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EDITORIAL

The courts in the USA are frequently requested to decide certain issues where in the eyes of the plaintiffs the state had not discharged its duties towards retarded citizens. Recent pronouncements by the USA courts will also be of interest to people in the UK and elsewhere because they could become relevant to developments in care practices generally.

There was, for example, the reaffirmation by the Court of Appeal in Boston stating "that school districts have the responsibility to use new educational methodologies to design a program to meet a specific child's individual needs" even though the School District had argued that this "would divert scarce public financial and personnel resources from other students". This is, of course a most encouraging pronouncement but one wonders whether this progressive approach will also be applied to the case of an adult with mental handicap. In another case a request for an out-of-state placement in a group home was rejected because the "state law guaranteed a right to appropriate care in an adequate placement but not to optimal care in a desired placement," which, of course, leaves open the question what is appropriate and adequate. Is mediocre care in a mediocre placement, adequate? A third example of court decisions is particularly relevant to today's de-institutionalization efforts. In this case the court decided that "institutionalized persons with mental retardation do not have a substantive due process right to habilitation in the community . . . while community placements were desirable, the state had no affirmative duty to expand funds to develop them, since institutionalization was consistent with professional standards of acceptable care." And further, the court stated that treatment "must be determined on an individual basis, not for the group as a class." which sounds a warning bell for those who want to restore rights which were taken away from the large group of mentally handicapped people ⁽¹⁾.

With due respect to the legal mind, the relevant issues are not so much institutionalization and community care but optimal, appropriate, adequate, acceptable care, which - surprise, surprise - could be given in either or both settings, if we were only agreed on what exactly is required. Unless standards of professional care are

defined, standards which include not merely requirements as to number, size, individual bedrooms, pocket money etc. but also statements on developmental objectives, programming, evaluation etc. - the hoped for advantages of community care could *in due course be eroded by the disadvantages of microinstitutionalization*⁽²⁾.

In these times of restricted financial resources, shortages of provisions and staff, and most of all, constantly changing priorities, we must become aware how easily and how quickly the momentum which carried us towards "optimal care" in the community could peter out into "acceptable" care in the community. The aim of "optimal care" is after all not merely to provide better care than was available in institutional surroundings, but to make available the best that professional expertise and knowledge can offer. If we should ever be content with professional standards of "acceptable care" and thereby lose the goal of striving towards optimal practices, we would after all the trauma of the deinstitutionalization policy, arrive finally on a similar level of inadequacy which compelled that upheaval of closing down institutions even though the abuses may not be as glaringly obvious as were illustrated by Blatt's classical condemnation of institutions in "Christmas in Purgatory".⁽³⁾

The move from institution to community was comparatively rapid because of political decisions. It would certainly have taken considerably longer if professionals had carefully tested in pilot studies the pros, cons and hows of such environmental changes. This must be freely admitted, but, nevertheless, those omitted, time consuming scientific contributions and evaluations must not be neglected now, when a stage has been arrived at where one must take stock of what has been achieved so as to make the necessary adjustments to a course which should lead to optimal results rather than only adequate results.

The loose way in which the American courts use the adjectives appropriate, adequate, etc. makes one wonder whether they refer to one agreed standard of care or whether they indicate different levels of professionalism. Why are standards not defined in a way which is widely understood and can be accepted and which would enable a client, e.g. a parent, to make a decision with a good conscience, whether to select the two star facility for his son because it is near his home and has a number of desirable features, rather than the four star facility some considerable distance away. A star system indicates usually only the presence of certain physical features whilst other aspects, such as atmosphere, cleanliness, friendliness depend much on individual expectations and are not easily classifiable. Nevertheless, various features which are objective and factual indirectly imply that the managerial attention is not limited to physical welfare only. Many a parent will be pleased to find that the two star rating assures him that the group home will provide for his son a room of his own and that he can use his TV set there; the two starrating of the workshop indicates that his son will participate in industrial work and that he will be taught to handle simple machinery. Another concerned parent, who has not given up hope that his son could, with professional guidance, learn to enjoy a better quality of life, may study with

increasing enthusiasm the description of three and four star ratings which are conferred only on facilities with a wide range of non-vocational teaching and special programmes to respond to individual needs and which send detailed progress reports regularly to the parental home.

The rare five star rating usually will be best reserved for those set-ups where workshop and grouphome collaborate to design a combined developmental programme which is discussed and formalised by both facilities, recorded and evaluated as a cooperative task, and in which parents, relations and friends are asked to participate.

The professional literature provides quite a few examples of what are in fact unofficial star ratings of residential facilities and Adult Training Centres (Social Education Centres). Such rating systems, designed for professional purpose and research are able to screen out inadequate, unattractive and obnoxious places, in short succeed in sifting the chaff from the wheat. Yet, since the time when these methods were first developed, we seem to have come to a standstill, because we accept all types and grades of wheat and assume that the "right type" will evolve in due course. This approach may well result in an "acceptable" minimum level of physical care, but is not inductive to the furtherance of personal development. The absence of comprehensive and specific operational philosophies which are applicable to residential and vocational facilities, to management and frontline staff, and which demand commitments to specific actions and requirements, make it impossible at present to clarify what can reasonably be expected from an "adequate" not to mention an "optimal" placement. Once the multidisciplinary profession has agreed on goals and conditions essential for providing a suitable framework for developing people with a mental handicap, a simple star system might help in introducing and maintaining the best aspects of professional competition in this field. Such competition may not be all that bad, because although enthusiasm and devotion by themselves will carry saints a long way, few of us are made that way so as to last us a professional lifetime.

H. C. G.

1. Examples quoted from recent issues of "NEWS & NOTES", Vol. 2, No. 6: Vol. 3, No. 1, No. 3 AAMR, Washington. (*BJMS Editor's italics*)
2. J. Sinson, (1990). Microinstitutionalization? *Brit. Journal of Mental Subnormality*, XXXVI, 2, 71, pages 77-86.
3. B. Blatt and F. Kaplan (1966). *Christmas in Purgatory: a photographic essay on mental retardation*. Allyn and Bacon, Boston, Massachusetts.

P.S. The BSSMS has arranged in conjunction with the Walsall Community Health Council a one-day Symposium about "WHO WILL CARE?". This will provide a platform for parents to voice their concern for the future of their children and whether the community provisions or a kind of institutional provision offers "optimal care". It will also give an opportunity of studying in some detail the working of the

Community Mental Health Care Teams and of the "New Look Institutions". Finally the Managers of Services will outline, in the light of the preceding statements, their own plans for the particular area of Walsall (see announcement on page 66).

Attention is also drawn to another project by the BSSMS (see announcement on p67) calling for papers on "Longitudinal Studies". Professional work can not be carried out without evaluating the effectiveness of the approaches and treatments which *have to be studied and corrected as the need arises. Longitudinal research helps to ensure control and accountability in an area where there is still much uncertainty about the most effective means to help individual people.*

WHO WILL CARE?

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