

THE USE OF SHOPS, CAFES AND PUBLIC HOUSES BY SEVERELY AND PROFOUNDLY MENTALLY HANDICAPPED ADULTS ¹⁾

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INTRODUCTION

The development of residential services in ordinary community housing (Mansell, Felce, Jenkins, de Kock and Toogood, 1983; Mathieson and Blunden, 1980; Ward, 1983) has been seen as a way of promoting integration and the greater use of local amenities. However, while few would dispute that the location of care settings in population centres sets the occasion for using the amenities available, there is little evidence on the extent to which severely and profoundly mentally handicapped people become involved in activities central to community living as a result. Moreover community acceptance of such involvement remains a matter of debate.

Research has addressed the issue of the frequency of community involvement (e.g. Birenbaum and Re, 1979; McConkey, Walsh and Mulcahy, 1981; Reiter and Levi, 1981) and the range of community contacts (McConkey, Naughton and Nugent, 1983). However, where the behavioural functioning of mentally handicapped people in the community has been the subject of research, the emphasis has been on teaching them skills: eating out (Marholin, O'Toole, Touchette, Berger and Doyle, 1979), pedestrian skills (Page, Iwata and Neef, 1976), handling money (Trace, Cuvo and Criswell, 1977) and shopping (Aeschleman and Schladenhauffen, 1984). No data seem available on the general level of participation, particularly of severely and profoundly mentally handicapped people, on routine outings.

The assessment of public attitudes to community integration of mentally handicapped people has mainly concerned the decision to locate residential services locally. Research has shown that the public express fears concerning lowered property values, the risk of harm to children, sexual deviance and other undesirable conduct, a lack of proper supervision, increased traffic, noise, demand on community resources, loss of business and an increase in crime (Lubin, Schwartz, Zigman and Janicki, 1982; Berdianeky and Parker, 1977). While some of these fears primarily concern the acquisition of local property to provide a residential service, others are to do with the actual use of the community's amenities and local businesses thereafter.

The purpose of the current study was to describe the activity of a group of severely and profoundly mentally handicapped adults resident in community-based homes when they visited local amenities in the company of staff. The study was designed to address the question of whether the role of severely and profoundly mentally handicapped adults was one of passively accompanying staff or one of meaningfully participating in the activities the community amenities occasioned, including meeting and interacting with the general public. Further, in order to assess the acceptability of such use, the views of people who work in or own the shops, cafés or public houses visited were sought. These people were singled out as the most likely to be sensitive to the issues concerning loss of business, the appearance

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and behaviour of the subjects and inconvenience to other customers generally. The frequency of use of community amenities by these subjects is being addressed in a more extensive, comparative study. (Note 1).

METHOD

Subjects

The subjects were 10 severely and profoundly mentally handicapped adults who at the outset of the study had been resident in two small community homes for an average of 13 months (range, 0 - 26 months). Prior to living in the community-based homes, six had lived in distant mental handicap hospitals, one had been a resident in a larger community-based unit elsewhere, and three had lived at home locally. Their mean age was 42 years, (range, 24 - 58 years), 7 were female and 3 male. Mean mental age (Griffiths, 1954, 1971) was 38 months (range, 18 - 56 months), mean receptive language age (Reynell, 1977) was 19 months, (range, 6* - 44 months) and mean expressive language age (Reynell, 1977) was 20 months, (range, 6* - 46 months).

Although the subjects were the majority of the most handicapped group of adults requiring residential care in a defined territory, all subjects were ambulant and multiple physical handicaps were absent. Subject 3 was profoundly deaf and partially sighted. Five subjects (1, 2, 3, 6, 8) had persistent behaviour problems such as stereotypic movements, stripping, aggression and self injury. Four subjects (1, 2, 6, 8) had the triad of social impairments described by Wing and Gould (1979). Subjects 1 - 5 from one small home and subjects 6 - 10 from the other are internally ordered by ascending mental age.

