

## **Chapter 8 (In 'Cabbage Syndrome': The social construction of dependence, Colin Barnes (1990) The Falmer Press, pp. 187-193)**

### The Demise of the Contact Group

The empirical research was concluded in July 1987. The following account is based on a number of separate visits I made to the day centres between January 1988 and March 1989 and an informal but lengthy discussion with the Residential and Day Care Officer (RDCO), Mrs B, responsible for the service in April 1989. I shall outline the changes which occurred within the group during this period in chronological order and comment on these changes with reference to the conversations held with some of the users and staff during these visits.

### Developments

In 1987 the composition of the Contact group changed dramatically. As noted earlier, Jamie had all but left the group by April due to his family commitments, Marilyn started work in the same month and Molly, whose attendance had progressively declined as the study drew to a close, stopped using the service altogether after July. In addition, several of the older Contact users were directed toward the Insight groups. I was told by senior staff that there were two main reasons for this policy. The first was that it was felt by senior staff that these users had outgrown the services provided within Contact and would benefit from mixing with slightly older individuals who were relatively more independent. It is said that the majority of Insight members had acquired impairments, were not dependent on their parents and generally took a more pragmatic approach to self-determination within the centres. Secondly, there were a number of prospective users in the younger age range waiting to join Contact. Whether or not this was the primary reason for this decision is open to speculation but three new members did join Contact in August 1987. These were the three boys who visited the group with the party from the local college of further education during the study period (see Chapter Five).

The first two to move to the Insight group were Spike and Philip, both of whom perceived the change positively. They felt that they had outgrown the Contact format and welcomed the opportunity to interact on a regular basis with people who were 'more mature'. + Next to go were Andy, Matthew, Roger and Charles, but unlike Spike and Philip who joined the Alf Morris Insight group, they were directed toward a similar unit at Dortmund Square.

Although the decision to leave was 'mutually agreed' between them and staff, it was evident that the idea had initially been suggested by the latter. It was also evident that it had met with some resistance from Matthew and Roger because of the limited resources at Dortmund Square.

Notwithstanding that senior staff were reluctant to comment on this point, I believe the decision to direct these users toward Dortmund Square rather than Alf Morris was because the former was undersubscribed while Alf Morris was not (see Chapter Four). In addition to these departures, Gavin contracted pneumonia in October and died in hospital.

With regard to the staff, the training programme for all newly appointed care assistants (CAs), whether on government-sponsored training schemes or employed on a permanent basis, was reformulated in July 1987. From this date no staff without previous experience of work with the physically impaired were allowed to start work in the centres prior to completion of a three-day induction course, condensed into three full days, this course was in effect the training scheme which up to this point had been split into six separate training periods. It was generally agreed by all the staff that this was a far better arrangement.

In 1988 the system of recruiting staff through government-sponsored training schemes stopped. I was told by one activity organizer (AO) that this was because the centres were fully staffed and there was no real justification for employing any more. The change was generally regarded as a good thing since several of these workers 'were more trouble than they were worth'. + It is notable, however, that, with the exception of Annie, all the government-sponsored CAs who took part in the study were subsequently taken on by the Authority when their year-long contract finished, either for similar work in the day centres or in local residential homes.

In January 1988 Jackie started a self-advocacy and assertiveness training class specifically for Contact users at Alf Morris in conjunction with a tutor from the local college of further education. Participation was voluntary and the class ran for just over two months. It subsequently folded through lack of user support. While two or three Contact members, particularly Joyce, Billy and one of the three new Dales, were extremely enthusiastic about the project, the others who took part apparently lost interest after the first month or so.

The most profound change occurred in May 1988 when the Contact group effectively ceased to exist having moved to a newly modernized day centre specifically designed for younger users aged between 16 and 45. The new centre is situated in a quiet suburb about five and a half miles from the middle of the city. The building originally housed a training centre for the mentally handicapped and stands in the same grounds as a residential home for the elderly. Although there are no stigmatizing signs outside this area, both units are relatively isolated and reached only by a quiet cul-de-sac leading from a busy main road. The nearest shops and amenities are approximately half a mile away, clearly out of reach for people with mobility difficulties.

Internally the centre has been completely refurbished and adapted to the needs of the physically impaired. It houses a plethora of facilities and amenities including a well-equipped computer workshop, games room, cafeteria and lounges. Transport to and from the unit is provided by the local authority in a social services' specially adapted 'red bus'. The policy of using local taxi firms to transport users to and from their homes has been virtually abandoned for economic reasons. It seems that taxis are now used only as a last resort. Users' views regarding this issue were inconclusive. While some, such as Joyce, were extremely critical of the change, others were apparently placated by the fact that because the new centre is allocated a bus of its own, vehicles are no longer full of 'old people' when users are picked up or taken home.

