

The British Journal of MENTAL SUBNORMALITY

Editor: H. C. GUNZBURG

Vol. XXIV, Part 1

JUNE 1978

No. 46

EDITORIAL

Terminology has a wretched tendency to just miss the essential nature of the very concept it tries to define in a precise verbal form. No one will argue against the necessity to adhere to terms which are to be used consistently by every professional in exactly the same way. Yet, this should not blind us against the danger that the very exactness of the definition, the assurance with which we bandy about well-established terminology, may, in time, make us less sensitive and appreciative of what we really mean, or ought to mean, by the terms. It seems inevitable that usage and the need for more and more precise definitions sacrifice those shades of meaning—the qualitative nuances—to the formulation of more scientific, accurate and unchallengeable statements. We may not be quite satisfied with terms such as “profoundly—moderately—mildly mentally handicapped people,” but we know, nevertheless, that in the cognitive dimension this refers to people who obtained certain IQ scores, and, provided one believes in the relevance of this evidence, this results in a fairly definite terminology. One is perhaps less satisfied with such a flexible term as “severely subnormal,” which seems to fit too many different levels of functioning to be acceptable in its wide range. But whatever the classification term we use it seems always to put emphasis on the degree of deficiency in the person himself, i.e., he is severely retarded, he is mildly handicapped.

Is this quite what we would really like to imply by using these terms? Does this terminology not shift the blame for inadequate performance on to the “defective” person to such an extent that the term itself carries already the excuse for any failure that might occur, and puts it squarely on the mentally handicapped himself? We used to say he has a low IQ and, therefore, he cannot read, and this is now followed by the equally ready-made apology—he is moderately retarded, we cannot really expect much of him.

Correct as it is that the term should refer to the subject, we tend, on account of this not to become conscious of the fact that this subject is also the object of our efforts to develop him to a higher level of functioning. The static terminology camouflages the need for emphasising that there is a developmental process going on which the professionals must further and encourage. Instead of emphasising that this man is “profoundly retarded” (and likely to remain a profoundly retarded man) we should really think of him as a man who is very difficult to teach—and thus move the onus of failure from him—as being so non-responsive—to us—as being not clever enough to overcome the difficulties in developing him. And in the same way the other terms which are so deterministic in their statement, should be interpreted in a more activating sense by making it clear that they refer to people with learning problems of different degrees, but learn, they can.

Let us look at another well-known and widely-used term: Normalisation. Everyone in the field is now familiar with the concept, and all efforts at improving and updating our organisational arrangements for the mentally handicapped are related to and justified by this concept! Most people do not quite appreciate the far-reaching results of a consistent application of the Normalisation principle as meaning in essence that the mentally handicapped person is equal to others and has the same rights, including those of having a sexual life and a family. Generally, professional workers are less inclined to argue about the validity of those logical consequences and are more interested in the immediate practical consequences of overcoming the segregation policy of the past. For the majority of workers “Normalisation” simply means the introduction of “normal” physical conditions and living in the community. In fact, there is much confusion by using the term either as a *goal* to be achieved—i.e., putting mentally handicapped people from institutions, hospitals, into the community—or as *means* to an end—i.e., creating environmental conditions which are not different from those commonly found in the “normal” community. The use of the same term to denote the means and the end, directs attention to some consequences of applying the philosophy. Our fashionable behaviour-shaping methods and programmes methods could certainly not be referred to as being “nor-

mal," yet they are intended to produce a "normal" behaviour—which would assist in avoiding the need for segregation.

By seeing "normalisation," whether it is regarded as a goal to be aimed for, or as a process to be used to achieve that goal, simply in physical terms, such as in the first case, a house in an ordinary street, and in the second case as having a bedroom for oneself, much of the essential nature of living a normal life, seems to get lost—though these are ingredients which are not to be disregarded. Leading a normal life—within the limitations posed by mental handicap—means more than having a house or having a bedroom to oneself. Having a house, having a bedroom helps, but is not essential for leading a "normal" life, which means to have a certain independence in decision making, in making choices in following one's inclination, rejecting and accepting, having likes and dislikes, and being able to arrange one's life accordingly.

Of course, this aspect of living one's own life is implicit in the "normalisation" term, but how much attention is paid to the need to develop people adequately so that they can make such decisions as far as they are potentially capable? If the professional man becomes accustomed to conjuring up a picture of physical well-being for the mentally handicapped whenever he uses the term "normalisation," or of the techniques to be developed to perform the various appropriate reactions required for social competence (e.g., social education), is there not a danger that he may overlook the need for creating the necessary attitudes to develop and apply the skills for leading a life of one's own? These skills may not be the natural consequences of simply living in that house in that ordinary street or having a bedroom of one's own to look after. The attitudes permitting these skills to be developed may have to be nurtured quite carefully, and though they will certainly flourish better in those good "normal" environments, their ready and spontaneous acquisition cannot be taken for granted.

