

The British Journal of DEVELOPMENTAL DISABILITIES

formerly "The British Journal of Mental Subnormality"

Editor: H. C. GUNZBURG

Vol. XXXIX, Part 2

JULY 1993

No. 77

EDITORIAL

Since the sixties the number of beds in UK hospitals for mentally handicapped people has dropped significantly, possibly by more than 50 per cent, due to handing over "patients" to care arrangements in the community. That this changeover has been often hasty and ill prepared, thereby producing unnecessary problems and hardships, is scarcely contended nowadays. Yet, on the whole, the new policy is a basis for creating opportunities to improve the quality of life for thousands of former custodial patients and has generally been exploited as such to varying degrees.

The success of the new policy has not been achieved without casualties. People, who, on account of inadequate preparation and missing support, can not adjust to the new demands made on them, are worse off than before. They are unable to adopt by themselves a conventional mode of living, being used to the safety net of institutionalization which is now no longer an easy option. They are seen lost and lonely in the big towns, roaming aimlessly in the streets, scavenging dustbins, looking for warmth and rest in the readingrooms of public libraries and, unwashed and uncared for, present a picture of misery. Some residents in grouphomes display such asocial behaviour that they disturb seriously the peaceful life of their peers so that their further stay can not be tolerated because dealing with their "challenging behaviour" requires particular expertise and special measures for which staff have generally neither time nor training.

This minority of mentally handicapped people with their special needs has to take its place in a long queue of other deserving cases who all cry out for attention. However, in the difficult economic situation of today not much of the financial cake is left for the individual services suitable for persons with challenging behaviour or mental health needs. After their basic requirements for shelter, food and occupation have been met they are no longer a top priority. It requires much political clout to obtain the necessary treatments for their problems, that little bit of extra which makes the difference between indifferent and optimal "treatment".

Gradually, the full implications of having to deal outside the framework of hospital provisions adequately with highly vulnerable human beings have become

clearer. The blanket term "Mental Handicap" which simplifies unduly the complexity of the situation relates, after all, to a great number of people with various problems of different etiological origin. One might wonder whether it is justified to smooth over the complexity of the task by disguising its true nature when referring to it as merely being one of "learning disability". This innocuous underdescription reminds the public only of the poor chap at the back of the classroom, who is a bit slow, but is not much of a problem once he has left school. And if some of these "learning disabilities" people also display "challenging behaviour", surely this would only refer to playing truant, perhaps being a bully outside the classroom and provoking the teacher.

The problems of that minority group are, however, more serious than those labels suggest. Some 95% of admissions to mental handicap hospitals today are their own former patients, who can not adjust to life in the open community with the kind and amount of help and support they can get now.

From this point of view one must warmly welcome the Ministry's acceptance that it is "crucial to the success of our community care policy for people with learning disabilities, . . . how well we meet the needs of people with learning disabilities *and* behaviour disturbance or mental health needs". This makes it at last clear that the *successful integration of mentally handicapped people depends on treating those of them who display also very disturbing behaviour and could be mentally ill*. As the Minister says: "If we don't address these needs properly, this group can occupy disproportionate amounts of time and money. Distress can be caused to the individuals themselves, to their relatives and carers. It can also prejudice people against having people with learning disabilities as their neighbours or, indeed, within the community generally".

The reorganization of the Health and Social Services in the UK according to the principles of a free market economy and the general aim of striving for "value for money spent" on treatment raises the question how to obtain for this small minority group the very individualized treatment to meet their *and* the community's other needs adequately. This is a question of ordering a la carte rather than a menu or, in other words, a more expensive individually prepared meal rather than the mass produced meal of the day, which may be perfectly adequate for most, but does not agree with everyone.

The choice will in most cases be influenced, whether in the restaurant or in the health and social services, consciously or unconsciously, by financial considerations. A manager administering a limited budget and having to satisfy legal, social, humanitarian and professional demands, requires not only much political skill but also a thorough appreciation of the issues involved and of the ethical principles affected by a "value for money" managerial policy.