Known as 'The Resource Centre for Disabled People', the unit is open from nine in the morning till nine o'clock at night and offers a six-day service. Sunday is the only day it is closed. Although giving users a greater choice of when they attend, this choice is limited for those who are reliant on social services' transport which is, only available at specific times of the day. There are twenty-one permanent staff employed at the unit. All work shifts. Several, including Jackie, Rick, Denise, Patrick, Sean and Maria, previously worked with the Contact and Insight groups. According to a publicity handout printed at the unit's opening, the general aims of the centre are to provide (a) an appropriate forum where younger people with impairments can meet for social interaction, skill development, education and rehabilitation, (b) a centralized information service for users, their principal carers, and other professionals involved in rehabilitation, and (c) opportunities for people with and without impairments to share knowledge, experience and leisure activities.

To promote these aims the centre offers a wide range of services and activities both inside and outside the building similar to those offered by the Contact group, including sports facilities (at the same sports centre previously used by Contact), further education (in conjunction with the same colleges discussed in Chapters Six and Seven) and youth club evenings in partnership with national Physically Handicapped and Able-Bodied (PHAB) clubs. In addition, the centre boasts facilities for individually structured social and life skills programmes, information and advice and informal carers' support services. It also offers easy access to a recently developed community care support service specifically aimed at the younger impaired, jointly funded by the local social services department and the health authority, which includes a doctor, a social worker, a physiotherapist, occupational and speech therapists. Although these professionals are not located in the centre, I was told that they work closely with Resource Centre staff. In addition, the centre provides facilities for users to study and acquire office skills on a two-year Royal Society of Arts (RSA) training scheme supported by European Economic Community (EEC) funding. On completion students are promised assistance with finding appropriate employment.

As in the Contact group, eligibility for user status at the new centre is dependent upon both age and physical impairment. When I visited it in March 1989 there were ninety users on the unit's register and only twenty-three were from the original Contact group. As well as those who moved on to the two insight groups or who left for personal reasons, three other user respondents who took part in the study, Tony, Wendy and Clive, no longer used the day centre service because they had moved out of the Local Authority's catchment area.

In order to obtain all the available ex-Contact users' reactions to these developments I went to the Alf Morris centre to talk to Spike and Philip, and Dortmund Square to see Andy, Matthew, Roger and Charles. It seems Spike's use of the centres had gradually dropped off since he left Contact. When the Resource Centre opened Philip left Insight and transferred to the new unit and immediately enrolled on the RSA office skills course. He is particularly enthusiastic about the course because he is learning something which he considers useful, and there is the hope of a job at the end of it. Although initially Matthew and Roger were opposed to their move to Dortmund Square, one year later they appeared relatively happy with the situation. Both said they got on well with other Insight users and the Dortmund Square staff. One of the main reasons for this change of attitude is undoubtedly the recent inclusion of sports facilities in Dortmund Square's

list of activities. Both Matthew and Roger are keen on weight training. In response to the question 'would you like to move on to the new Resource Centre?' both said they were happy where they were. A similar response came from Charles. Andy, on the other hand, uses both Dortmund Square and the Resource Centre as and when he feels like it, although officially he is now a member of Insight.

On both occasions when I visited the Resource Centre there was plenty of user-centred social activity in progress, and there was clearly a warm friendly atmosphere throughout. Everybody gave the impression that user / staff interaction was distinctly positive. It was also clear that the longstanding social ties between some ex-Contact users had not been severed by Contact's demise. For example, on both visits Margaret, Norman, James, Curt, Millie and Angela from subgroup B were sitting together, and Barry and Henry were busy playing snooker. Most of the ex-Contact users I spoke to seemed genuinely enthusiastic about the recent developments. Norman, for example, told me how he was 'a bit worried at first' but had since decided that the new centre was 'alright because nobody bothered you' + . Even Joyce, who was especially despondent about the future when the empirical research finished, saw the Resource Centre in a relatively positive light, if only because of the RSA course and the chance of paid employment when it is completed. These reactions, however, are not surprising considering the quality and extent of the facilities available within this centre, the general expansion of services by the Local Authority for this particular user group, the influx of new users -all in roughly the same age group - and the fact that the majority of the more critical Contact members, particularly those in subgroup D, either stopped using the centres altogether or were located elsewhere. One notable exception, however, was Billy.

Billy's involvement with the Resource Centre has declined markedly since it opened. On both occasions when I visited the unit he was absent. It seems he now only attends to join in activities which he is particularly interested in, namely, weight training and judo. This is in contrast to his daily attendance throughout participant observation, irrespective of what activities were offered. In addition, according to the other ex-Contact users, his behaviour has become more aggressive and volatile. He is said to be increasingly critical of others, both users and staff, as well as the service generally. Although the reasons for this apparent dissatisfaction are likely to be many and complex, I believe that part of the explanation must lie in the fact that his two principal friends, Jamie and Spike, no longer use the centres and

his illness has apparently deteriorated to the point where he is now totally reliant on a wheelchair.

With regard to the issues of user participation and/or user involvement in policy formulation, it was evident that little had really changed. In terms of activities, the principle of user autonomy was still given priority and user interest in explicitly social activity predominated, at least among ex-Contact members. When talking about the RSA course, Sheila, for example, said that she and a couple of the others had only 'stuck it for a week' + because it was just like school. When I suggested that this may be the best way to learn, she replied that she was not interested if it meant being told what to do all the time. Neither Philip nor Joyce felt that the course was too demanding, or that the tutors were excessively authoritarian.

