

A COMPARISON OF THE SERVICES PROVIDED TO PEOPLE WITH PROFOUND AND MULTIPLE DISABILITIES IN TWO DIFFERENT DAY CENTRES

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A recent report by the Social Services Inspectorate (1989) noted a significant growth in day service provision for people with learning disabilities over the last 15 years. This provision has developed as more people with learning disabilities, including people with more profound and multiple disabilities, now live in their own communities rather than in hospitals (Wertheimer, 1987).

A number of criticisms have been levied at Day Centres purely for people with a learning disability. Possibly the most powerful criticism is that they provide a segregated service which tends to exclude the people they serve from the general community. Other problems such as a low level of client "through put" to more integrated services and work, possibly maintained by the generally poor standards of individual programme planning found in Day Centres have also been

described (Social Service Inspectorate, 1989).

Due to these difficulties a number of debates have developed on the future development of day services. It is argued that a more dynamic form of day service could meet individual needs while using community resources (Bender, 1986), but others argue that Day Centres should be phased out entirely (Wertheimer, 1987) to be replaced by either smaller, community based services (Taylor and Rose, 1990) or teams of people working from home (Allen, 1990). Some programmes have demonstrated improved client outcomes but have proved to be expensive when compared to traditional models. For example, Allen (1990) showed a community based day service to be better than a traditional special care unit when compared using a number of indicators including levels of engagement.

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Perhaps more fundamental than these arguments is the existence of separate Special Care Units within the Day Centre setting, providing a service for people with profound learning disabilities, multiple handicaps or challenging behaviour. The view that partial integration can provide wider experiences for profound and multiply disabled people whilst retaining the improved staff/client ratio afforded by a separate unit is one that still finds support (Hughston, 1990). However, in the last major policy document on day services, the National Development Group (1977) envisaged Special Care Units becoming an integral part of Day Centres, rather than remaining "an isolated haven of care", (p. 65). This view is elaborated by Seed (1988) who argues that "parents will not want their children, once they become adults, to go back to a segregated service", (p. 139). The principles of integration present a challenge to the established practice of special care environments.

Evaluation of Services

There is relatively little research evidence to support the efficacy of different models of day service provision. Evaluation of the quality of any service should reflect the individual's experience as a service user.

One technique which has been used to do this is the direct observation of behaviour. There is a growing body of evidence from evaluation of residential services that observing a number of features of an individual's behaviour

including levels of engagement is a useful measure of the quality of the clients' lives (e.g. Felce, 1986; Mansell, 1988).

Engagement with the physical or social environment is probably the most common criterion employed in direct observational studies. It has been used to illustrate a number of important factors representing residential service quality such as: the nature of activities available to residents (e.g. Mansell *et al.*, 1984; Hewson, 1991); moves from hospital to community housing (e.g. Felce *et al.*, 1991; Mansell and Beasley, 1989); the relationship between staff interaction and client activity levels (e.g. Saxby *et al.*, 1988); and staff/staff interactions (Orlowska *et al.*, 1991; Repp *et al.*, 1987). The predominant finding is that residents typically spend less than half of their time constructively engaged, although a number of studies also indicate that improvements can be achieved through specific staff training (e.g. Mansell *et al.*, 1982; Midence, 1991; Porterfield *et al.*, 1980).

Direct observation has been used to a lesser extent in evaluating the quality of day services. One example is the assessment of room management procedures (Porterfield *et al.*, 1980). This showed improved engagement levels in group activities by employing specific management techniques. These results have been replicated elsewhere (e.g. Pope, 1988) but other authors report that the procedure is difficult for staff to maintain over time (Mansell *et al.*, 1982). In further studies engagement levels and contact initiated by staff have been demonstrated to be higher in small, fully enclosed teaching areas when compared to large open-plan

Day Centres (Dalglish and Matthews, 1980); in one to one rather than directed group settings (Coburn, 1989); and when specific training and feedback is given to staff (Midence, 1991). Another recent study has indicated that the ability level of the individual being observed is important when considering levels of engagement in Day Centres. Pettipher and Mansell (1991) found that in a Day Centre more able people were engaged significantly more than less able people despite lower staff/client ratios. These results confirm previous reports in the literature (Crisp and Sturmey, 1984; Grant and Moores, 1977; Mansell *et al.*, 1982; Moores and Grant, 1976).