Settings

The two homes were located in residential streets in a market town in Southern England of approximately 30,000 total population. They were designed to retain characteristics of ordinary domestic dwellings and were situated on either side of the town centre some 5 to 10 minutes walk away. The houses had been established as part of a research programme, staff had received induction training from researchers and the activities of staff and clients within the houses had already been the subject of research evaluation (Felce, de Kock and Repp, in press). The involvement of mentally handicapped residents in meaningful activity within the houses and outside in the community was emphasised in the operational philosophy and training.

The town was a fairly typical centre of its size with a central market place, a wide range of shops and supermarkets, a departmental store and branches of all the main banks and building societies. Subjects were observed while using shops, cafés and public houses; the types of amenities they used most frequently and which appeared to present the fewest practical difficulties to direct observation. Virtually all the shops in the town centre were visited in the course of the study as were four cafés and two public houses. In addition, two shopping trips in nearby cities and two outings to pubs in the country were observed.

*The score of 6 months has been taken to indicate the lowest possible score — under 12 months. Data on individual Adaptive Behaviour Scale assessments are available from the authors.

Observational definitions

Subject behaviours were observed and coded according to the definitions set out below. Appropriate and inappropriate categories could be coded concurrently, and took precedence over neutral categories.

Subject behaviours - appropriate

- a. **Substantive** - meaningful participation, as demonstrated by some motor activity, relevant to the particular setting visited (e.g. in shops, pushing a trolley, picking up items, offering money to cashier; in cafés or pubs, ordering, consuming food, smoking, paying.).
- b. **Interacting** - appropriate speech, gesture or touch as a means of communicating to another person; observable signs of attention towards another person who is in turn communicating (e.g. shaking hands, looking at someone talking). Within this category, interactions were distinguished as with i) an accompanying subject from the same house, (ii) an accompanying member of staff, and (iii) a member of the public.

Subject behaviours - Inappropriate

- c. **Self-stimulation** - intrusive, repetitive gross or fine motor behaviour which serves no apparent appropriate purpose (e.g. body rocking, head weaving).
- d. **Other inappropriate behaviour** - (a) aggression: any behaviour directly or potentially harmful to the subject, another person or property; (b) inappropriate vocalisation: intrusive noises or verbalisations which are inappropriate in context or to the situation; (c) other antisocial behaviour.

Subject behaviours -neutral

- e. **Carrying** - incidental carrying of a shopping basket or item of shopping in the absence of a substantive activity.
- f. **Other neutral behaviour** - manipulating materials to no apparent end, walking, passively sitting or standing.

Observational procedure and analysis

Observations were taken of each subject on six occasions when shopping and three occasions when visiting a café or pub. The former included three shopping trips longer and three less than twenty minutes which in the event produced similar results and were combined. The occasions observed arose in the usual course of each household's activity.

The observations followed a 30-second momentary time sampling procedure which is considered accurate for presentation of single subject data for behaviours of moderate duration (Brulle and Repp, 1984). The main observer was cued by a pocket-sized (5cm × 10cm) battery-run device which emitted an electronic signal into an ear piece at 15 second intervals enabling two subjects to be observed on the same outing. The observations were recorded into a small notebook (15cm × 21 cm). The number of observations of each category was summed and expressed as a percentage of the total number of observation points for each individual for each outing.

Questionnaire

Thirty-eight business people (14 managers/proprietors and 24 assistants) from the two cafés, two pubs, six large and six small shops visited most frequently by the subjects participated in a 10-min structured interview. It addressed issues of frequency of use by the subjects, the preferred size of the group, the extent of involvement of the subjects in activity, the acceptability of their appearance and behaviour and also the perceived impact on the subject, the respondent and other customers. The questionnaire is given in the appendix to this paper. The proportion of respondents giving each answer was calculated.