If one keeps firmly in mind that "Normalisation" as a goal means for the mentally handicapped the ability and opportunity to satisfy his needs for living a life of his own—and most "normal" people can do this only in a fraction of their daily routine—then the physical aspects of living in the community or in a room of one's own, become merely a means for achieving this result and they may not be the only ones. Knowing the learning difficulties of the mentally handicapped, we must not expect that the mere provision of a "normal environment" as a "means" will automatically produce the desired end of living as a normal human being. In the same way as a fairly a-normal procedure such as systematic behaviour shaping is aiming at producing one particular facet of normal behaviour, it is arguable that other means, besides the popular and fashionable "normal environment," could and should be utilised to achieve the "Normalisation" of the mentally handicapped's life, when he can satisfy his needs in the same way as other people.

Once the term "Normalisation," referring to a goal, is correctly interpreted as giving mentally handicapped people the possibility of living a life of comparative independence within the limitations of their abilities, to live as persons (and why not use a less confusing terminology, such as "personalisation" to signify the real aim?), then professional workers will be less easily forced into a one-track type of action. The means to achieve this desired effect of making people behave more normally, are then not merely limited to creating normal physical conditions—necessary as this is. It may be that "normal" conditions—such as small non-medical units in the open community—are not automatically conducive to reaching the personalisation intent, because the organisational practices are not flexible, permissive and individualised enough to encourage the decision and self-determination processes by the mentally handicapped. It may well be that more thought should be given to how to assist in nurturing such processes than trusting in the beneficial effects of a "normal environment" as such. This may lead to the careful evolving of specific formal and informal teaching methods to give the mentally handicapped a feeling of security when applying his knowledge and expressing his preferences. It may be that, in order to provide as many opportunities for learning how to be oneself, the "normal" environment for the mentally handicapped has to be planned in much detail to give more and better learning opportunities than would be found in an ordinary normal environment.

It appears that "normalisation" regarded as a means, is only one of several components required to achieve our goal. The deliberate manipulation of learning programmes and of learning opportunities provide at least two more components needed for achieving a fertile soil which could help in realising "personalisation."

It looks as if the advocates of "normalisation," when considering it as a means, are oversimplifying the magic of this concept. To achieve what is really intended, it needs more than administrative re-shuffling of the pieces—including making the patient of a hospital into a resident in a hostel. Perhaps, one could begin to think in much broader and imaginative ways by not being spellbound with wrongly interpreted terminology. If there are "normalising" processes—not only consisting of de-institutionalising long-stay patients, but also of developing

people to behave normally—then this might have to be done in a far more deliberate way than has been conceived so far.

It may well be that a completely reformed, educational, non-medical, learning environment governed by therapeutic principles and charged with developing a person so that he can feel at home in ordinary life, may be the setting required for a deliberate normalisation policy. This may be something of an educational institution, where the millstone of over-protective medical/nursing traditions and practices has been removed, to give way to systematic and deliberate development work.

Much of what is being done now is an understandable reaction to the shortcomings of the past. Transferring the problem from one, admittedly completely inadequate setting to another untried one, in the hope that it contains a self-curing potential, seems to be completely inadequate. The undeniable humanitarian improvement brought about by this movement must not disguise the fact that we are probably missing the opportunity for assisting the mentally handicapped over hurdles which he could only master when he trains for them in the same intensive way as "normal" people train for other hurdles. In this sense a residential learning environment—a reformed institution—is not a denial of normalisation seen as a goal, but another, perhaps more effective way for achieving its essence.

**THE BRITISH SOCIETY FOR THE STUDY OF
MENTAL SUBNORMALITY**

NEWSLETTER

Vol. 3 No. 3, March, 1978

contains

Editorial

**Policies for the Mentally Handicapped by the Rt. Hon. Roland
Moyle, M.P., the Minister of Health**

**Dichotomies in Mental Handicap by Douglas A. Spencer, M.B.,
Ch.B., M.R.C.Psych., D.P.M., F.R.S.H.**

The Research Viewpoint by D. G. Race, B.Sc., Ph.D.

Publication Office:

Crnage Hall Hospital, Cranage, Crewe, Cheshire.