

Chapter 9 (In 'Cabbage Syndrome': The social construction of dependence, Colin Barnes (1990) The Falmer Press, pp. 194-203)

Summary and Conclusion

Introduction

This study was undertaken against a background of increasing awareness of the extreme socio/ economic disadvantage experienced by young people with physical impairments, the general criticisms levelled at professional helpers engaged in the process of rehabilitation, the emergent demands by some sections of the disabled population for increased participation in, or control of, services which purport to cater for their needs and the general lack of empirical research in day centres for the younger physically impaired. In this conclusion I shall first summarise the implications of findings in respect of the three principal themes outlined in Chapter One, namely, the role of the day centre for the younger physically impaired, the nature of the helper/helped relationship within the day centre environment, and the extent of user participation and control. I shall then outline a number of policy recommendations which relate to both the day centres studied and provision generally for this particular user group. I conclude that current policies which effectively disable young people with impairments are no longer simply morally unacceptable. They are economically inept.

Summary and Implications

From the data collected during participant observation it was evident that the Contact group provided a range of services and activities which gave many of the users a degree of autonomy and independence unavailable in the community at large. It was also clear that a minority of the relatively moderately impaired contact members who no longer needed those services would stop using the centres while the majority would not. In addition, because the facilities within the Contact framework were limited in their capacity to provide these young people with the necessary motivation, skills, and opportunities to achieve the same levels of autonomy and independence outside the centres as well as in, it was also evident that their attendance would almost certainly be long-term and that as a result their already substantial disadvantage would be compounded, if only because of the stigma generally associated with day centre use.

Although the evidence presented in Chapter Eight reported that there had been a number of important changes in the day centres after the main study was completed, I do not believe that they undermine this general conclusion. Indeed, the majority of the users still using the service in 1989 were unlikely to benefit from the expansion of services subsequent to participant observation, given the substantial limitations of the new Resource Centre. These include the general role of the new unit, which broadly speaking is analogous to that adopted by the Contact group emphasizing the social over the re/habilitative aspects of day centre use, its admissions and transport policies and most importantly, its size and location. I suggested that rather than making integration into the community easier these considerations are likely to make it more problematic. Moreover, since the experience of many of the users outside the day centre environment is limited to the family home, partial institutionalization, whereby users come to accept that life outside the domestic sphere is limited and preferable in an institutional setting, is also likely to ensue. This has particular significance for the user group studied, those aged between 16 and 30, since many are disproportionately dependent upon ageing parents or guardians. Consequently, there is a very real danger that partial institutionalization may lead to institutionalization proper, where users come to accept that for people with impairments life inside an institutional setting is both acceptable and inevitable.

Moreover, while it may be true that due to the degree of oppression experienced by young people with disabilities, the voluntary nature of day centre use and the general lack of resources in this type of provision, partial if not total institutionalization is to some degree unavoidable for many, these tendencies have serious negative implications for both the users concerned and policy-makers generally. Besides being contrary to the users' best interests, since most of the available data regarding this issue suggests that individuals with impairments prefer to live in a domestic environment rather than a residential setting, this runs counter to the general ethos of community care which is to ensure that people are 'helped to stay in their own homes for as long as possible' (Griffiths, 1988, p. 28). The tendencies towards institutionalization have particular significance for policy makers, both at the local and national levels, who are charged with the responsibility for the provision of services for the growing numbers of younger people with impairments.

One solution to this problem, suggested by one of the staff who took part in the study, would be to abolish day centre provision completely for this particular user group. However, besides being unacceptable to the general

population (West *et al.*, 1984), particularly those with first-hand experience of disability, any social and economic gains made by such a policy are only likely to be short-term, given the disabling effects of the social isolation experienced by many young people with impairments and the inevitable consequences for informal carers. Such a policy is likely to stimulate a greater demand for residential care rather than less and relatively sooner rather than later.

Moreover, in view of the apparent divisions among the younger impaired it may be argued that no single solution is possible and that there needs to be a range of options provided. Apart from the problem of who should decide which of the options is most suitable for potential users, such a policy would encourage differentiation, perpetuate ambiguity and do relatively little to promote integration.