Even though people with profound learning disabilities tend to be engaged less than their more able peers, the research suggests that they can achieve higher levels of engagement in activities, but this is usually dependent on factors in their physical or social environment. When faced with the opportunity to investigate two very different day care environments for people with profound learning disabilities, one a traditional segregated Special Care Unit and the other a group of individuals who had previously received care in a Special Care Unit which had now been integrated into the main body of the Centre, it seemed an excellent opportunity to evaluate the effectiveness of these services to the clients concerned.

It was decided to do this by direct observation of the individuals in each group, concentrating on levels of engagement and levels of interaction.

Method

a) Setting

This study was carried out in two Day Centres. Both Centres are based in small towns and aim to provide day services for all people with learning disabilities, with activities available within the Centres and through the use of local community amenities.

Centre A provides day services for 57 clients and employs 11 full time equivalent staff (including the Centre manager). Centre B provides services for 58 clients and employs 17 full time equivalent staff. Activities within the Centres vary from basic education and skill development to leisure pursuits such as horse riding and swimming. Both Centres have active work experience programmes.

At Centre A there is a distinct Special Care Provision for 5 profoundly disabled people based in two rooms at one end of the training centre. This is staffed by three whole-time equivalent staff with additional volunteer input available for some activities. The Unit has a separate programme of activities from the mainstream centre although there is some integration at meal and break times.

Centre B maintained a separate Special Care Unit for 9 people with profound learning disabilities until 1989. This had been staffed by five whole-time equivalent staff with occasional help from volunteers. Since then the Centre has integrated these people into most aspects of the Centre's programmes. Clients were included in groups and

activities with fellow participants who are less severely disabled, both within the Centre and out in the community. This enabled staff from the special care unit to work with their own clients and more able clients. Staff from the main body of the Centre were also expected to work with clients from the special care unit. This meant that the composition of groups of staff and clients would change, as activities changed twice or four times each day.

b) The People Concerned

All 12 clients included in the study attended the respective training centres for five days a week. Five people attending the Special Care Unit at Centre A and 7 of the 9 clients who had previously been in the Special Care Unit at Centre B were compared. Of the two people not included in the study, one had left, and the other had had an individual care assistant assigned to her to enable integration into the Centre's general programmes.

No individual in either setting had any expressive vocabulary, but some could use one or two Makaton signs.

The mean age of Centre A sample group was 27 years 9 months (Range = 20 years 10 months - 47 years 8 months), and for Centre B, 27 years 1 month (Range = 21 years 4 months - 48 years 8 months).

The 12 clients were assessed using the AAMD Adaptive Behaviour Scale (Part One) (Nihira *et al.*, 1974) by direct observation and by interviewing staff

who knew the clients well. The ABS is a structured, pre-coded scale which is commonly used as a research tool and a clinical instrument. Part One is designed to assess people's adaptive behaviour (their competence in daily living). These skills are grouped under ten main headings: independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, vocational activity, self-direction, responsibility and socialization skills.

Part Two is designed to assess "maladaptive" or problem behaviour. We decided not to use Part Two because a) parts of it showed low levels of reliability (Nihira *et al.*, 1974), and b) some of the questions imply moralistic undertones (for example, people are given a negative score for "homosexual tendencies"). It would appear that no distinction is made between behaviour that fails to conform to a narrow set of norms and that which is genuinely disruptive or difficult to manage.

