Correspondence

Meeting the needs of mentally ill or handicapped people: what matters most, our attitudes or our behaviour?

DEAR SIRS

I read with great interest the article by Ann Boucherat, 'Normalisation in Mental Handicap—acceptance without questions' (*Bulletin*, December 1987, 11, 423–425). She does a scholarly job of raising and examining issues associated with normalisation especially that of attitudes. I am currently working with people who have mental illness or brain damage but feel that some of the issues raised are relevant to these patient groups also.

Attitudes and behaviour have an uncertain relationship in that attitudes and thoughts are to a greater extent covert whilst the way we behave can be publicly verifiable. Behaviour towards mentally ill or handicapped people can be appalling if, like other devalued groups, they are not seen as people like us. Thus in terms of perception, attributes can be added to a person until they are no longer perceived as people like us and procedures based on normalisation can remove devaluing attributes until the target is less noticeable, more like us.

This can be effective in altering perception, and, subsequently, behaviour. I will give one anecdotal example. The manager of an adult training centre for people with mental handicaps in our region received a letter from the Licensed Victuallers Association stating that people attending the centre were welcome "in all our pubs at any time". The manager took pride in replying that trainees from the centre frequently used local pubs, and always had since the centre had opened 15 years earlier! Apparently they had not been noticed, possibly because they did not attend in groups, nor in a minibus, etc.

As professionals working with mentally ill or handicapped people we can often choose interventions and procedures that are not only efficacious, but also valuing. Skills teaching is a good example as absence of skill is highly noticeable and highly devaluing. This allows patients to go unnoticed or, when they are noticed, allows the non-handicapped person to learn that there is nothing to fear and that these people too, can and do join in the game of life with the rest of us.

So far so good. Normalisation can apparently alter perception and therefore behaviour. The big problem, particularly in mental health, is motivating staff to carry out such procedures. This is where the issue of attitudes raised by Ann Boucherat comes to the fore. People are attracted to working with patients for many reasons, but attitudes towards people with mental illness will be crucial at the stage of choosing a career. Staff bring to their jobs a number of needs which they hope to satisfy, including for example the need to comfort, the need to nurture, the need to be needed, etc. These staff needs, well known for their potentially sabotaging effects on rehabilitation, can obviously have the same effect on the revaluing process also.

Staff often act and speak in a way that suggests that they have invested patients with alien identities. From this comes the satisfaction of belonging to professions with the reputedly super human and saintly qualities needed to care for such beings. Even case conferences begin with the notorious sentence "I am going to present X. He is a young schizophrenic/chronic schizophrenic/paranoid schizophrenic/manic depressive . . .". The language that we use is no academic issue. It affects our perception of people and events. I will give one example here. I read a KARDEX entry written by a general nurse working in a general hospital which went as follows: "This schizophrenic from hospital X kept all the patients on Y wing awake last night". This was incorrect. The patient concerned had been kept awake by the torment of schizophrenia, which had subsequently disrupted other patients' sleep. There had not been a schizophrenic on Y wing. Schizophrenics do not exist!

Staff attitudes, because they are covert, will lie undiscovered until manifest by behaviour, often well into training. If the organisation supplying the training validates devaluing attitudes by its own devaluing language, what hope for change, and what should we actually be trying to change?

Attempts are often made at attitude change by holding workshops. Many of these workshops preach to the converted, and the converted can hardly be said to value mentally ill or handicapped people as ordinary people if they resort to expressions such as "an inspiration to others", "helps normal people to be humbler and self-aware", "more simple and loving" which are surely patronising and insulting, a different manifestation of the alien being syndrome.

Less ambitious than attempts at cognitive restructuring (today the nursing school, tomorrow the world) is to formulate ways of meeting the needs of users (both special needs and those common to most of us), in which staff behaviour is specified and monitored and where there is accountability for personal action. This sounds a tall order and yet needs led services of this sort do exist, Portsmouth District's Mental Handicap service being a good example. Services of this type often use Life Planning procedures and documentation.[1]

Life Plan documentation examines every facet of the life of the user and compares it with a typical life of somebody of the same age and gender but without mental illness or handicap. Disparities between the two are examined and, in full consultation with the user (where possible) defined as needs. At a meeting called a Life Plan meeting attended by the user and people who know and can generally be of help to the user, actions are agreed to begin the process of meeting these needs. Accountability comes from recording the

names of those who agreed to carry out actions and the date by which they are to be carried out. Monitoring is achieved by weekly action review meetings and new life plans are drawn up to regular intervals (for example six monthly) recording needs that have been met and those still unmet.

