

## POINT OF VIEW

### The Right to Training

The Government's White Paper "Care in the Community"<sup>(1)</sup> is a continuation of a policy trend from "Better Services for the Mentally Handicapped"<sup>(2)</sup> onwards towards achieving the discharge of mentally handicapped people from long stay hospitals. *Community care* has, up to now, been largely a slogan in relation to the mentally handicapped and ironically for those mentally handicapped people who have moved to the community much of the care provided in hostels has been custodial in nature. Community care has been in reality a change of location rather than a change in caring practices. The move to the community has not been informed by an educative ideology but by a continuation of the notion of medical symptomatology: "We are observing this phenomenon strikingly in many human service settings today, such as in the effort to de-institutionalise, when the basic value which has led to the creation of institutions still persists. In such instances, de-institutionalisation only returns to equally bad or even worse dumping and destruction of people in the community."<sup>(3)</sup>

The prevailing ideology is often the same. It is simply that those sent to the community do not have symptoms which are severe enough to warrant hospital care. Ironically, some of the most progressive training developments have happened in subnormality hospitals. By contrast, the traditional hostel can often seem to have little to offer. One of us has argued earlier<sup>(4)</sup> that there is nothing inevitable in this but rather that it is the lack of a working alternative which inhibits improvements in the existing services in Great Britain. In addition there has been little of the activism associated with service development in countries such as the United States which forces people to define much more clearly what it is they wish to put in place of the form of care to which they are opposed. In Great Britain policy initiatives have been largely characterised by assimilated drift. This lack of clarity about the objectives of community care for the mentally handicapped in Great Britain has led to the notion of the "care continuum", with the move from hospital to hostel being the 'transfer of the fittest'.

### COURT ACTION

Parents groups and other pressures groups have used Court action to highlight the conditions in institutions in the United States in a way which has not been attempted in Britain on any large scale. In Britain, it is conventional to think of the Law in terms of using the existing legislation or in terms of pursuing new legislation for the benefit of consumers. In the United States the use of Law Suits to achieve developments in services is much more common. Of course this trend mirrors the proliferation of the Law in all aspects of life in the United States. Pressure groups in the United States have used the courts as a mechanism to take power away from structures which have abused it in the past.

Geraldo Rivera of ABC News made a film in 1975 which exposed the appalling conditions of Willowbrook State Hospital on Staten Island, New York. This was the beginning of a long campaign of publicity and court action in what came to be known as the "Willowbrook Deinstitutionalisation Suit".

There is a growing awareness in the welfare field in the United States that the Law is not a neutral arbiter but rather that it has an ideological basis. Welfare pressure groups have attempted to expose the ideological basis of specific laws and have moved away from an orientation to the Law as solely concerned with technical problem-solving to challenging

the existence of laws which many would regard as culturally normative. They have sought laws which are based on "unequivocal written statements of service ideology".<sup>(3)</sup> In other words there is an insistence that the law should embody not just order but also justice. This approach to the law is part of a particularly American liberal tradition. The law is regarded as capable of creating favourable pre-conditions for service development and of enabling funds to be appropriated. It is an approach to the law which means that ideologies have to be overtly stated.

The Willowbrook deinstitutionalisation suit established the principle that patients should be returned to the community. State funds were made available to develop alternatives. The Community Resource Centre of the South Bronx, opened by its Director, Sister Barbara Eirich, began to set up "Intermediate Care Facilities", including one in Harlem, Taino. Taino caters for the lowest functioning mentally handicapped people in Harlem. Taino turns on its head the conventional notion that only the most able patients can be considered for discharge from long-stay hospitals by *deliberately* selecting the most severely handicapped patients for any vacancies which arise. By adopting this policy, Taino has dispelled the myth of the need for subnormality hospitals at all.

Surprisingly, Taino has achieved this by using unqualified staff, recruited locally, who are known as "direct care counsellors". There are three residents to one counsellor at any one time, except on outside trips when the ratio is one-to-one. During the Summer E.S.N. teenagers are employed on a special programme and other workers seem to just drift in. For instance, a deaf and dumb man did odd jobs and drove Taino's mini-bus while we were there. His brother was able to interpret for him when communication was difficult and both of them appeared to be valued team members.

The unqualified staff are backed up by a "clinical team". The team consists of two psychologists (working shifts), a Physiotherapist, a Speech Therapist, a Health Care Co-ordinator (Qualified Nurse) and a Social Worker to maintain contact between residents and their families.

Taino's philosophy of care is based on normalization. All of the service providers believed that mentally handicapped people had the right to a *full* life in the community, not just to be *located* in the community, whatever their degree of functioning. The Taino staff strive for maximum physical and social integration. The surrounding community is involved as much as possible. On our visit to Taino, a local hairdresser was there to discuss how each resident could visit his salon for individual hair styling, an illustration of Taino's commitment to the specific needs of individual residents.