Reliability of observation

A second observer collected reliability data at least once for each subject in each type of setting. Reliability observations were taken at 60 second intervals; the main observer alerting the reliability observer 15 seconds before an observation was due and at the cue.

Occurrence reliability was calculated as a percentage by dividing all occasions on which both observers agreed on the category recorded at an observation by the sum of all agreements and disagreements of that category and then multiplying by 100. For behaviours occurring for more than 5% of the total number of observations, occurrence reliabilities were: **substantive** 96%, **carrying** 95%, and **other neutral behaviour** 91%. Occurrence reliabilities for behaviours occurring for less than 5% of the total were: **interactions with the public** 90%, **self-stimulation** 75%, **interactions with people from the homes** 67% and **other inappropriate behaviours** 57%. Non-occurrence reliabilities for these categories were 99%, 98%, 99% and 99% respectively.

RESULTS

Subject Behaviour

Engagement in appropriate activities occurred for all subjects while shopping and while visiting cafés or pubs. Substantive behaviour was recorded on average 29.3% (range, 10.3 - 43.3%) of the time on shopping trips and 36.3% (range, 14.4 - 60.6%) when in cafés or pubs (Figure 1). While the latter appears a more successful activity in terms of engagement, three of the five most intellectually impaired subjects experience higher levels of occupation while shopping.

Contact with members of the public occurred for all except one subject while shopping and for six subjects in cafés/pubs (Figure 2). However, the average duration of such contact was low, 1.7% (range, 0 - 5.6%). Interactions with members of the household party were considerably more extensive than those with the public; 5.9% (range, 2.7 to 12.27%) on shopping trips and 10.7% (range, 5.5 to 15.7%) in cafés/pubs. Of the four subjects that had relatively little substantive behaviour in cafés/pubs, three (1, 7, 8) also experienced low levels of interaction. There were only six occasions when subjects were observed interacting with each other.

Seven subjects showed inappropriate behaviour at a mean level of 6.4% in shops and 11.3% in cafés/pubs, but it occupied more than 3% of time for only three subjects (1, 3, 6) in the former and five subjects (1, 2, 3, 6, 8) in the latter. Self-stimulatory behaviours, comprising hand rotation, head weaving and body

rocking, were the most prevalent and accounted for 74% of the total with subject 1 showing particularly high levels: 21.4% in shops and 52.8% in cafés/pubs. For 15.2% of the time, self-stimulatory behaviour occurred together with substantive behaviour. Other inappropriate behaviours consisted mainly of inappropriate vocalisations (77%). No incidents of aggression towards other people were recorded. Other inappropriate behaviours were minor self-injurious behaviour, heavy-handedness, spitting, drinking another's drink and sitting on the pavement.

Figure 1 The substantive activity (% of time) of severely and profoundly mentally handicapped adults at shops and cafes or pubs .

