

Developmental psychiatry – insights from learning disability*

SHEILA HOLLINS

Background The Blake Marsh lecture, an annual lecture on learning disability, was endowed in 1963 in memory of Dr Blake Marsh, the former medical superintendent of Bromham House Colony in Bedford. The first lecture was given in 1967.

Aims To review the speciality of the psychiatry of learning disability and how it is currently practised in the UK.

Method Clinical, service, research and educational issues in learning disability psychiatry are reviewed and illustrated.

Results Key issues which emerge in all four areas include the importance of communication skills, consultation with users and carers, professional education and partnership.

Conclusions The psychiatry of learning disability is a complex, varied and stimulating branch of psychiatry with a strong developmental focus.

Declaration of interest None.

I am going to focus on development in a number of ways, including the development of the speciality in the UK in the past 20 years, but of course primarily the impact on development for a person with a learning¹ or developmental disability as she or he makes the transition from one life stage to the next. I plan to do this by looking at clinical, service, research and educational issues in turn. But I will start by describing how I came to this speciality, because I am aware that many people perceive quite a gap between other specialities of psychiatry and the psychiatry of learning disability. This was recently highlighted by psychiatrists who surveyed the career choices of all higher trainees in this speciality (Carvill *et al*, 1999). They found that (apart from one who had family experience of learning disability) they all chose to work in the learning disability field after a placement as a junior psychiatric trainee. The majority of such trainees will choose another speciality, but I believe that they will still take something with them from their experience in learning disability which will enhance their practice. I will return to this point later.

Another key introductory point is that learning disability is best developed in the UK and Ireland, is struggling to establish itself in Australasia and North America, but is virtually non-existent elsewhere in Europe.

IN THE BEGINNING

I fall into the category of those having family experience, which led me to develop an interest in the needs of children and families with severe disabilities during my training in child psychiatry. My first formal post in learning disability was in 1981. I

had never been to a mental handicap hospital as a trainee, and it was a shocking experience to arrive in a run-down institution housing 600 people as residents, and a similar number of demoralised staff. A former consultant, a general psychiatrist, commiserated with me: “How sorry to hear I was going into ‘subnormality’”. Just after I accepted the job, a whistle-blowing film about abuse in a long-stay hospital elsewhere in England was shown on prime-time national television, thus delivering another blow to my confidence in my decision. My new job was to include academic work (including teaching medical students and trainee psychiatrists) and community service development, in addition to consultant responsibility for 350 in-patients in two different hospitals. It was very daunting, and seemed to have little in common with my personal knowledge of children and adults with learning disabilities, who were living ordinary family lives.

Many were questioning the role of the psychiatrist in learning disability. In 1980 Joan Bicknell had been appointed to the first UK chair in the speciality to try and answer that very question. This lecture is dedicated to Joan Bicknell’s vision for our future role, and to her leadership during the 1980s. As my senior consultant colleague, and Professor in the Academic Department, I was guided by Joan as I struggled to apply my skills as a child psychiatrist and psychotherapist in this new setting. I have no regrets about choosing this speciality, which has turned out to be intellectually stimulating and extraordinarily varied.

CLINICAL ISSUES

One of the skills I brought with me from child psychiatry and psychotherapy, and from my experience of parenting a child with no spoken language – but which is an experience some people will first meet in a learning disability placement – was the ability to recognise the importance of non-verbal communication in expressing distress or illness.

First impressions – a clinical vignette

A middle-aged man with Down’s syndrome had taken to his bed and was refusing food and was self-injuring. Staff were worried about his eyes and the possibility that he might blind himself. He had no speech and developmentally was functioning as

*Originally presented as the 1999 Blake Marsh Lecture at the Annual Meeting of the Royal College of Psychiatrists, Birmingham, 29 June 1999.

