

A house of straw: Interpreting and responding to distress amongst people with a learning disability

Written by Peter Bates 23 December 1999

Talking about distress

Over recent years there has been a growing interest in 'mental health in learning disability'. Fifteen schools of nursing are approved to run post-registration courses, and one university is offering an MSc programme. The academic press publishes a small but constant stream of papers and one or more conferences have been offered each year since the mid 1990s. Whilst it is extremely important to respond appropriately to distress amongst people who use learning disability services, current work appears to have a number of structural weaknesses.

At the outset it is important to note that an international review of the literature will be affected by the different service configurations in each country. It is generally understood (though not formally reported in any published materials I could find) that the UK has more psychiatrists per head working in learning disability than anywhere else in the world, and some conclude from this that the service is therefore more highly developed. America has more psychologists than psychiatrists working in learning disability, which means that behavioural analysis is likely to be the primary intervention, rather than medication.

Diagnosis and prevalence

Published materials about mental health issues amongst people with learning disabilities tend to be written in a confident tone. It gives the impression that a rigorous, analytical approach had been applied and, as a result, the body of scientific knowledge is steadily growing. Prevalence studies suggest much less certainty. They find that as few as 14% or as many as 67% of people with learning disabilities have psychiatric symptoms. This can be explained in a number of ways:

- different groups are under examination - the general population, those on a register of people with learning disabilities, or those who use a particular service.
- each study uses a different measuring instrument, tests for different psychiatric symptoms or sets a different threshold for attributing a diagnosis.
- The concept of mental illness has weak construct validity when applied to people with a learning disability.

Further work is needed to identify the source of these variations.

A variety of assessment tools have been developed by the Institute of Psychiatry and the Hester Adrian Research Centre amongst others. The aim is to assist professionals in the diagnosis of psychiatric disorder amongst people who have a label of learning disability. Professor Sheila Hollins at St George's medical school is working with others to integrate these with user and carer views to create a comprehensive perspective on the person.

Where the person with a learning disability has very limited verbal skills, the psychiatric diagnosis rests upon observed behaviour. The situation is parallel to cross-cultural

mental health work where the patient speaks a different language from the psychiatrist and others in the care system. Moss notes that people with learning disabilities are more likely to say what they believe the interviewer wants to hear, and language may be limited or unusual. These factors make the diagnosis less secure and so the ethical justification for prescribing medication or other invasive approaches must be balanced against the risks of doing nothing. There may be some similarity with section 48 of the National Assistance Act 1948 where doctors are allowed to act in order to save life without the patient's consent but these actions could be construed as assault if the risks are less severe.

Epidemiological studies can either examine the prevalence of specific symptoms within a given population or can explore the pattern of diagnostic labels that have been assigned to a group of people. This latter approach conflates factors that affect the distribution of symptoms and those which govern the application of the labels to some people and not to others. The distribution of psychiatric diagnoses amongst people with a learning disability reveals a surprising pattern. While in the general population the lifetime prevalence of affective disorders is ten to fifteen times higher than that of schizophrenia, the majority of people in learning disability services who carry a psychiatric label are considered to have schizophrenia. One explanation that has been offered for this disparity is that affective disorders have been under-diagnosed in the learning disabled population, but the difference is so great that other factors must also be at work. Furthermore, the age of first onset of schizophrenia is lower in the learning disabled population than the non-disabled population. This may occur because learning disabled people are less adept at hiding their symptoms, or people in the individual's social network may be more willing to pathologise unusual behaviour.

While the majority of studies have explored the prevalence of mental illness amongst a population of people receiving learning disability services, two further groups warrant attention. There are a group of people in the criminal justice system who have mild learning disabilities and may well have signs of mental distress. There are also a group of people who have received long term psychiatric care, commonly live in private registered homes and have mild learning disability. This highlights the similarity between the negative symptoms of schizophrenia (amotivation, slowness of thought and action, poverty of speech and emotional blunting), mild learning disability, long term unemployment and poor educational attainment.

Co-existing physical or sensory impairment may compound the problems of diagnosis. For example, some 50% of people experiencing sight loss experience visual disturbance which can be interpreted as hallucinations. As 12-15% of people with learning disabilities also have significant sight impairment, then step changes in visual acuity could lead in turn to inappropriate psychiatric diagnosis.