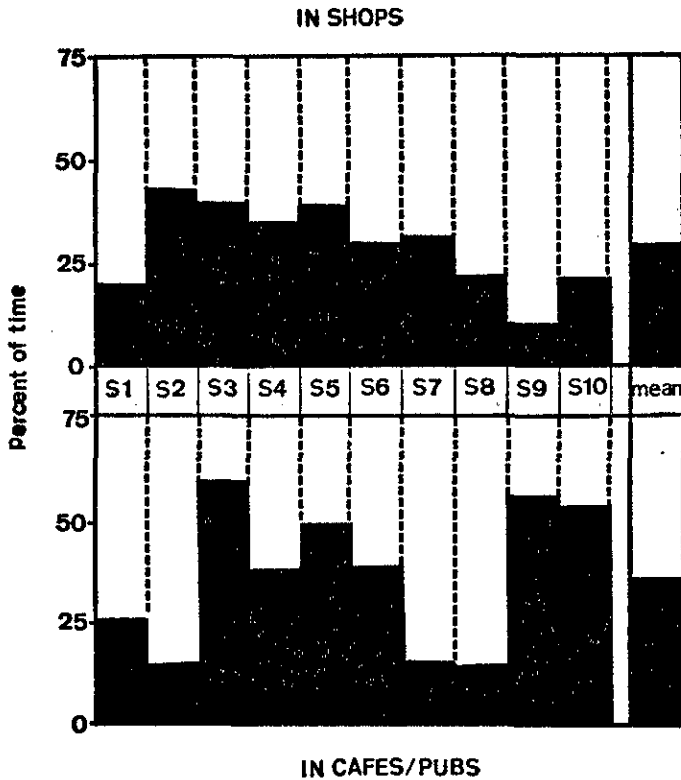


Figure 2 The social interactions (% of time) of severely and profoundly mentally handicapped adults at shops and cafes or pubs .

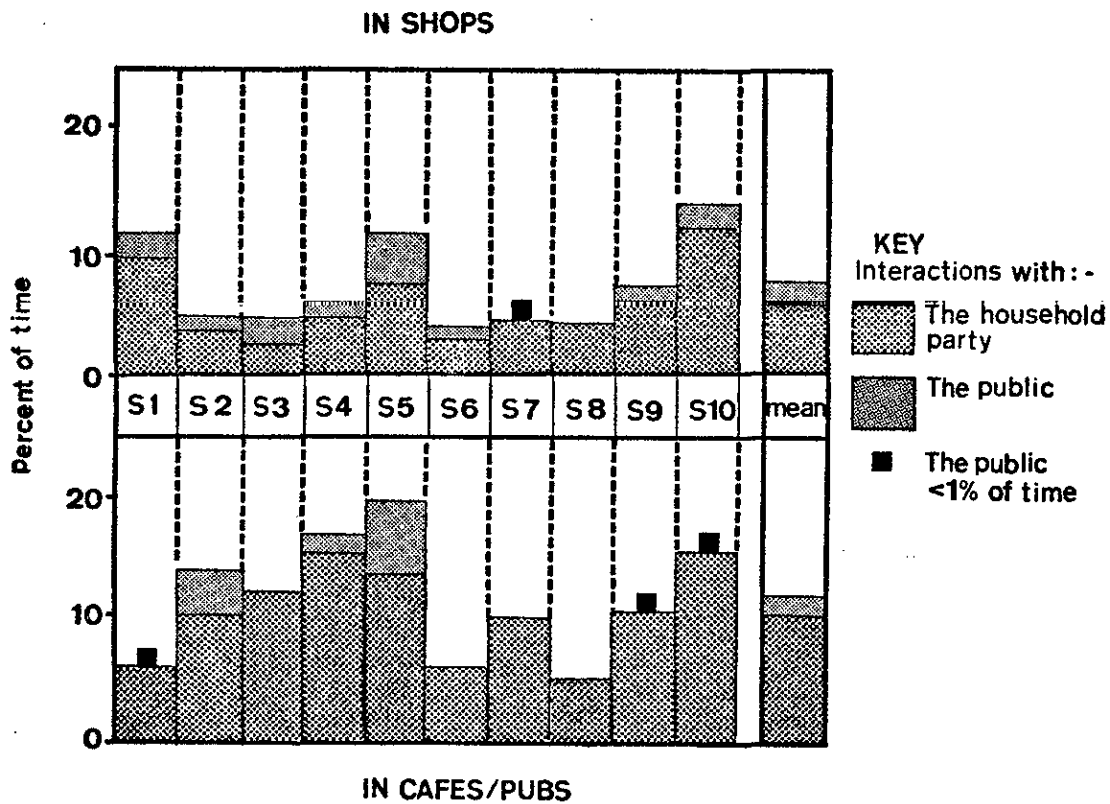


Figure 3 The inappropriate behaviours (% of time) of severely and profoundly mentally handicapped adults at the shops and cafes or pubs.