1. Learning disability is the term preferred by the Department of Health in England and is synonymous with mental retardation as defined in ICD–10.

an infant of 12 or 18 months. Up until this time I had had the usual requests to sign for patients' money, or permission for leave, none of which seemed relevant to the psychiatrist's role. But this man was the first patient I was called to see in my new role, that is, the first patient for whom a clinical opinion had been sought. And I found that he was clinically depressed. Recent research has pointed to the higher prevalence of depression in Down's syndrome, but this evidence was not available in 1981 (Cooper & Collacott, 1994). He showed biological features of depression, loss of interest, a reduction in energy and lowering of mood. He was also self-injuring and his attempts at communicating directly with his carers had diminished in frequency and effectiveness. The question was: 'Why now?' A careful history revealed that his father had stopped his weekly visits about 6 months earlier, although this fact was only elicited from the domestic staff, the nurses being too new to be aware of it. My preliminary diagnosis was depression, and atypical grief, in a vulnerable man with a limited social network who was mourning his father. His father had in fact died but no one had thought to inform the hospital.

This early clinical example eventually led to the creation of the *Books Beyond Words* series, in an attempt to improve communication with people who were grieving. Our search for non-verbal means of communication did not mean that one should not talk to people who have been bereaved, or should not offer them sympathy and understanding. But, for some, words provided no comprehensible explanation. We found that explanations and comfort could be provided through pictures, and through personal photographs (Hollins & Sireling, 1994a,b, 1999).

Our research has shown that grief is often pathological, delayed and/or prolonged for people with learning disabilities (Hollins & Esterhuyzen, 1997; Bonell-Pascual *et al*, 1999). We have also found that ignorance, and fear of people being upset, typically leads to carers not telling them about a significant loss, and excluding them from funerary rituals. Careful preparation and inclusion at the time of a major life event appears to be protective, but more research is needed in this area.

It is usually assumed that the concepts of the universality, inevitability and irreversibility of death are beyond the intellectual comprehension of people with learning disabilities. But experience of bereavement

counselling interventions suggests that these concepts are within the emotional comprehension of many people. If we accept that life experiences contribute to emotional development and understanding, then it is a small step to recognise that emotional intelligence can be more advanced than cognitive development.

Family issues

Family issues are so relevant for the prevention of secondary disability, and, as in child psychiatry, we have to pay attention to the role of parents and other caregivers (Hollins & Grimer, 1988; Sinason, 1992; Todd & Shearn, 1997). Parenting a child with a severe disability is different, particularly at times of transition from one life stage to another. Whether parents like it or not, and whether professionals like it or not, most parents will have a continuing role in ensuring that their sons' and daughters' life-history and individual needs are remembered. Parents feel angry and rejected when they are dismissed as over-protective, or excluded from important reviews and decisions – at the request of a support worker or professional – on the grounds that parents have no rights with respect to their adult child. My own experiences since my son left school have included being refused access to information about his care (despite his regular weekends at home), and being expected to provide him with a home again at short notice.

The three secrets

All mothers bravely give birth knowing that their child will die some day, but they usually assume it will be after their own death, and that their child will, by then, be capable of looking after him- or herself. But if the child is disabled, parental fear of their own or their child's mortality may become an early preoccupation, particularly if insecure attachment patterns have become established. Denial of their own mortality may provide a more comfortable way of coping with the extra dependency and interdependency needs of their son or daughter, and may lead to no plans being made for their child's own adult life. Is this why the whole subject of death is such a painful secret where people with learning disabilities are concerned? The denial of a person's emotional life by parents and others may seem to be protective, but should have no place in our professional care. A person with learning disabilities will

have similar emotional needs to other people, but their expression of emotion may or may not be similar. This will depend on whether they have found an acceptable form of expression for their feelings. Sometimes the expression of a normal human emotion may be dismissed as attention-seeking behaviour, or described in different terms. For example, when my son loses his temper, instead of having a 'short fuse', he has 'challenging behaviour'.

There are two other secrets which are commonly kept from people with learning disabilities: one is the secret of their sexuality, and the other is the secret of their disability and dependency (Hollins & Sinason, 2000). Ignorance of both of these can lead to behavioural and relationship difficulties, and both are probably contributory to the increased risk of abuse faced by people with learning disabilities (Turk & Brown, 1993).

Those examples illustrate some of the diagnostic and communication challenges we face; and our need to take account of developmental, family and service factors in diagnosing mental illness, while recognising that our patients' linguistic, intellectual and emotional development may each be at different stages. The prevalence of most types of mental and behavioural disorder is much greater than in the general population and increases with the severity of learning disability.

I will now turn to the context in which we practise.

SERVICE ISSUES

How have things changed over the past 30 years?