The average age of the learning disabled population is increasing even faster than the general population, and this means that the mental health risks associated with ageing are on the increase too. People with Downs syndrome are at high risk of early-onset dementia, and there is also a link between dementia and late onset schizophrenia in the general population, which suggests that people with Downs are particularly at risk.

The cause of mental illness

There is a general recognition that mental health problems can be caused by one or more of the following:

- physical factors, such as brain damage or dysfunction
- psychological factors, such as early life disadvantage or adverse life experiences
- social factors, such as poor confiding relationships, poverty of social networks and stigma
- developmental factors, such as the developmental stage and communication skills.

A biological model will readily associate chromosomal and metabolic abnormalities or birth trauma with subsequent mental illness. At first glance it seems entirely reasonable to assume that the physical imperfections which result in limited intelligence and function also manifest themselves as psychiatric disturbance. Work has been done to isolate the specific behaviour patterns that commonly associate with genetic abnormalities. This is valuable, but the mental health in learning disabilities field seems to have a much stronger focus on medical and genetic causation than does mainstream psychiatry. While there is a body of mainstream psychiatrists examining the family history of schizophrenia, for example, most would only cast these medical and biological forces in the role of vulnerability factors.

Quality of life

Personal identity and status in the general population are defined in part by access to positive social roles, control over one's own environment, and supportive social networks. These things confer a sense of personal value and esteem, as well as providing a buffer against times of crisis. The depressed employee quickly comes to the attention of the line manager, who recommends a holiday or referral to the employee counselling service. Friends rally around in times of bereavement, and it is possible to move house when the neighbours become too troublesome. In contrast, people who use learning disability services are rarely bolstered by similar support systems. For some, fundamental choices such as scratching an itch or ending a social encounter are denied and this can lead to a heightened sense of powerlessness and consequent anxiety. In addition, learning disability brings increased vulnerability to abuse - ranging from negative media representation through bullying to crime and sexual abuse. Personal distress can arise from either long-term exposure to an impoverished lifestyle or specific trauma.

In mental health services, the proportion of women who have been subjected to sexual abuse rises as one moves along the spectrum from mild to severe mental health problems. One long-term psychiatric rehabilitation service found 70% of its female users had been abused in the past. It appears that such assault has a complex and long-lasting impact that may include absorption into psychiatric services. The challenge for mental health services is to find effective responses to these issues that take individual symptomatology and reframe it as a response to trauma, a survival strategy in an unsafe world or a mode of communication.

Like people in the mental health system, people with learning disabilities are also susceptible to experiences of poverty and abuse that inevitably bring distress. Insufficient work has been done to identify the psychological sequelae of poverty and

abuse amongst learning disabled people, and so the signs of distress continue to be at risk of being either ignored or treated as symptoms of psychiatric illness.

Conclusions regarding interpretation of distress

While much of the academic literature is confident in tone, neither care staff nor the epidemiology appears to support this confidence. A recent survey of 166 staff working in learning disability services found that four out of five (81%) believed that there were people in their service with undiagnosed mental health problems. Where psychiatric illness had been identified and treated, staff were anxious about the suitability of the treatment, and two thirds of respondents (64%) felt that there were people in their service receiving inappropriate treatment. The epidemiological data also suggests that we know very little for certain about mental illness amongst people with a learning disability apart from some genetic disorders that correlate well with specific psychiatric problems. Little is known about the psychiatric effects of powerlessness, stigma, trauma and poor quality of life upon people with learning disabilities and some signs of distress may be inappropriately attributed to mental illness. Communication limitations substantially reduce our ability to be sure of the thoughts and feelings of some people with learning disabilities. Taken together, these factors permit only tentative diagnoses and advise caution in the use of invasive treatments.

Responding to distress

Support systems

Support can be construed as a pyramid of four levels, comprising: self-help; informal social networks, including family members; mainstream health and social care services; and finally, specialist provision. In bereavement, for example, one might look over old photographs and attend the funeral with family and friends before seeking additional help from the formal system. Some services have worked with learning disabled people to assist in the development of a personal framework for comprehending the loss. However, one continues to hear of people with learning disabilities who are not told of the death of a relative and denied the opportunity to attend the funeral.