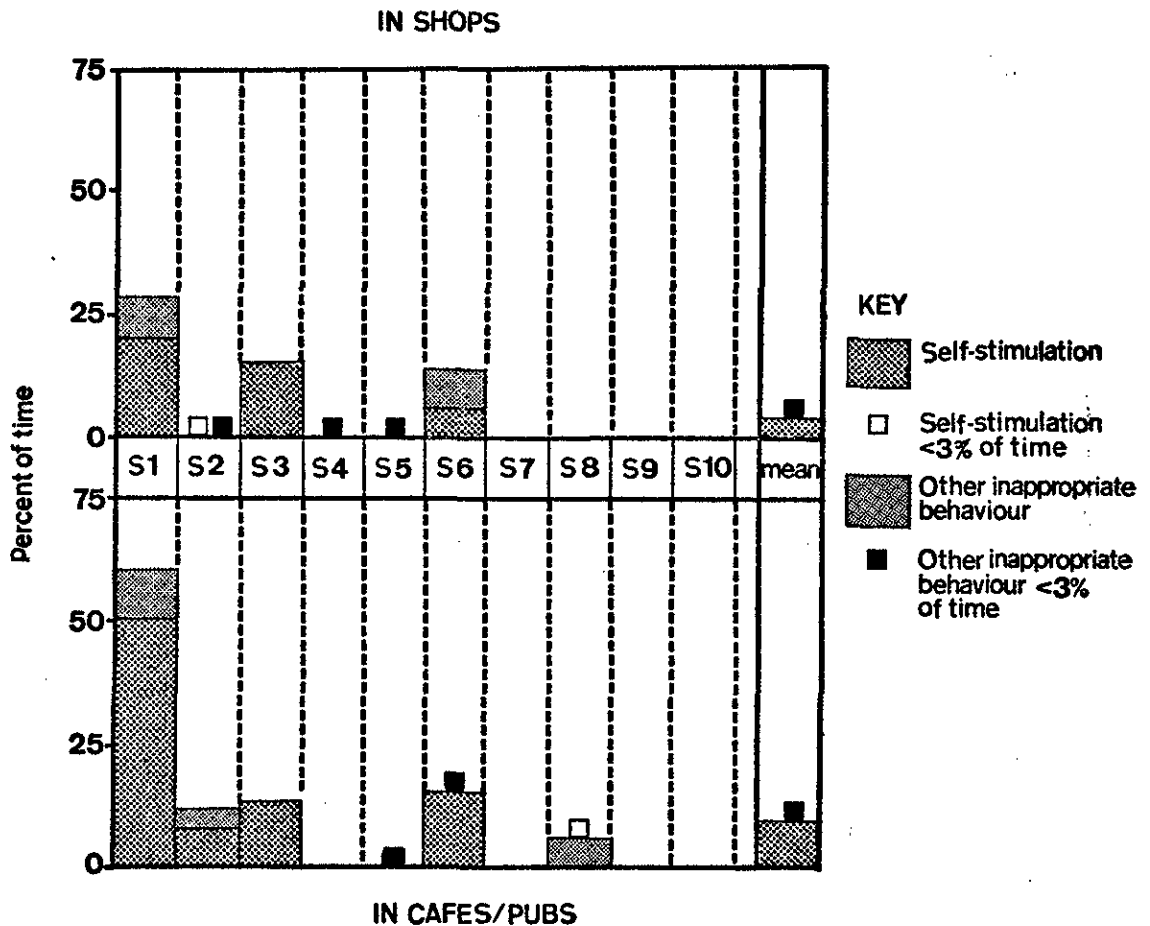


Figure 4 The neutral behaviours (% of time) of severely and profoundly mentally handicapped adults at the shops and cafes or pubs.