It is nearly 30 years since the White Paper *Better Services for the Mentally Handicapped* (Department of Health, 1971) and just over 20 years since the Normansfield inquiry into neglect of the residents of Normansfield Hospital in Middlesex. The movement, *An Ordinary Life* (King's Fund Centre, 1982), which began in the early 1980s in the UK, was inspirational in encouraging service managers to work for a better quality of life for people with learning disabilities in community settings. Parallel developments were occurring elsewhere, including the USA, Canada and Scandinavia (Nirje, 1976; Thomas *et al*, 1978; Grunewald, 1983; Neufeldt, 1983). However, it is important to remember that the majority of these people have always

lived at home with their families – often with little outside support. English Government policy statements in 1992 made explicit the rights of people with learning disabilities to have access to the same treatment and care as anyone else, and also reminded commissioners and providers of services about the continuing need of many for specialist services – including mental health services. Slowly, resettlement programmes have led to the closure of most of the long-stay institutions, with a reduction, for example, from 70 000 residents in England in 1970 to 3000 in 1999. The change has been away from hospital care to a social care model. Research on cost and quality in residential care points to gaps in quality across all types of care, but also illustrates the lower quality of life experienced by people living in residential National Health Service (NHS) campuses, whether on former long-stay hospital sites, or in newly built homes on green-field sites. “Residential campuses developed as a direct result of the contraction or closure of NHS Mental Handicap Hospitals are of significantly poorer quality than community-based dispersed housing schemes on a wide range of measures of benefits. These differences cannot be accounted for by differences in the characteristics of people supported” (Emerson *et al*, 1999).

The emphasis in re-provision programmes has been placed on home-making skills to support people in the community, but 80% of carers or direct support staff are untrained, and staff turnover is high (Department of Health, 1999). There is an increasing realisation by commissioners that some specialist knowledge is needed to teach new skills, to support access to health care, and to work with people with challenging or mental health needs. Training and skills development are now seen as key to the recruitment and retention of staff. Given the current lack of expertise within primary care and among direct support staff, the specialist learning disability team has an important educational role. Such training could include an understanding of how to promote healthy lifestyles rather than waiting for a crisis to develop.

The nature of specialist services

Our client group is quite different demographically from the groups involved in the psychiatry of old age (where there is a much quicker turnover of patients who

are reaching the end of their lifespan), or in child and adolescent psychiatry (where the patient soon becomes an adult), or even in general adult psychiatry, where many patients get better and do not have continuing specialist needs. Learning disability specialist services are more than mental health services – and although some colleagues in the Faculty of Psychiatry of Learning Disability argue for separate psychiatric teams for adults with learning disabilities, my preference is for a more integrated model of support. Experience suggests that whether specialist services operate at primary, secondary or tertiary levels depends crucially on the skills of those working at an earlier stage in the pathway to care. So if direct support staff and practitioners in primary care are relatively unskilled, then we, as specialists, need a closer interface with them. Multi-professional work is on the agenda of commissioners, and to be truly multi-professional, a team must include doctors. This does not mean that doctors have to be in charge of all aspects of care, rather psychiatrists should concentrate on psychiatric care. In an integrated service there is room for different disciplines to take a lead on different aspects of support, and this should not be a problem for us.

Where next for services?

Learning disability services have probably been subjected to even more organisational change in the past two decades than other psychiatric services. In the USA, performance indicators are monitored by the President’s Committee on Mental Retardation (PCMR), thus allowing inter-state comparisons to be made: for example, about waiting lists for day and residential services (PCMR, 1999). The ‘England Team’ which participated in the PCMR’s 1999 International Collaborative Policy Academy was unable to provide comparable information (Towell, 2000). Good practice guidance has been issued in the UK but there are no plans for a national performance framework. The jury is still out on which organisation in the new NHS should provide learning disability specialist health care. Could those aspects of health which are managed within primary care for the rest of the population, be managed, and appropriately supported, for people with learning disabilities within primary care too? At the moment few primary care practitioners have the skills

or inclination to do this. For this model to work effectively, both direct support staff and the primary care team will need to be stronger in what they have to offer.