A more acceptable approach would be for day centres to adopt a more pragmatic approach to rehabilitation and integration similar to that advocated by Kent *et al.* (1984). But while there have been tentative moves in this direction by some local authorities, the general perception of day centres remains ambivalent. Consequently there needs to be a definite clarification of the day centre role. I believe this can only be achieved by the formulation of a consistent and coherent national policy which provides the appropriate resources and impetus to determine a shift away from philosophies of 'warehousing' and 'enlightened guardianship' toward 'horticulturalism' and 'disabled action'.

It has been shown elsewhere that because the traditional or 'warehousing' approach to day centre management is founded upon essentially negative views of people with impairments, it provides little more than a respite for informal carers and a forum where people with impairments can meet others in a similar situation (Kent *et al.*, 1984). As noted earlier, while these are important goals, they do little to promote user independence and integration.

On the other hand, while this study demonstrates clearly the main strengths of 'enlightened guardianship' in providing a variety of facilities within a limited set of resources and giving users a degree of individual autonomy, it also brings into focus the fundamental weaknesses of this approach, namely, that its scope for providing users with the skills and opportunities to achieve higher levels of self-determination outside the day centre context is restricted to the most able.

Because 'enlightened guardianship' as we observed to operate in the Contact group is founded on both negative and positive perceptions of impairment and incorporates both 'warehousing' and 'horticulturalism', its objectives are vague and lack clear direction. Consequently, although the facilities provided within Contact included both social pastimes and rehabilitative activities, there was relatively little scope for staff guidance. This has particular significance for young people with impairments, especially those congenitally impaired whose experience of life outside the family home and/ or institutional settings is severely limited and whose motivation, aspirations and expectations regarding self-determination are already low. It is also accepted by many that a lack of direction is contrary to their needs. For example, in their study of adolescence and physical disability Anderson and Clarke stated

What the young people lack is the continued guidance and support which they need throughout the later years in school and in the post school period, to help them understand what opportunities are in reality available, not so they merely accept passively the low status society often offers but so they can begin to construct for themselves a satisfactory life, despite the problems posed by the handicap and society's response to it (Anderson and Clarke, 1982, p. 353).

As a result of this lack of direction, it may be said that 'enlightened guardianship' encourages users, albeit implicitly, to accept passively their disadvantaged status. Moreover, while this ideology acknowledges the drives for independence and autonomy, the boundaries for achieving these goals are determined by 'able-bodied' reality. And since able-bodied reality oppresses people with impairments, autonomy and independence are generally restricted to the confines of the day centre. This was clearly evident by the degree of freedom users had within the centres and the constraints imposed on them outside.

Because 'enlightened guardianship' incorporates negative and positive perceptions of the disabled and accepts the needs of both the dependent and the not so dependent, there are inherent contradictions in this ideology which inevitably undermine any progress towards user participation and control. This was elaborated in Chapter Six. As a result 'enlightened guardianship' has inherent coercive and controlling overtones which, although absent during participant observation, came into play subsequently when a number of users were 'directed' elsewhere, some, albeit a minority, against their will.

In addition, because 'enlightened guardianship' encompasses notions of 'significant living without work', a concept which is reserved almost exclusively for the impaired, in a world where work determines both economic and social status, day centre use inculcates in many people the seeds of a descending spiral of personal expectations and self-esteem which is difficult to break. Although the deleterious effects of this process were alleviated to some degree by the changes which took place in the centres during 1988-89, it is probable that they will re-emerge when the novelty of these changes wears off. The only way this and the other problems outlined above might be resolved within the day centre context is by the complete abolition of this approach in favour of a shift toward 'horticulturalism' and, where possible, user control.

As noted earlier 'horticulturalism' is founded on perceptions of people with impairments as 'really normal'. It is favoured by both rehabilitation professionals and representatives of the 'disabled population' from both the left and the right of the political spectrum. Its aim is self-determination and independence, which for people with impairments is generally taken to mean the ability to devise and control their own lives in exactly the same way as does the rest of society (Brisenden, 1986).