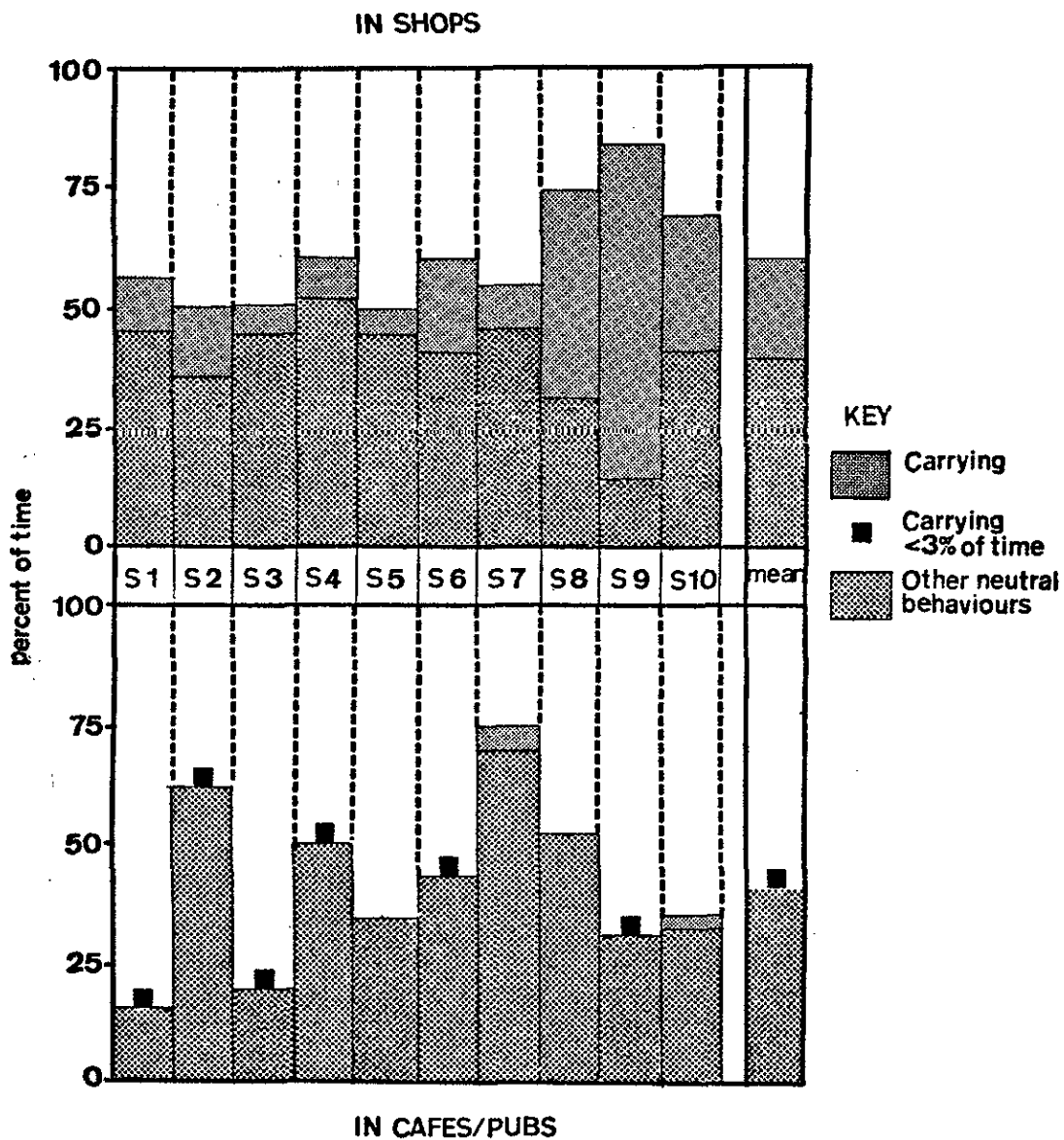


Figure 4 shows the extent of residual activity: passively carrying goods and other neutral behaviours. These comprised the majority form for most subjects while shopping (mean, 61.9%). Subject 9 spent 69.7% of the time in shops carrying a basket or goods and to a lesser extent subjects 8 and 10 were similarly engaged. These three subjects showed lower than average participation in substantive activity while shopping despite their relative ability. Neutral behaviours in cafés/pubs, occupied an average of 40.4% of time (range 19.2% to 74.18%).