In their day-to-day work the staff use goal planning techniques. All staff at Taino are given training in this approach. There is an interval review every three months on each resident, attended by the whole clinical team and the relevant direct care counsellors. At the interval review the strengths and needs of the residents are discussed in detail. Each resident's needs are listed in priority order and goals are planned for the next three months. The unqualified direct care counsellors appear to be competently running individual programmes for each resident, with the help of consultation from the clinical team. The goal plans<sup>(4)</sup> are developed within three general rules laid down by New York State:

- no negative reinforcement.
- no physical restraint
- no restraint by drugs (drugs may be prescribed for medical conditions only)

Asked for his comment on how these rules affected the work of Taino, Miguel Sanchez, Head of the Facility, said approvingly "We have no option but to look for alternative, more positive methods of dealing with what might normally be defined as problem behaviour". For instance, self-mutilation has to be replaced by other sorts of behaviour rather than being simply restrained. Aggression is channelled into large inflatables.

The State's rules stipulated that if a resident achieved a goal, a new programme had to be worked out within a month. A State survey team visited annually to ensure the rules were being adhered to and reviewed the total care for all residents from goal plans to the fabric of the building. Any deficiencies had to be put right within 30 days.

It would be wrong to give the impression that Taino is characterised exclusively by an emphasis on technical competence. The staff of the Community Re-source Centre talk openly about their personal and social values, about accepting the norms of life in Harlem and the Bronx. They seem to reach an understanding of themselves through their work and are open about the impact of their work on them.<sup>(5)</sup>

This was a refreshing change compared to our experience of many residential establishments in Britain. But, as one Canadian publication states: "In human services, hardly any measure can succeed if its rationale is not deeply accepted by those who must carry out a policy. For instance, a human service will never be normalising if those who provide it attempt to implement normalising measures on a check-list basis, rather than on a basis of their own deep understanding of and commitment to the underlying values and rationales. In the absence of this commitment, the tactical motions remain just that; superficial and empty motions which grind wheels aimlessly and futilely, and which may merely result in replacement of one non-functional technology with another."<sup>(3)</sup>

One example of the "deep acceptance" of the rationale of normalisation by the Taino staff is their attitude to physical deformity. Coming from Britain we had always taken for granted the inevitability of distorted and twisted limbs when visiting large institutions. Taino staff were not so acquiescent when they received their residents from Willowbrook. Tony, one of the residents, was receiving surgery on his hands with the promise of an electric wheelchair if he worked on manual dexterity. Some residents with athetoid spasms had individually designed, moulded polystyrene chairs in order for them to be able to sit upright in the position that was uniquely comfortable for them. Other residents had aids to enable them to stand up. No resident was written off because of physical deformity. If a resident could not participate in communal craftwork, staff members worked with them using hand-over-hand techniques. This emphasized the need for individual work as a necessary pre-requisite for group work in which all can participate, regardless of their degree of disability.

We should be wary of making the assumption that it is the principle of State Purchase of Services<sup>(6)</sup> which makes Taino progressive. While this allows imaginative, innovative projects like Taino, it also allows wide differences in style, values and practice. It also results in substantially different proportions of services from one State to the next. The flexibility of response of the independent sector, which is often hailed as the benefit of State purchase, is therefore both a pro and a con. In the case of Taino it has proved progressive. Taino sets high standards of service, with a high input of voluntary help from the local community to the most disadvantaged. However, the argument that a State purchase agency has to be more responsive to consumer need than a public agency is dubious. The independent sector can be rigid. It can provide every conventional, traditional services.

However, with economic retrenchment continuing it could be that we too will have to campaign much more vigorously for the right of mentally handicapped people to treatment and as a consequence may have to be much more specific about not just the level of service that is needed, and whether it should be in hospital or the community, but also about the content of the care that is required.

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#### REFERENCES

- 1) D.H.S.S. (1981) *Care in the Community: A Consultative Document on Moving Resources for Care in*
- 2) H.M.S.O. (1971) *Better Services for the Mentally Handicapped* Cmnd. 4683.
- 3) Canadian Association for the Mentally Retarded (1976) *The Limitations of the Law in Human Services.*
- 4) HARRIS, J., (1981) *From Tender Loving Care to Training.* British Journal of Mental Subnormality. December.
- 5) This is a point made by observers of some other American agencies. See, for example, Campaign for the Mentally Handicapped (1978) *E.N.C.O.R. — A Way Ahead.*
- 6) For a discussion of State Purchase, see UTTING, B., (1982) *Personal Care by Government Purchase Social Work Service.* Autumn.