With reference to user involvement in the general running of the centre, Jackie suggested that individuals do help out but nothing was formalized and it should be mentioned that on both occasions when I rang the centre to arrange my visits a user answered the telephone. However, she also pointed to the difficulties in trying to 'change the habits of a lifetime' + and said that participation was limited. At the time of writing there was no written formal constitution in the centre and user involvement in policy formulation, as in Contact, took the form of group or 'community' meetings. Jackie pointed out that user interest in these forums was still poor and that although staff had tried on a number of occasions to organize a users' committee, so far they had failed. She also said that getting individuals involved within the context of the Resource Centre framework was far more complex than it had been in Contact as there is no longer a clearly discernible group identity. This may be explained with reference to a number of factors. -At the new centre, unlike the others studied, users are not formally organized into specified user groups according to age or day of attendance. Moreover, because of the extended opening hours many people attend at different times of the day and on different days of the week. There has also been a rapid expansion of the centre's users, the majority of whom only use the centre for particular activities.

Discipline is apparently less of a problem at the Resource Centre than it was in Contact. This can be explained with reference to at least three important factors. Firstly, all the users and staff at the centre are relatively young. No longer are the needs of the younger users swamped by those of the elderly. Secondly, the rowdier and more disruptive elements from the Contact group have either left or do not attend the Resource Centre on a regular basis. Thirdly, there are few spatial constraints on users'

movements in or outside the centre. Those who are able use the unit as a 'drop-in centre', while those who are not can take advantage of the spacious grounds which surround it. Moreover, because the centre is located so far away from the local shops and amenities, staff do not have to worry about users leaving the centre's grounds, simply because there is nowhere for them to go. 2

This point clearly brings into focus one of the most important limitations of the Resource Centre, namely, its isolation. Because of the unit's location attendance completely removes users from the rest of the community. This problem is compounded by the extensive facilities available within it, since it has been noted that large well-equipped centres tend to discourage users from using or seeking to use those which are available to the general public (Carter, 1981).

It was evident that the Resource Centre staff were aware of these problems. I was assured that all those involved in the delivery of services, including the RDCO, had expressed concern about them within the Department. The decision to locate the centre in its present site, however, was taken at the executive level for reasons of limited finances and growing consumer need. Within the budget available the Authority was presented with only two options. The alternative to the site chosen was centrally located but could only accommodate twenty users at a time. In view of the fact that the new centre was fully subscribed in the first year, this decision is understandable. But since it is generally acknowledged that segregating the younger physically impaired from the rest of the community on a regular basis perpetuates difference, stigma and dependence, any economic gains made by it are likely to be short-lived (see Chapter Nine).

Several senior staff also pointed out that despite recent developments, general perceptions of the day centre service with regard to this particular age group had not really changed. Many informal carers and most other agencies outside the local authority's social services department still tended to see the Resource Centre as simply 'somewhere to go' for people who because of impairment could not be fitted in anywhere else. The careers services, for example, were conspicuous by their non-involvement in the Resource Centre project. Only a matter of weeks before my second visit a party of 16-year-olds from the Christy Brown special school, who were clearly perceived by users and staff as potential users, had visited the new unit 'to have a look around'.

Conclusion

After participant observation was concluded a number of important changes occurred within the context of the Contact group and the day centres generally which not only underpin the study's general conclusion, discussed in the following chapter, but also raise a number of questions which demand further study.

Prior to the group's demise several of the Contact members either left the centres altogether or were 'directed' elsewhere. While Contact staff were instrumental in the successful rehabilitation of at least two of the former, Jamie and Marilyn, it is unclear if this is true for the remainder. Although directing individuals into another user group may not be construed as strictly rehabilitative, since the motives for this policy are unclear and users are not leaving the day centre system, the data suggest that from the users' perspective the effects were positive. But how long will this perception last? The training programme for the newly appointed care staff has also been transformed. While this change is viewed positively by staff, it raises the question how it will affect staff/user interaction (see Chapter Four). A final question is how user/staff relations will be affected in the long term by the submergence of the relatively small Contact group within the much larger Resource Centre framework.

The development of the Resource Centre project and the expansion of services for the younger physically impaired must be seen in a relatively positive light, particularly in view of the economic and political constraints under which local government currently operates, because it signifies official recognition by the authority's policy-makers that the needs of this user group are distinct from those of the elderly. However, the data suggest that there are a number of significant factors which, rather than promote independence and integration for Resource Centre users, may accomplish the reverse. These include the centre's transport and admission policies, the general philosophy of the unit and, most importantly, its location. When juxtaposed against the substantial environmental, economic and social barriers to integration facing young people with impairments in the local community generally (discussed in detail in Chapter Seven), these considerations make it difficult to reach any conclusion other than that the positive aspects of the Resource Centre project will be relatively short-lived.

Notes

- 1 The girl in the party chose not to attend for reasons unknown.
- 2 I noted in Chapters Six and Seven how Contact users with mobility difficulties were all too aware of the environmental barriers confronting them in the wider community.