Within this frame of reference the primary aims of day centres must be to provide users with access to a range of facilities, including 'social rehabilitation' (Henshall, 1985) and careers opportunities which enable people with impairments to live in the community and promote integration. Consequently, day services would have a specified positive role and day centre attendance a specified purpose.

Such an approach does not, however, ignore the fact that within the present societal context complete rehabilitation may not be possible for all day centre users. But while some may be rehabilitated and use the centres as a jumping-off point for a fuller integration, those who remain would be encouraged to promote the needs of people with disabilities in able-bodied society and thus work toward changing that society.

While 'horticulturalism' places an emphasis on skill acquisition, participation and a definite shift away from passive inactivity, it does not deny users access to social or leisure pursuits. This is an important point considering the level of loneliness experienced by many people with impairments. The incorporation of social pursuits follows firstly from the fact that social interaction occurs in most forms of human activity and the debilitating effects of social isolation can just as easily be offset by activities with a didactic content as they can by those without, secondly, that leisure pursuits are appreciated far more if they are experienced in conjunction with non-leisure activities, and finally, that many so-called leisure activities have an implicitly therapeutic content, particularly for those whose education was lacking and whose experience is limited. On the other hand, 'horticulturalism' may involve a number of problems associated with the helper/helped relationship. But I believe they are less apparent within the context of the day centre.

Critics of 'horticulturalism' might contend that professional intervention impedes individual adaptation and innovation and compounds disability. But in view of the fact that day centres are generally viewed as 'dumping grounds' for the 'no hopers', it is difficult to see how this argument applies, unless it is related to professional non-involvement. It is generally acknowledged that there is a paucity of professionals specifically concerned with rehabilitation in the day centre service. In keeping with other research in this field, the findings of this study suggest that there is an urgent need for more professional involvement rather than less, particularly from the careers services.

Because day centre personnel and the users live in the local community, staff are not subject to the same level of emotional pressure as those in other sections of the caring industry such as residential institutions. Moreover, since the overwhelming majority of day centre workers are from similar socio-economic backgrounds to those of day centre users, there is usually less of a social barrier between the two. With only two exceptions, this is clearly evident in this study. In addition, since day centre use is explicitly voluntary there is an element of interdependence and reciprocity between the helper and the helped in the day centre context, which might not be present in other institutional settings. Staff are less able to exert excessive pressure on users in order to achieve.

However, due to external factors such as poor education and limited opportunities user motivation is likely to be a problem for realization of the horticultural approach. This might diminish if day centre attendance is able

to offer more than simply child-like dependence and semi-confinement. Motivation would probably also increase if users participate in the services they use. As Brimblecomb has suggested, 'if there is participation by the consumers in the running and development of services, motivation is likely to be higher' (Brimblecomb *et al.*, 198:5, p. 120). Consequently, participation in the general running of day services must be a necessary prerequisite of attendance. Moreover, since participation often stimulates a desire for control, 'horticulturalism' is far more likely to stimulate 'disabled action' than either 'warehousing' or 'enlightened guardianship'. Consequently, it is likely that in many cases the dominance of the 'horticultural' approach will be relatively short-lived. However, because of the emphasis placed on self-determination and independence by 'horticulturalism' there is an inherent danger that debilitating psychological consequences might ensue for those people who cannot achieve them. While this is an important and valid point, much of the problem can be averted by adequate and appropriate consultation between the helper and the helped, where realistically attainable goals are mutually agreed, and if day services have sufficient resources, both human and material, to achieve them.

Due to the degree of oppression faced by people with impairments, it may be argued that any serious thoughts of their complete rehabilitation are futile. I believe that this view is unacceptable within the day centre context. Moreover, while at the present juncture there is little cause for optimism in this regard, particularly at the national level and that many policies which pursue this aim are limited, there is some light at the end of the tunnel. This takes the form of the unprecedented politicization of some sections of the 'disabled' population and the recent rapid expansion of self-help groups, and their subsequent achievements at the local level (see Chapter Six). Any philosophy of rehabilitation must generate this type of self-help and political involvement. As this study has clearly shown, 'enlightened guardianship' is incapable of doing this. 'Horticulturalism', on the other hand, is not.

