

When I was a Health Minister in the 1990s we 'benefited' from the publicity surrounding one man jumping into the lions' den at London Zoo and another stabbing a stranger to death on the London Underground. We benefited because the shock-horror media stories led to public, Parliament and press demanding action. Indeed, each case of violence had a triple impact. The media gave dramatic coverage first to the event, then 6 months later to the trial and then another 6 months on to the inquiry report in the purple prose of Louis Blom-Cooper and others. So the public thought the number of cases was multiplying and turned against care in the community. The result was more money from finance ministers for better health and care services, but at a price – the terrible stigmatising price of lost public confidence and a demand to reverse the policy of community treatment and care.

Mental health suffers a quadruple whammy

There is constant public, professional and media pressure on government and health service managers to do more, spend more, achieve more. Unlike with heart disease or AIDS or cancer, though, with mental health problems there is little political, press or public understanding of what can be done to treat, cure and rehabilitate. There is even less understanding of what can be done to prevent mental illness and promote mental health. And there are few outcome measurements that health departments and managers, much less public and politicians, can understand. There is little point in campaigning to put mental health up the political and budgeting agenda if the minister cannot convincingly argue to his colleagues that €x million invested will lead to a y% improvement in problem z.

If you accept that stigma was there in and around the old institutionalised regimens but that it is multiplied 100 times when you move to treatment and care in the community and attempt to integrate people with community, working and leisure life, then it becomes 100 times more important to convince people that the policy can work. If you place people neatly into a hospital ward, politicians, press and public feel you have dealt with a health problem and will not enquire too closely what you are achieving behind the hospital gates. If people are visible, then so is the nature of their health problem and questions are asked as to whether the policy is working, how much is being spent and what it is achieving.

So services need to be as visible as patients; their regimens need to be as well understood as are the illnesses; and the safety net needs to be accessible and to build confidence for patient and community alike. An effective and comprehensive spectrum of services; outcome measurements that are more easily understood by lay people; visible and responsive local services; rehabilitation and retraining services that bring people back, at a pace appropriate to each, to active and involved life, so that their friends, family and neighbours can see the progress – all will aid the defeat of stigma.

But the twin peaks are to convince the public to believe and to convince governments to spend. And they are inter-dependent. If the public believe, they will put pressure on the government to spend. If the government spends, it will make public belief possible.

Further reading

Ramsey, R., Page, A., Goodman, T., *et al* (eds) (2002) *Changing Minds: Our Lives and Mental Illness*. Royal College of Psychiatrists.

The College anti-stigma campaign has compiled a good online list of sources at <http://www.rcpsych.ac.uk/campaigns/changingminds/>

THEMATIC PAPERS – INTRODUCTION

Empowering people with intellectual disability

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Services for people with intellectual disabilities are not necessarily a high priority even in the high-income countries. We look in this issue at the way in which approaches to support are provided in three contrasting regions, with different cultures and histories. We begin with an account of intellectual disability in India, where Dr Satish Chandra Girimaji discusses past and present frameworks for care and education. It is a cultural norm within the subcontinent that families are expected to look after relatives with disabilities, both in childhood and in adulthood; it seems that this long-standing

tradition continues. On the other hand, rapid industrialisation and urbanisation mean that it is ever more difficult for families to cope with disability, because of other pressures, without externally provided support services. The tension between tradition and economic development is palpable.

In our second paper, by Dr Meera Roy and Sivasankaran Balaratnasingam, the plight of Australian Aborigines is discussed sympathetically. Here we have a culture that is little understood it seems, even in Australia, and the closest many readers will have come to appreciating the complexity of Aboriginal culture is through books like Bruce Chatwin's *Songlines*. The

authors discuss the apparent excess of intellectual disability among Aborigines, which may be exacerbated by their cultural dislocation and consequent loss of their traditional relationship to the land and nature. Their history of appalling treatment by settlers from Europe has resulted in a cultural limbo, with high rates of drug and alcohol misuse, which fosters developmental disorders in the children of users. There are no culturally appropriate ways of measuring 'intelligence' in a people for whom the Western way of relating to the world is completely alien. This is a very thought-provoking essay on an important and neglected subject.

Finally, Dr Allen-Leigh and colleagues from Mexico present a qualitative account of the way in which adults with intellectual disability are benefiting from recently developed services that are designed to encourage their sense of independence and self-efficacy. This has come about in part through changes in societal attitudes and in part because of new legislation. Their conclusion, that it is particularly important to combine practical training with services to support greater social inclusion for people with intellectual disabilities, is applicable to all regions represented by these articles.

THEMATIC PAPER – EMPOWERING PEOPLE WITH INTELLECTUAL DISABILITY

Intellectual disability in India: the evolving patterns of care

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Intellectual disability was recognised in ancient Indian literature, but organised services have a history of just five decades. India shares many features of low- and middle-income (LAMI) countries regarding intellectual disability. There is a low level of awareness about its nature, causes and interventions. One can come across many superstitions, myths and misconceptions about intellectual disability. In general, services are inadequate, being concentrated in big cities and urban areas. There is generally limited access to support services and few government benefits, and these, in any case, are often of little value (World Health Organization, 2007). Locally and nationally, there are few relevant and reliable epidemiological data on the prevalence of intellectual disability. However, there have been some positive developments within the past three decades, and they are the focus of this paper.

The limited epidemiological data in India on intellectual disability suggest a prevalence of around 2–2.5% in the general population. An excess prevalence in males, rural areas and low-income groups is reported. Acquired causes account for about 30% of cases. It is estimated that at least 25% of intellectual disability is preventable in India (Srinath & Girimaji, 1999).

Legislation

The first attempt by the central government to provide legislation for people with disability resulted in the Persons with Disabilities Act 1995, an Act that emphasised equality of opportunity and non-discrimination, together with the range of services that needed to be developed, such as prevention, early intervention, education, training and social benefits. This Act is currently undergoing revision to bring it in line

with the United Nations Convention on the Rights of Persons with Disabilities. Both central and state governments have introduced many social justice measures such as disability pensions, family pensions, travel concessions, income tax exemption and health insurance, but, as noted above, limited access to the benefits and the extent of utilisation are causes for concern.

Later legislation that specifically addressed those with intellectual disability included the National Trust Act 1999 for persons with 'mental retardation', cerebral palsy, autism and multiple disabilities. This Act was intended to empower persons who could not speak for themselves, as well as their families. It was envisaged that it would permit greater participation of parents' associations (see below) and non-governmental organisations (NGOs) in service development. Subsequent Acts, policies and issues, including progress in research and in human resources, have been reviewed elsewhere (Girimaji & Srinath, 2010). One notable development has been a remarkable growth in the number of professionals trained in special education (Narayan, 2007).

Services

India has many prevention and promotion programmes that concern intellectual disability. These include integrated child development services as well as reproductive and child health services. Their main focus is on health education, health promotion during pregnancy, optimum perinatal care, childhood nutrition, immunisation and, to some extent, early detection and intervention.

A recent and widely acclaimed programme is the National Rural Health Mission. Of great interest is the role of 'accredited social health activists'. These are women from the local