With only 40 patients with learning disabilities on the average general practitioner’s (GP’s) list of 2000 patients, a primary care team could employ a specialist learning disability nurse or health advocate to help them. Specialist occupational therapists and physiotherapists could also find a home for themselves. One of the best arguments for this approach comes from research into the general health of this client group. Despite several studies which clearly demonstrate the failure of GPs to pick up significant treatable morbidity in people with learning disabilities, there are few areas where comprehensive and regular health checks have been put in place (Wilson & Haire, 1990; Kerr, 1998; Stein, 2000). Comorbid medical conditions which mimic psychiatric disorder are not restricted to this speciality, but they are probably more common, and include thyroid disease and sensory impairments.

Commissioners are likely to purchase some specialist services from either mental health or learning disability providers – these will probably include some regionally commissioned services, such as forensic learning disability services. They should also include dual-diagnosis in-patient units, community support teams similar to the assertive outreach teams in general psychiatry, epilepsy and neuropsychiatric clinics, and psychotherapy services. A key professional in these secondary and tertiary level services will continue to be the speech and language therapist. But communication skills and a sound understanding of language development and disorder are also essential for the psychiatrist in this speciality.

I will finish my discussion of service issues with two clinical vignettes to illustrate the importance of good communication skills, and of an openness to hear what our patients are trying to tell us. Sometimes it may seem as if we are working in the dark – our patients may find it difficult to make sense of their world, and find it hard to describe their experiences, their understanding and their feelings. Sometimes, as clinicians, we have to create hypotheses by observing and understanding human nature, but without scientific diagnostic proof. An open mind about the possibility of abuse may help to restore mental health in our patient, even without any

possibility of proof and usually no prospect of a conviction. Even when people disclose painful experiences their testimony may be thought faulty, although there is good evidence that people with learning disabilities can be reliable in their recall of events. As a psychotherapist my experience is that people have few defences to protect them from disclosure of their real feelings, even if these have to be expressed behaviourally. This is not a new observation!

The heart of the fool is in his mouth, but the mouth of the wise man is in his heart (Benjamin Franklin, *Poor Richard's Almanac* for 1733)

Clinical vignette (1)

My first example is of an adolescent woman who was electively mute, and was showing sexualised behaviour suggestive of a reaction to abuse. On being offered a book in the *Books Beyond Words* series (Hollins & Sinason, 1992), she scanned the book very quickly and then chose four pictures in quick succession. The first showed a frightened young woman curled up in the corner of an empty room, the second the same woman shouting out in protest, then a man with his finger on her lips saying "Ssh", and finally the woman sitting on the man's lap with his hand touching her breasts. The possibility of abusive experiences with a familiar male authority figure had to be considered.

Clinical vignette (2)

Sometimes the perversions which our adult patients show can be traced so clearly to their own childhood experiences. This is true of the men who attend a weekly outpatient psychotherapy group, all of whom have a sexual problem, although the nature of these varies. They have all given permission for the group to be discussed in educational settings.

Sean and George live in the same locked ward of a hospital which is facing closure. They are lovers, but their relationship is often a violent one. They were both hit repeatedly as children, and sexually abused. They are sexually aroused by the violence, but they would like to love each other without hurting themselves. Sean has taken another lover of whom he is afraid, and who hurts him, so that he can enjoy a different kind of relationship with George. But George is jealous of the other man and wants to be reassured by Sean's love for him. The question in the group one week was: if Sean and George can love each

other without hurting themselves, then why couldn't their parents love them without hurting them? This was the first time that they had been able to make a connection between their childhood experience and their present behaviour.

The group members all have moderate or mild learning disabilities, and all can communicate verbally. None is classically autistic, and all have some of the social, communication and imaginative skills needed to understand each other. They have some capacity for "talk of the mind" (Hadwin *et al*, 1997), and the group provides an opportunity for them to develop empathy for each other. As time passes, their secondary emotional disability is diminishing, and several of them seem more able than we had first thought (Sinason, 1992).

RESEARCH ISSUES

You are probably picking up that my two mantras are: communication, communication, communication; and education, education, education. There is a third key aspect which psychiatry is in a strong position to be able to support, which has little to do with our specific professional role, but which can strengthen our leadership contribution. This is continuity. Most of us stay in touch with the same patients for years, and this can have many advantages for them. If we used this opportunity wisely, we would probably take Dame Margaret Turner Warwick's advice to young consultants closely to heart. She suggested that at the start of a consultant career each of us should collect data about a cohort of patients and follow them up throughout our careers. This way, she said, we would begin to understand so much more about the natural course of a condition.