To provide guidelines for those who, as commissioners i.e. managers, have to organize local services for people with challenging behaviour, the minister appointed the "Mansell Committee" which very wisely did not simply consult particular experts

but was itself constituted of representatives of four services which had specialized in facing the very issues posed by this small minority of problem cases. One could expect that these people with their practical experience should be able to elucidate common aspects, practices, and approaches which could solve or at least reduce the difficulties mentally handicapped people find in fitting into the community, difficulties which are at present beyond the competence of ordinary community services.

The recommendations of the Mansell committee are numerous but perhaps the most significant statement which is applicable to all resource hungry services is the sentence "the key to the difference between good and indifferent community services lies not in resources, but in the quality of management". The very first introductory statement in their Guidance for commissioners emphasizes therefore "Commitment" to developing good quality local services. The presence of commitment in all professional services can not be taken for granted. This has been commented on here (see e.g. Editorial, January, 1992, No. 74) and elsewhere and the Mansell report recounts that "Many people . . . expressed anxiety that . . . commitment was diminishing".

Commitment to improving responsiveness to the needs of mentally handicapped people is a good, sound and promising basic principle for creating the right climate for service delivery. If effectively put into operation it will take care of many of those "problem cases" who are, at present, passed on to others as being beyond the competence of ordinary community services. There will, of course, even after making ordinary provisions more efficient, be a hard but less numerous core of people "with challenging behaviours or mental health needs" who require specialist treatment. Research and experience indicate that their problems can be dealt with and the evidence suggests "that these services are not more expensive than the higher priced institutional placements". Commissioners, however, will not fail noticing the qualification "higher priced institutional placement" although they are also assured that this is preferable to the much poorer outcomes achieved in low-staffed hospitals or private homes.

The weakness in applying the concept of individual care within a market oriented system, which aims at purchasing the best value for money, is that the purchaser has to decide what is the best value. The commissioners, the managers will always be faced not only with the task of setting aside from their limited largesse for deserving minority groups such as drug addicts, battered wives, children in care, people without homes, etc. but also with having to decide between the optimal best recommended good services and those services which fulfill laid down minimum requirements and which they may be just able to afford. Can one really expect that management generally will purchase those good quality services claiming unspecified long term gains when there are available perfectly acceptable, lower cost services delivering physical care and attractive living accommodation at a time, when there is tremendous demand and pressure for the improvement of acute services?

The diagnosis has been made "officially": there is a minority group of people whose needs have not been met adequately and who will cause unnecessary extra problems if not dealt with.

The prescription has been issued "officially": A commitment by policy-makers and senior management to give priority to **good quality** local services will not only achieve marked improvement in the present situation but also avoid a constant worsening of community care in the near future. The consequences of inadequate community care have been described by the committee as: hurt to users, carers and staff; struggling carers left alone; demoralization of staff; increased risk of abuse; bad care practices; crises and placement breakdowns; "silting up" of special services; less control and choice of services; lower efficiency; public criticism; and reinstitutionalization - a scenario easy to visualize.

There remains the taking of the medicine "even if this diverted some management attention from acute services". The ministry is setting up an "implementation working group" whose role "would be strategic, keeping the issue on the agenda of those responsible for planning and commissioning services, and identifying ways of removing any potential blocks to progress". It will, however, be left entirely to the commissioners whether they accept the necessity of committing themselves to policies which secure a reasonably good future for social and health services by setting aside resources for long term aims and diminishing thereby perhaps their ability to respond fully to short term pressing demands and unforeseen crises. How will they decide where there is "value for money"?

H. C. Gunzburg

All quotations have been taken from:

The Health Minister's speech for Mansell Report launch on 2nd February, 1993 (GM00527.01/1).

Report on Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs, HMSO 1993.