All clients scores came in the bottom tenth percentile of a normative sample, based on adults in residential institutions (except for one client in Centre A and 3 clients in Centre B whose physical development scores fell between the 40th and 20th percentiles).

c) Observation procedures

Each individual in the study was observed four times on different days and at different times to represent the pattern of daily activities in the Centre;

early morning, late morning, early afternoon, late afternoon. Each observation period lasted approximately one hour, and only one individual was observed in that time. Breaks and lunchtimes were excluded from data collection, as these appeared to be relatively similar across settings.

A total of 44 hours and 19 minutes of data were obtained from 48 observation periods across both centres (mean observation period = 55.5 minutes). Numbers of staff and clients present were

recorded every five minutes. Data were collected by non-participant observations using a hand held micro-computer programmed for a 20 second momentary time-sample. The procedure and behavioural codes were the same as those developed by Beasley *et al.* (1989), with one modification; problem behaviour was recorded only in terms of occurrence or non-occurrence rather than type.

The range of observation categories is listed in TABLE I.

TABLE I
Codes used in data collection by direct observation

Codes and Definition	ACTIVITY
A	No activity (neutral or problem only)
B	Leisure/recreational/unstructured Educational
C	Personal/self care
D	Practical tasks/chores using electrical/gas equipment
E	Other practical tasks/chores
F	Work/'formal' education
L	Out walking
	SOCIAL (from client's perspective)
G	No social act by client
H	Clear social act by client
I	Unclear social act
J	To observer
	CONTACT BY STAFF/VISITORS
M	None
N	Positive
O	Neutral/indeterminate
Q	Assistance
R	Contact from other client (in addition to one of above)
	PROBLEM BEHAVIOUR
S	None
T	Challenging behaviour
STAFF AND CLIENTS NUMBERS	
Number of staff present	
Number of clients present	
This data is recorded every 5 minutes	

From Beasley, Hewson and Mansell (1989)

d) *Reactivity and Reliability*

A number of measures were taken to ensure that the collected data were reliable and accurate. Difficulties with staff reactivity to being observed are well documented (Orlowska, 1990). However, attempts were made to minimize this effect by the observers being familiar to people in both settings prior to the study. The data presented here was also taken following a pilot study that allowed habituation to the observation process. This took place in both settings, and included about 15 hours of observations over a four week period. Observer protocol stipulated that interaction with anyone in the setting must be minimized (one behavioural code recorded any contact to the observer initiated by the client being observed).

The data was mainly obtained by one observer, apart from two subjects in Centre B. As a check on the reliability of the coding activity, behaviour and staff/client ratios, a second trained observer was present for 14.17% of the observation periods. From this, the agreement on individual observational codes averaged 88.46% (range 72.77 - 100%) after excluding codes H, I and J (clear social act by client, unclear social act by client, social act to observer), which occurred infrequently and showed correspondingly low agreement (from 0% to 73.17%, mean 55.33%).

The inter-rater agreement on staff and client numbers averaged 87.76% (range 77.78% - 100%).

Results

Levels of Activity and Staff Contact

A breakdown of the behavioural observations made is presented in TABLE II.

The clients at Centre A, the Special Care Unit, spent an average of 62.77% of their time unoccupied and the clients at Centre B, the integrated setting, were unoccupied an average of 74.0% of the time.

Clients at Centre B were more likely to be occupied doing leisure activities, whereas clients at Centre A were more likely to be carrying out personal care tasks or to be out walking. The differences between the two groups with regard to personal tasks was statistically significant (two tailed t-test, $P < 0.05$). Levels of formal programming were very low at both centres (2.77% and 1.67% respectively), and clients were not observed doing chores in either setting.

Trainees at Centre A received no contact from staff 59.65% of the time, those at Centre B 71.95% of the time. The differences between the two groups are statistically significant (two-tailed t-test, $p < 0.01$). Looking at types of contact more closely, it can be seen that in both centres neutral contact occurs more frequently than positive or negative contact. (Centre A, 29.24 vs 0.80% and); Centre B 11.13% vs 0.80% and 0.21%). Neutral contact occurred significantly more frequently in Centre A than Centre B (two-tailed t-test, $p < 0.01$).

