Developmental psychiatry – insights from learning disability*

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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 of a person with a learning disorder 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 330 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

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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 psy-
chiatrist’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 effective-
ness. 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 symp-
athy and understanding. But, for some,
words provided no comprehensible ex-
planation. We found that explanations and
comfort could be provided through pictures,
and through personal photographs (Hol-
llins & Sireling, 1994a,b, 1999).

Our research has shown that grief is of-
ten 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 irre-
versibility of death are beyond the intellec-
tual 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 preven-
tion 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, particu-
larly 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
views 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 experi-
ences 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, particu-
larly 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 feel-
ings. 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 sexu-
ality, 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 contri-
butory 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 recog-
nising that our patients’ linguistic, in-
tellectual 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 Handi-
capped (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 learn-
ing disabilities in community settings.
Parallel developments were occurring else-
where, including the USA, Canada and
Scandinavia (Nirje, 1976; Thomas et al,
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 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 “Shh”, 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 somewhat 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


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.

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