued people

Somewhat surprisingly, the Government decided against recommending annual health checks. In part this was because of a concern that GPs would demand additional fees to carry out additional tasks, but also because of a reluctance to impose further duties on family physicians. Instead of health checks the Government endorsed the concept that each individual with an intellectual disability should have a health action plan (HAP).

The HAP includes details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects, and records of any health screening tests. It is intended that HAPs will be offered and reviewed at critical stages in peoples' lives. Detailed guidance on how the health action plans will operate is now awaited.

Valuing People also endorsed the concept of the 'health facilitator'. The health facilitator, who may be a nurse or other health worker, helps general practitioners and others in the primary care team to identify patients with intellectual disabilities, in collaboration with colleagues from social services, education and health. Their task is to facilitate, to advocate and to ensure that people with intellectual disabilities gain full access to the health care they need, whether from primary or secondary health services. It is intended that the role of the health facilitator will embrace mental as well as physical needs. The health facilitator's role is expected to be especially important in helping people with intellectual disabilities navigate their way around the health service.

In England and in New Zealand the challenge is to achieve improved health care for people with intellectual disabilities, wherever they live. Perhaps Prime Minister Tony Blair's foreword to *Valuing People* provides a suitable note on which to conclude:

'People with intellectual disabilities can lead full and rewarding lives as many already do. But others find themselves pushed to the margins of our society. And almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives...The challenge for us all is to deliver the vision set out in Valuing People *so that the lives of many thousands of people with intellectual disabilities will be brighter and more fulfilling.'*

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