TABLE II
Average percentage levels of observed behaviour by clients in the special care and integrated settings

Behavioural Categories	Centre A (Special Care) (N = 5)	Centre B (Integrated) (N = 7)
A. No Activity	62.77	74.0
B. Leisure	12.71	14.05
C. Personal	14.35	7.61*
D. Tasks using appliances	0.03	0
E. Other chores	0	0
F. Formal Programme	2.77	1.67
L. Out Walking	7.51	2.75
G. No social act by client	95.00	97.12
H. Clear social act by client	0.50	0.52
I. Unclear social act by client	4.37	2.10
J. Social act to Observer	0.03	0.23
M. No contact from staff	59.65	77.95+
N. Positive contact	0.80	0.80
O. Negative contact	0	0.21
P. Neutral contact	29.24	11.13+
Q. Assistance	9.96	9.87
R. Contact by another client	0.03	3.96
S. No problem behaviour	88.55	76.91
T. Problem behaviour	10.90	22.78

* Significant difference at the 0.05% level
+ Significant difference at the 0.01% level

Levels of assistance were comparable in both Centres (9.06%) as were the extremely low levels of positive contact (both 0.80%) and negative contact (0% and 0.12%).

Clients in the integrated setting received some contact from other clients (3.96%) whereas this was negligible in the Special Care Unit (0.03%).

Staff:Client Ratios

The mean group size observed in the Special Care Unit was 3.08 staff to each 4.09 clients. In the integrated setting

the mean group size was 2.07 staff to 6.69 clients.

Average staff:client ratios for the two settings were:

Centre A = 0.75 staff:1 client

Centre B = 0.31 staff:1 client

Discussion

When considering the data presented here, some of the methodological difficulties of this study need to be taken into account. Probably the most obvious difficulty is that of comparability between

the two settings. Ideally a longitudinal study should have been conducted. Unfortunately this was not possible in this case, but there were many similarities between the two settings in that they were both managed by the same organisation, the Centres had similar aims, ideas and philosophies, staff had the same terms and conditions of service, and assessment indicated that the individuals in the study were similar in terms of their abilities. However, there were some differences, for example the buildings in which the Centres were housed were dissimilar, and there were differences in the way that staff were deployed and to some degree the range of activities offered.

The main finding of the study is that people were more likely to be receiving contact from staff in Special Care Units (Centre A) when compared to the integrated setting (Centre B).

In general individuals in the Special Care Unit tended to be engaged in activity more than those in the integrated setting. Even though this finding tended towards significance (two tailed t-test, prob. 0.1), further investigations need to be done to confirm this trend. Although individuals in the integrated setting were observed to spend a greater proportion of the time in leisure activities, the proportions of time spent on personal activity, outside walks, and formal programming were higher for clients in the Special Care Unit (significantly higher in the case of personal care). It should be noted that observations of formal programming were infrequent in both settings, and chores or domestic tasks

were not observed at all. The relatively infrequent occurrence of chores and domestic tasks is perhaps not surprising in a Day Centre. However, the lack of formal programming should be a great cause for concern considering the emphasis on education and skill development that the Centres are attempting to adopt.