The following section outlines a number of recommendations which I believe are necessary if day services for the younger physically impaired are to move in this direction. They draw on the observations made during this study and the work of other writers in the field, notably Carter (1981) and Kent *et al.* (1984).

Recommendations

As noted earlier there is a need for a clear national policy and planning framework for day services for the physically impaired. If this framework is to adopt the general approach outlined above then it must include the following objectives.

- 1 Day centres must provide the facilities and services for 'social rehabilitation' (Henshall, 1985) for those who require it.
The appropriate facilities should be available for users to learn the practical skills needed to cope with impairment themselves rather than depend on others. Staff should encourage and assist users to develop necessary social and intellectual skills, including the ability to organize their own lives, make their own decisions, and function within the community.
- 2 Day centre users can and should be encouraged to participate in the general running and organization of the facilities and services they use within the day centre environment.
This should include self-help and mutual support, routine maintenance, preparation of food, stock control, finance, and the organization and deployment of staff. Opportunities for users to become helpers should be enthusiastically supported by the sponsors of the day services, and there should be a clearly defined, appropriate training programme and promotion ladder for users to rise within the system for those who seek it.
- 3 User participation and mechanisms for user participation in day centre policy making should be mandatory, and should be organized around a formal constitution which stipulates users' rights as well as their responsibilities.
The contents of this document should be arrived at by mutual agreement between users and staff. It should be based on democratic principles which guard against factionalism, misrepresentation and excessive paternalism by those with authority. Representative bodies should be periodically elected and accountable to the users as well as the management.
- 4 Day centres must provide information, advice and counselling services, both for users and their families.
There is an increasing tendency for local authorities to view day centres as resource centres for people with disabilities (Jordan,

1986). The importance of this function was clearly evident in this study. However, users should be encouraged to take responsibility for the collection and delivery of these services.

- 5 There should be effective and efficient cooperation between day centre staff and agencies concerned with rehabilitation. This proposal will require a radical reappraisal of professional perceptions of day services and their primary function. It is apparent from most of the literature as well as the data provided by this study that most agencies, particularly careers services, view day centres as 'dumping grounds' for the 'cabbages' and 'no hoppers' who are forgotten once attendance begins. This is clearly not in the users' best interests. If individually structured programmes geared toward independence training are to be provided within a day centre setting then it is essential that professional involvement, if and when required, is properly planned and coordinated.
- 6 Day services must identify and try to break down the barriers to integration which confront people with impairments in the local area. Day centres must become more outward looking and actively promote understanding and integration within the local community (Kent *et al.*, 1984). Where possible this should include (a) the adoption of an open door policy, (b) the regular provision of practical services for other sections of the community, (c) active opposition by users and staff to localized barriers to integration, and (d) facilities within units for educating families and other informal carers to the needs of individuals with physical impairments.
 - (a) Day services should not be exclusive to one section of the local community.

The idea that day centres for the impaired should be used by the non-impaired has been suggested by several authorities on this subject (for example Tuckey and Tuckey, 1981) and was enthusiastically endorsed by all the user respondents and all the care assistants who took part in this study. Senior staff, however, took a more cautious approach, arguing that if day centres adopted this policy then care must be taken to ensure that the needs of users with impairments were not overlooked. This could be achieved by the inclusion of written safeguards in the formal constitution similar to those adopted by the Stonehouse at Corby in 1985 (Carr, 1987).

While there is general agreement that the needs of younger users are different to those of the elderly, user status should not be dependent on age. But care must be taken to avoid swamping by one particular age group.

Although admission policies dependent on age have definite advantages in terms of user induction and heightened social interaction, there are latent disadvantages to this policy which were apparent during this study. Some users did not wish to leave the Contact group when they reached the prerequisite age limit. And there is no reason to suppose that this would not occur at the new Resource Centre.

- (b) If the status of people with impairments is to change then they must be seen to be making a practical contribution to the local community rather than simply consumers of resources (Kent *et al.*, 1984).

To help achieve this, and also enhance user self-esteem, day services and day centre users should seek to provide practical services for other sections of the community. Users at the Stonehouse, for example, ran a toy library for users and local residents (Tuckey and Tuckey, 1981).