Procedures like Life Planning do not encourage the denial of special needs, for example the need for medication to treat a mental illness, the need to control the intensity or quality of social contact, or the need to be protected from sexual exploitation etc. Life Planning does not therefore negate the right of a psychiatrist to utilise the concept of efficacy for treating the illness itself. It does, however, look at more than the illness. It lists strengths, skills, personal assets and ambitions however meagre or mundane, and builds upon them.

The tight specification of such a process for meeting the needs of people whose very existence pays our salary, people with special needs of whatever origin, is more likely to establish the living of "valued lives" than attempts at direct attitude change. This is because the procedure specifies and guides staff behaviour irrespective of their attitudes.

We might, however, predict that life planning and procedures like it, could over time, affect staff attitudes. A behavioural requirement, that of completing Life Plan documents in full consultation with the patient, forces the keyworker to reorganise the way they store or categorise information about the patient. This is because the documents are actually templates for describing ordinary lives led by ordinary people. Discrepancies between the current life of the patient and ordinary life are categorised as needs on separate sheets. Staff might therefore come to respect the patient as an ordinary person but with very special needs, rather than a special person who is "an inspiration to others"! The patient will often have many special needs, some of which can be phrased as skill deficits requiring training, but others simply revealing weaknesses in the service he currently receives, for example basic material needs, or advocacy needs.

At the hospital where I am working we have been experimenting for some time with Life Planning for people with mental illnesses. Only a tiny minority of our patients have had Life Plan documentation drawn up but already the results have been of benefit to the patients concerned as well as illuminating to staff. We are starting to realise what can be achieved by naming people responsible for action. We are also beginning to realise what needs are not met and often cannot be met by our service.

To include Life Plan documents in patients' case files (which, as confidential documents is their proper place) is an act of bravery but also an act of honesty and respect towards the patient. Those few sheets constitute a snapshot of a person living a life within a service which we provide. The quality and comprehensiveness of that service is boldly described in terms of needs met and unmet. It could make embarrassing reading particularly if we would rather only advertise the needs that we can meet. If, however, we decide to take a more positive attitude, this documentation, by

revealing shortcomings in our service could guide us towards better service provision, particularly when planning future services, community based or otherwise.

ALLAN READ

Knowle Hospital
Fareham, Hants

REFERENCE

[1]CHAMBERLAIN, P. (1986) *Life Planning Manual*, second ed. British Association for Behavioural Psychotherapy.

DEAR SIRS

Dr Boucherat is to be congratulated for her thoughtful review of the principle of normalisation as applied to individuals with a mental handicap, and some of this principle's shortcomings (*Bulletin*, December 1987, **11**, 423–5). However, there a couple of points which I feel warrant further comment.

Firstly, many of Dr Boucherat's criticisms relate to the more recent writings of Wolfensberger, and the behaviour of his more fanatical adherents. I believe these criticisms to be well-founded, but it is important to distinguish between them and longer standing more fundamental concepts which underlie the normalisation ethic. The move towards deinstitutionalisation of people with a mental impairment, and their re-establishment as valued members of society within the community would probably not have progressed so fast and so far without the normalisation lobby. Furthermore, many of us, without a thought for Wolfensberger, and without the enlightenment of PASS workshop experiences, utilise aspects of normalisation in our daily life and work. Children with a mental handicap are seen now (educationally at least) as having "special learning difficulties" as opposed to being simply "educationally subnormal". Many of us make a deliberate effort to refer to "individuals with a mental handicap" rather than a "mentally handicapped person". Similarly, it must surely have greater adaptive use to advise somebody that they have epilepsy or diabetes, rather than being an epileptic or a diabetic. These comments may sound simplistic, but they remind us of the individual's many other attributes, and place his/her needs in context. They are more than pleasantries.

Dr Boucherat emphasises the failure of the normalisation philosophy to recognise the existence of peoples' internal world. Of course, Wolfensberger's exposition, along primarily sociological lines, does not *ipso facto* deny the presence and importance of other psychological factors— be they conscious or unconscious. What is more amazing is the volume of existing literature which has not been utilised in explaining the phenomena of stigma, dehumanisation, and discrimination. An illustrative example, which shows how far back you can search for relevant literature, is Hebb's early work on the nature of fear.[1] He demonstrates the importance of simultaneous perceptions of familiar and unfamiliar features in the generation of fear and avoidance. This research is rarely quoted yet it has important messages regarding the above social phenomena.