In learning disability this is just as valid. Paediatricians and child psychiatrists have been poor at predicting what children with severe learning disabilities will be like in adulthood. Usually they are too pessimistic. Or sometimes, a disability which seems very clearly delineated in childhood becomes indistinguishable from another in adulthood (Howlin *et al*, 2000).

Funding for research

NHS funding for health and social care research in learning disability has decreased. The Department of Health in

England has commissioned some reviews of present research funding, research strengths and priorities. I suspect that the particular challenges which face health researchers in this speciality have not been adequately considered by commissioners and funders of research. New methodologies are needed to cope with the ethical and demographic factors which make randomised controlled trials particularly difficult. For example, we could apply mainstream findings in carefully defined case series, and look for reasons to predict different outcomes.

As a general principle, research needs to be informed by a range of evidence, drawn from many disciplines: for example, education, social policy, social care, ethics, linguistics, developmental psychology and genetics. In psychiatry we need to retain our roots in the scientific community and invest in research into neuropsychiatry, psychopharmacology and the biological basis of behaviour and mental illness, as well as in psychotherapy. In my own department we have also been exploring the use of anthropological field methods in conjunction with small-scale quantitative studies. Combined quantitative and qualitative approaches take longer and are not highly valued in the environment in which medical research is currently conducted in the UK. The recent series of articles in the *British Medical Journal* will help to increase understanding and recognition of qualitative research, but few medical journals yet have the skills to judge it (Greenhalgh & Hurtwitz, 1999). For example, participant observation and narrative analysis certainly require skills different from those of more traditional medical research methods. Meanwhile, as practitioners we can learn by listening to the stories our patients tell. One indication of the effectiveness of the services we provide will be the number of good or bad stories we hear.

The chair of the American PCMR addressed a seminar in London on "Pursuing quality in the lives of people with learning disabilities: exploring partnerships between Higher Education and the world of practice" (Hollins & Towell, 1999). Representatives came from government, research foundations, universities, the NHS and social services, and people with learning disabilities and carers. Researchers talked of their difficulty in sustaining research and development programmes in this field, and the constant drift of

colleagues into other areas. Other stakeholders expressed their wish for universities to be more committed to their social concerns, and to be influenced by user and carer priorities, with a greater emphasis on development and implementation than research. However, the context within which researchers work does seem to constrain their ability and willingness to engage in such partnerships. University posts are increasingly funded according to the value placed on their work by the major grant-giving bodies. But if academics in learning disability cannot achieve high ratings for their work, or obtain grants from the prestigious research councils, then they will struggle to attract university funding and become part of the mainstream. The problem of being 'on the edge' is one that British academics share with people with learning disabilities themselves.

THE ROLE OF ADVOCACY

This contrasts strikingly with the situation in the USA since 1963, and now incorporated into the Developmental Disabilities Act. The Federal US Government has provided pump-priming finance to promote partnership between universities and their local services. This academic expertise is made available through a range of activities including multi-disciplinary training, service development and research and development. There is now at least one such partnership, or University Affiliated Program, in each US state.

This brings me to two important points. The first is that some things will not change. Learning disability services will always be needed, and the problems and challenges I have highlighted will recur in one form or another in each generation. People with learning disabilities will always need advocates to ensure their fair share of resources. The second is that some things will change: for example, the way we learn to listen to, and learn from, people with learning disabilities themselves. The self-advocacy movement has had a profound impact on service development. For example, in England, the Minister's Advisory Group on learning disability has a reference group of members who have learning disabilities, thus giving them a powerful voice in the policy arena. A national advisory committee on screening women with learning disabilities includes

two self-advocates. Listening is not just a clinical skill, but one which services and universities need to develop for planning too, and in recognition of this my department employs two people with learning disabilities as teachers, who are also beginning to contribute to our research and development programme.

My experience of working with self-advocates and service users has heightened my awareness of the role universities could play in furthering the social change agenda. In England, applications for Department of Health research funds require information about how the proposed research will impact upon the quality of health care received by people with learning disabilities, on its relevance and importance for local and national priorities, and other questions which show how health research is inextricably linked to government policy. The emphasis in health services research is shifting towards a new focus on development.