Many of the users in the Contact group, both males and females, expressed a desire to work with children and/or animals. With a little help and training there is no reason why they should not be involved in a day- centre-based childminding service or creche or short-term pets' boarding kennels. It is important to note that the primary motivation behind these activities should not be economic, but any income generated from these or similar enterprises could be used to supplement the centre's funds.

- (c) If environmental, economic and social obstacles to integration at the local level are to be overcome, users and staff must promote programmes designed to change public perceptions of day services and those who use them.

More emphasis must be placed on activities which go out into the community and change people's attitudes and understanding (Kent and Massie, 1981). The music and drama group's successful attempt to entertain children in a local nursery provides a good example of

this type of strategy. Users should also be encouraged to form self-help groups which take a more active role in local affairs and lobby local authorities and other institutions for the removal of barriers which preclude people with impairments.

- (d) Facilities should be provided by and within centres to educate families and other informal carers to the needs of people with impairments.

This is particularly important with reference to the problem of parental over-protectiveness, a problem which was so apparent for many of the users in this study. It is pointless people learning social and life skills for use outside the centres if they only get the chance to practice them in an institutional setting.

- 7 Sponsoring agencies should ensure that buildings used for day centres are an integral part of the local community rather than apart from it.

Large centres situated close to, or in the grounds of, other segregated institutions such as the Alf Morris complex or the Resource Centre should be abandoned in favour of smaller centrally located units similar to Dortmund Square which are close to local amenities and shops. While there are clear advantages in large centres because of the range of services they offer there is the danger that over-provision discourages users from using facilities available to the general public (Carter, 1981). This is contrary to the general principle of integration.

- 8 Day centre staff should receive a salary in accordance with their skills and responsibilities.

In accord with trends in other areas of social provision this study shows that the level of professional training among senior day centre personnel was relatively high and the training programme for CAs has been recently improved. Although all these workers were happy with the work they were doing, they were concerned about the inadequacy of their salaries. This was particularly applicable to the CAs, whose gross income during the study period was less than the net income of the average day centre user. If day services are to recruit and maintain a dedicated and proficient workforce then they should receive the appropriate re-muneration for the job.

Day centre transport should be flexible and subject to users' needs, rather than those of a central authority.

The policy of transporting users to and from day centres in large specially adapted stigmatizing vehicles at specific times of the day should be abandoned in favour of policies which transfer control to the individual user. To some degree this had been achieved in the Contact group by the policy of using a local taxi firm, although the choice of taxi was determined by the Local Authority. Alternatively users could be given a grant for transport which gave them complete freedom of choice.

If large specially adapted vehicles are required for group outings, then control must rest with day centre management committees and not with a centralized transport office. This control should include the type of vehicle chosen as well as its appearance.

In areas where public transport facilities include the smaller 'Access' type minibuses which offer a far more flexible service because they have no specific routes or timetables, day centre management committees should liaise with bus companies so that users reliant on public transport are adequately catered for in terms of getting to and from the centres.

10. In accordance with the recommendation of the Griffiths report on community care (Griffiths, 1988) sufficient funding should be provided by central government to enable local authorities to provide adequate and appropriate day services within the local community.

Whether or not local authorities run the services themselves or look to the private sector for this function, they should take a broad view when evaluating the cost effectiveness of day care provision and recognise that it makes good economic sense as well as being socially desirable to provide services which encourage personal autonomy for disabled individuals (Kent *et al.*, 1984, p. 24).

Conclusion

Considering the unprecedented demographic changes which will almost certainly affect Britain over the next two or three decades, notably the rapid expansion in numbers of the elderly and the envisaged acute shortage of

labour -especially in the lower age ranges, the need for a radical reappraisal of societal attitudes and social policies regarding children and young people with impairments has never been more acute. Existing policies which successfully disable many children and young adults with impairments by not providing them with the confidence, practical and intellectual skills, and opportunities necessary to live outside institutional settings are no longer simply morally reprehensible, they are likely to prove economically disastrous. Any provision, such as the type of day services proposed here, which holds out the possibility of circumventing the profoundly negative social and financial consequences of existing policies must be supported and expanded without delay, at both the national and local level. Society can no longer afford the social construction of the 'cabbage syndrome'.