The example of bereavement reveals the multiple factors that will influence the processing of any distressing life event. Firstly, the person who has been bereaved may have some sense of loss. A person with learning disability may have a limited or idiosyncratic comprehension of the absence of the individual or the reason for the visible unhappiness of others. Secondly, grief will be manifested in a manner that reflects the individual's personality, culture, socialisation and opportunity. Thus a learning disabled person may be denied the opportunity of visiting the grave by mobility difficulties, be unable to afford to buy a wreath, and may have been taught that negative feelings should never be expressed. This is reminiscent of the pathologising of ordinary emotions, in common with psychiatric services where long-term users sometimes expect to be shielded from any uncomfortable life experiences by variations in medication.

Finally, that manifestation of grief will be interpreted by the people around the bereaved individual.

When a person with a learning disability is identified as needing psychiatric help, there appears to be a bias in favour of medication over other approaches. Counselling and other cognitive services for people with a learning disability are comparatively scarce. An assumed limitation on the capacity for abstract conceptualisation combined with communication difficulties is often cited as a reason for this. These prohibitions seem a little surprising since many branches of counselling do not assume that healing comes through the conscious development of abstract concepts, and all emphasise the need for counsellors to attend to the non-verbal aspects of communication.

Medication

The reality in many mental health services is that prescribing is at least in part a retrospective process. This means that the diagnosis generates a hypothesis, which leads to a drug selection. If the patient improves, then this confirms the diagnosis. This process presses the service to clearly define 'improvement'. Over the last ten years the focus of attention in services for people with learning disabilities has been upon services for people with challenging behaviour. While the broadest definition of challenging behaviour has included anything we haven't figured out yet, it is violence and aggression that have served as a magnet for resources. Challenging behaviour teams have been appointed to prevent breakdown of residential placements. Individuals who become depressed and withdrawn or obsessive in the ritualistic completion of household chores do not draw attention. 'Improvement' becomes narrowly defined as the reduction of severe problem behaviour, and almost any powerful tranquillising agent will do that.

Krajewski has noted that the side effects of psycho-active medication are more severe in people with a learning disability and so this adds an additional risk to the use of medication which cannot therefore be viewed as universally benign. The appropriate response to adverse side effects requires the patient to recognise the experience, attribute it to the medication, balance the benevolent and adverse consequences of the medication in order to tolerate continuation and communicate all this to others, so that adjustments may be made in the prescribing pattern. Many people with a learning difficulty will have problems at one or more of these stages, thus increasing the risk of mistreatment.

Access to services

At **primary care** level, General Practitioners are expected to look after the general healthcare needs of people with a learning disability who live in the community. However, they often don't. The Department of Health has noted that people with learning disabilities have the same rights of access to NHS services as everyone else but may require assistance to use the service.' Social services departments are largely invisible in the literature.

Where **Secondary care** is provided by the specialist learning disability service within an NHS Trust, then the majority of those services expect to provide the bulk of mental

health care to those individuals. There are a number of service responses to meeting the mental health needs of patients:

- Many services make occasional use of psychiatric acute inpatient facilities, but patients revert to the care of the learning disability team as soon as possible. Mental health staff generally have little specialist training in learning disability, and do not always welcome input from their colleagues in the learning disability service.
- Most services already have or are establishing a specialist assessment and treatment unit which will lie within the learning disability service and can take a crisis admission, so that the person does not have to use the psychiatric inpatient facility.
- In most services it is almost unknown for a patient to receive a care package which includes regular input from both health-funded psychiatric and learning disability community or day services.

This leads to the conclusion that NHS Trusts are not yet creating joined-up services where mental health and learning disability specialists collaborate to meet the mental health needs of people with learning disabilities. Moreover, the likelihood of utilising both mental health and learning disability services (one definition of having a dual diagnosis) varies according to the configuration of local services, rather than the needs of the person.

People with a learning disability and a mental health problem may test service quality in two distinct ways. They may serve as a litmus test for the degree of inter-departmental collaboration which is evident in the service. More fundamentally, this group of people may be poorly served simply because the core learning disability or mental health services are inadequate.