Contact from other people occurred at slightly higher rates than engagement in both Centres, so again the Special Care Unit showed the highest rates of contact. In both Centres, contact was most likely to be neutral in content (for example, "processing the client", e.g. doing up his/her coat, general conversation). This was observed in the Special Care Unit (Centre A) at twice the rate of the integrated setting (Centre B). Contact provided as assistance, which is likely to be more important for the development of new skills in people with profound learning disabilities (Beasley *et al.*, 1989), was observed at similar frequencies in both settings. A marked difference between the two environments was observed for people receiving contact from other clients. This was negligible in the Special Care Unit but 5% of all observations recorded came from other clients in the integrated setting, which shows a particular benefit of the integrated environment. When considering some of the reasons for these differences a number of factors may be important. For example, some features of the individual clients themselves may encourage greater contact in the Special Care Unit. However, this is unlikely if simply considering ability level, as assessments would

indicate that the individuals in the integrated setting were somewhat more able and as such may be more likely to be engaged (Pettipher and Mansell, 1991). The observed frequency of challenging behaviours was higher in the integrated setting, although none of these behaviours presented major management problems. However, higher levels of challenging behaviour is one characteristic that, if present has been associated with a tendency for relatively lower levels of staff contact (Grant and Moores, 1977). An alternative explanation for the higher incidence of challenging behaviour may simply be that the individuals concerned were receiving relatively less staff contact in the first place, and may be having to resort to challenging behaviours to attract staff attention or to stimulate themselves. When staff : client ratios are examined a major difference in favour of the Special Care Unit is found. For each individual in the Special Care Unit there is effectively 0.75 of a staff member, whereas the comparable figure in the integrated setting is 0.32 of a staff member. This is despite a more generous staff ratio overall in the integrated setting. (17 staff : 58 clients vs. 11 staff : 57 clients).

The potential for contact by simply having more staff available for fewer clients in the Special Care Unit is more than twice that in the integrated setting. However, it should be noted that most clients within groups in the integrated setting were more able than those in the study and had previously been assessed as requiring much lower staffing levels. Indeed, the non-special care clients in these groups are probably benefitting

from relatively high staff : client ratios. However when considering the overall staff ratios which are very much in favour of the integrated setting, it is possible that staff are spending more time with more able clients at the expense of the less able. Another organisational explanation may be that if any individual clients are absent from the Special Care Unit this will have a much greater effect on improving the staff : client ratio. This effect would be more negligible in the integrated setting with relatively larger groups and lower staff ratios. It seems that the overall level of staffing is more difficult to maintain in an integrated environment where all activities and individuals are considered equally.

These results seem to demonstrate some of the potential difficulties with the integration of Special Care Units directly into the main Day Centre activities. For the integrated setting one obvious recommendation must be to ensure that staffing levels are maintained and possibly increased for work with this client group. Having a more structured and programmed approach to teaching and interaction may be one way of ensuring that profound and multiply disabled individuals receive appropriate levels of engagement. Clearly, there are still some lessons to be learned in terms of programming and structure within the Special Care Unit in this study. However the importance is not so clearly highlighted as in the integrated setting.

A number of measures are now being implemented within the integrated setting with the aim of increasing engagement for the profoundly and multiply

handicapped individuals concerned. This has included more specific individual skill teaching programmes to be carried out regularly within the Centre. The use of room management strategies for small groups of clients which include a mixture of general trainees and those included in the study have recently been implemented. Also a number of training sessions for staff started during an annual training week, are being continued at approximately monthly intervals during staff meetings. It is hoped to evaluate these changes in due course.

The difficulties which may have been experienced with the integration of profound and multiply handicapped people into an already segregated Day Centre environment lead to many questions about the appropriateness of segregated Day Centres per se. It may be more useful to use the relatively high staffing levels afforded within Special Care Units to try and integrate people who use these facilities directly within the general community (a tactic that was used to some extent in the segregated setting by taking people out of the Centre on most days). Examples include the use of whole staff groups based away from Day Centres (Allen, 1990) or the development of integration with an emphasis on using vocational skills and work. Some of these types of programmes are starting to be developed for even the most disabled individuals (Bellamy *et al.*, 1988; Porterfield and Gathercole, 1985). These alternatives are probably more attractive than integration via an already segregated setting as it is possible, if not likely, that if this route is taken, the most profoundly

and multiply disabled people may have to wait for improvements to services to other less disabled people before real improvements are seen in their quality of experience and they become more fully integrated into society.

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