A cornerstone of current British policy is the determination to promote social inclusion (King's Fund Centre, 1982; Beardshaw & Towell, 1991). Unfortunately, many people with learning disabilities still experience both overt and unconscious discrimination in their attempts to access the support they need. The Disability Discrimination Act 1995 is now being implemented, and we may soon see the first legal cases being brought against the health service for alleged discrimination. The Down's Syndrome Association launched a campaign in 1999 to end discrimination in health care against people with Down's syndrome (Down's Syndrome Association, 1999).

EDUCATIONAL ISSUES

It would help us in our role as psychiatrists if other medical professionals were more competent in health care delivery to people with learning disabilities. I believe it is too late if we wait until doctors have qualified before we try to influence their practice. The attitudes, knowledge and skills we want them to acquire are part of the essential attributes of the pre-registration house officer, and therefore the undergraduate course is where our effort should be concentrated (Hall & Hollins, 1996). Health care students will need to familiarise themselves with the social model of disability which is enshrined in the Disability

Discrimination Act, and it is vital that they learn to apply their medical knowledge in practice, while seeing the patient as a whole person, not just their disability.

They must become familiar with the law on consent as it affects people who are unable to give informed consent, and they must learn how to assess competency, and recognise how this varies with the choices which need to be made. They need to learn how to work appropriately with informants, and to practise communicating with people with learning disabilities.

Developmental psychiatry

My paper finishes with a short reflection on the value of a placement in psychiatry of learning disability for junior trainees. They will have an opportunity to see the life experiences and adjustment difficulties of people who start life with a biological or environmental disadvantage. They will have first-hand exposure to developmental issues and transitions at different points in the life-cycle. They will practise an integrated medical, psychological and social approach, usually in a multi-professional, community setting. They will consider factors which contribute to mental health, as well as learning to diagnose and treat mental illness, often without the benefit of an easily obtainable history. They will acquire an understanding of the theory of mind through their contact with autistic children and adults, and those with Asperger's syndrome; a useful skill which avoids misdiagnosing them as having a psychosis when they present to general psychiatric services. They will become skilled at finding new ways of understanding and communicating with people who rely more than most on non-verbal communication. They will also gain a deeper understanding of the importance of the interaction with carers in the genesis of mental disorder, because of the continuing dependency needs of people with learning disabilities. They may have to confront uncomfortable and primitive fears about people who are different from themselves. They may even experience some of the stigma which is so powerfully associated with intellectual disability.

Finally, I hope they will also discover that, if they can get it right for people with learning disabilities, they can probably get it right for everyone else.

REFERENCES

- Beardshaw, V. & Towell, D. (1991)** *Enabling Community Integration: The Role of Public Authorities in Promoting an Ordinary Life for People with Learning Disabilities in the 1990s*. London: King's Fund Centre.
- Bonell-Pascual, E., Huline-Dickens, S., Hollins, S., et al (1999)** Bereavement and grief in adults with learning disabilities. A follow-up study. *British Journal of Psychiatry*, **175**, 348–350.
- Carvill, S., Marston, G. & Hollins, S. (1999)** Trainee attitudes within the Faculty of the Psychiatry of Learning Disability. *Psychiatric Bulletin*, **23**, 86–89.
- Cooper, S.-A. & Collacott, R. A. (1994)** Clinical features and diagnostic criteria of depression in Down's syndrome. *British Journal of Psychiatry*, **165**, 399–403.
- Department of Health (1971)** *Better Services for the Mentally Handicapped*. London: HMSO.
- (1999) *Facing the Facts*. London: Department of Health.
- Down's Syndrome Association (1999)** *He Will Never Join the Army*. London: DSA.
- Emerson, E., Robertson, J., Gregory, N., et al (1999)** *The Quality and Costs of Residential Supports for People with Learning Disabilities*. Manchester: Hester Adrian Research Centre.
- Greenhalgh, T. & Hurwitz, B. (1999)** (eds) *Narrative Based Medicine*. London: BMJ Books.
- Grunewald, K. (1983)** Sweden: community living for mentally retarded adults. In *A Way of Life for the Handicapped* (eds G. Jones & N. Tutt). London: Residential Care Association.
- Hadwin, J., Baron-Cohen, S., Howlin, P., et al (1997)** Does teaching theory of mind have an effect on social communication in children with autism? *Journal of Autism & Developmental Disorders*, **27**, 519–537.
- Hall, I. & Hollins, S. (1996)** Changing medical students' attitudes to learning disability. *Psychiatric Bulletin*, **20**, 429–430.
- Hollins, S. & Esterhuyzen, A. (1997)** Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry*, **170**, 497–501.
- & **Grimer, M. (1988)** *Going Somewhere: People with Mental Handicap and their Pastoral Care* (Pastoral Care Series). London: SPCK.
- & **Sinason, V. (1992)** *Jenny Speaks Out*. London: St George's Mental Health Library.
- & — (2000) Psychotherapy, learning disabilities and trauma: new perspectives. *British Journal of Psychiatry*, **176**, 32–36.
- & **Sireling, L. (1994a)** *When Mum Died* (2nd edn). London: St George's Mental Health Library.
- & — (1994b) *When Dad Died* (2nd edn). London: St George's Mental Health Library.
- & — (1999) *Understanding Grief*. London: Pavilion.
- & **Towell, D. (1999)** Pursuing quality in the lives of people with learning disabilities and their families. Exploring new partnerships between higher education and the world of practice. London: King's College.