Specialist services

A group of independent sector service providers offer residential care for people who have been given a 'dual diagnosis' (MacIntyre Care, Sons of Divine Providence, Norwood Ravenswood, Home Farm Trust). The national campaigning and advocacy bodies (MIND, Mencap, Mental Health Foundation, Values into Action, Sane, People First, National Schizophrenia Fellowship) are conspicuously silent and do almost nothing to advocate for the interests of people who have a dual diagnosis - although a number of local groups are welcoming individuals who have used both services. There is no national user or carer group. A small new charity called the Judith Trust is working to stimulate research and training for staff.

While service users appear capable of integrating learning disabilities and mental health problems, this does not appear to be true of academic systems. For example, Bill Fraser noted that there are a total of 97 journals on learning disability, but only one of them appears in the psychiatric databases. Within the literature there is a dearth of accounts from users themselves, and psychiatrists and psychologists have 'assumed the power of definition' of the issues.

Alternative interpretations

The social model of disability proposes that disability is a social process which occurs when the institutions of society stigmatise and reject people who they classify as different. In this model, using a wheelchair is not a problem until someone builds steps. Both the learning disability and the mental health fields have focused upon the processes by which service users are excluded from mainstream society through discrimination. They have sought to champion an alternative interpretation by celebrating difference and challenging stereotypes. They point out the presence of these stereotypes within health and social care systems as well as within the wider society, and so, for example, challenge the way in which African Caribbean men are channelled into forensic services. Despite the energy that has been applied to this point of view in other areas of disability, it has not been applied to the ways in which people with a learning disability acquire a psychiatric label or find themselves referred to mental health services.

A poverty model

A materialist analysis may be considered a close neighbour to the social model of disability. Proponents argue that financial poverty restricts opportunities, lowers status in the community and eliminates buffers against crisis, as well as attracting additional labels, so that poor people are more likely to be labelled with mental illness or learning disability than those who are financially secure. Money can also be viewed as related to one aspect rather than permeating everything, so that, for example, it is the learning disability that leads to unemployment, but, as not everyone who is unemployed is diagnosed with mental illness, then the distress must be due to a psychiatric cause. Such compartmentalisation is unlikely to make much sense when we know that poverty and its attendant restrictions on opportunity and status will simultaneously effect the person's experiences and opportunities in respect of both their learning disabilities and their wellbeing.

Money usually expands choice, but choice also involves a number of other factors. The importance of self-determination and advocacy has been articulated by the user movement in learning disability and mental health services. This has led to a few user-managed services, but more often the impact has been to increase the focus on self-advocacy and user choice within statutory services. One important consequence has been the reframing of the traditional narrative about the cause, meaning and response to disability. For example, the recovery movement has provided a setting where psychiatric survivors can share their personal journey from crisis to resolution, which includes making sense of the experience in their own terms and then moving on into a fuller life. Similarly, support which enables people with a learning disability to become performance artists or community activists can allow a redefinition of identity which has little to do with disability labels. This work has yet to begin with people who have been assigned a 'dual diagnosis'.

The challenge for services in the opening months of the twenty first century lies in the field of community participation. Since the 1960s the hospital closure programme and a heightened awareness of the damaging effects of institutionalisation have spurred on the relocation of most learning disabled people into smaller residential units. Latterly a few services have attempted to support people in taking up citizenship alongside other

students, employees and neighbours while focusing upon the challenge to support the development of social networks and citizenship in the wider community.

Community presence and participation can provide valuable benefits for everyone and may be especially important for people who need the highest level of support. People with few difficulties may need little in the way of skilled support to rejoin their community, while those who pose complex challenges to the ingenuity of staff are at particular risk of a poor quality of life. Unfortunately, while the need for intensive community support becomes ever greater with increased disability, so does the prospect of containment and institutional care. The Emerson definition of challenging behaviour, which includes to 'seriously limit the use of ordinary community facilities', and the definition of mental impairment which includes social adaptation, both help to identify this group of individuals. Despite these real difficulties, living in the community is a realistic option for people with severely challenging behaviour, if appropriate support is available.

In summary, alternative explanations of disability have not been sufficiently put to use in the field of mental health in learning disabilities. Stigma, poverty, limited choices, few opportunities to develop a personal narrative, disempowerment, institutionalisation and social exclusion all feature in the aetiology of distress. While there is a cursory acknowledgement of these issues in the literature, they remain underdeveloped in comparison with clinical and diagnostic approaches.