CLINICAL IMPLICATIONS

- Clinicians should foster links with local university departments to support research and development initiatives.
- Partnerships with user and carer groups will support more sensitive service provision.
- Communicating with people who have a 'limited communication' repertoire requires practice and a willingness to try non-verbal techniques.

LIMITATIONS

- The article is a personal and reflective account of service and professional changes in a 20-year period in England.
- The psychiatry of learning disability is virtually non-existent as a speciality elsewhere in Europe and in most of North America.
- The author has a psychotherapeutic approach to the speciality which is not universally shared.

SHEILA HOLLINS, FRCPsych, Department of Psychiatry of Disability, St George's Hospital Medical School, Jenner Wing, Cranmer Terrace, Tooting, London SW17 0RE, UK

(First received 7 December 1999, final revision 24 February 2000, accepted 24 March 2000)

- Howlin, P., Mawhood, I. M. & Rutter, M. (2000)** Autism and developmental receptive language disorder – a follow-up comparison in early adult life. II. Social, behavioural and psychiatric outcomes. *Journal of Child Psychology & Psychiatry*, in press.
- Kerr, M. (1998)** Primary health care and health gain for people with a learning disability. *Tizard Learning Disability Review*, **3**, 6–14.
- King's Fund Centre (1982)** *An Ordinary Life: Comprehensive Locally-Based Residential Services for Mentally Handicapped People* (KFC Project Paper 24, revised edition). London: King's Fund Centre.
- Neufeldt, A. (1983)** Canada: Canada's ComServ plan – a nation-wide strategy of service development. In *A Way of Life for the Handicapped* (eds G. Jones & N. Tutt). London: Residential Care Association.
- Nirje, B. (1976)** The normalisation principle and its human management implications. In *Normalisation, Social Integration and Community Services* (eds R. J. Flynn & K. E. Nitsch). Baltimore, MD: University Park Press.
- President's Committee on Mental Retardation (1999)** *1999 Profiles, International Collaborative Academy on Mental Retardation*. Washington, DC: US Department of Health and Human Services Administration for Children and Families.

Sinason, V. (1992) *Mental Handicap and the Human Condition: New Approaches from the Tavistock*. London: Free Association Books.

Stein, K. (2000) Caring for people with learning disability; a survey of GPs' attitudes in Southampton and SW Hampshire. *British Journal of Learning Disabilities*, **8**, 9–15.

Thomas, D., Firth, H. & Kendall, A. (1978) *ENCOR – A Way Ahead*. London: Campaign for Mentally Handicapped People.

Todd, S. & Shearn, J. (1997) Family secrets and dilemmas of status: parental management of disclosure. *Disability and Society*, **12**, 341–366.

Towell, D. (2000) Achieving positive change in people's lives through the National Learning Disability Strategy: lessons from an American experience. *Tizard Learning Disability Review*, in press.

Turk, V. & Brown, H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research*, **6**, 193–216.

Wilson, D. & Haire, A. (1990) Health care screening for people with mental handicap living in the community. *British Medical Journal*, **301**, 1379–1381.

World Health Organization (1992) *The ICD–10 Classification of Mental and Behavioural Disorders. Research Criteria*. Geneva: WHO.