The views of the businesses visited

The frequency with which the subjects used the businesses varied from daily to less than once a week. All 38 respondents to the interview found their particular frequency acceptable and 31.6% said it could be more. The preferred number of mentally handicapped people in a group was one or two. Although this was the usual group size from the community homes, some adverse reference was made by respondents to larger groups of mentally handicapped people from other services in the area. In response to the question of whether the subjects stood out from other customers, 10.8% considered they did to a considerable degree, 21.6% to a moderate degree, 45.9% a little and 21.6% not at all. In answer to an associated question on appearance, 85% said that the subjects were as presentable as the average customer and 2.6% said they were more so. Noisiness was singled out most frequently as an intrusive characteristic which distinguished subjects from other customers. One respondent felt that the subjects' behaviour needed improvement and one expressed "a little concern". Otherwise respondents felt their behaviour to be similar to other customers (34.2%) or reasonable considering their handicap (63.2%).

The subjects were also seen as being involved in activity and direct interactions with respondents. Only 5.6% (all managers) said the subjects were rarely involved in activities and only 11.1% of respondents said the subjects were rarely involved in interactions with them. A high proportion (97.4%) felt that the mentally handicapped person benefitted from community involvement, 21.1% felt that they benefitted personally and in contrast to the latter 42.2% felt other customers benefitted. Nearly two-thirds thought there were advantages for the business, not only from their direct custom but also in creating a good public image.

DISCUSSION

This study illustrates the level of appropriate participation that severely and profoundly mentally handicapped adults with little or no language can have when using local amenities with staff support. All clients were able to engage in substantive activities appropriate to the setting while shopping or visiting cafés and public houses and most had some contact with members of the community. This level of integration can be acceptable to the businesses used even though some inappropriate behaviour occurred.

However, with the exception of one comparison, the mean substantive engagement of subjects from Homes 1 and 2 while shopping (36% and 23%) and while in cafés and pubs (38% and 35%) was somewhat lower than appropriate participation found within the houses in two separate studies: 51% and 56% (Felce, de Kock and Repp, in press) and 53% and 27% (Thomas, Felce, et al, 1986). So while the access to the increased range of normal activity would justify the use made of such community amenities, the data indicate that further attention might be given to how to increase the direct participation of the subjects. However, interactions with staff in the two settings for both household groups were within the

range of those found in the two studies inside the houses. Therefore, particularly in relation to trips to cafés or public houses, the normal social character of the event has at least been approximated. Interactions with other citizens were experienced at relatively low levels: on average 2.3% of time for subjects from Home 1 and 0.7% of time for subjects from Home 2. The former represents one minutes interaction in approximately three-quarters of an hour. Although this may not be considered untypical for say the busy shopper, such interactions do represent these subjects main links with the public and as such the subjects can still only be seen as marginally integrated into local society.

Substantive behaviour and social interaction show some variability between subjects. Some depends on chance variation in activity content or staff management. Thus a trip to a pub involving eating a meal contributes more prolonged substantive engagement while staff choosing to take the more active part of shopping and assigning the client the job of carrying the goods being bought reduced substantive engagement. However, there is also an indication of variety in activity with subject ability; the most severely mentally handicapped are least engaged in appropriate substantive activity in cafés/pubs and in social interaction in both types of setting. The phenomenon of the most handicapped experiencing least interaction with staff and engaging least was not apparent in a study within the homes (Felce, de Kock and Repp, in press). This may be due to the fact that some effective means of staff support (e.g. substantial and prolonged physical guidance) are available within the houses which are insufficiently discreet for more public settings.

The views of the questionnaire respondents show that regular use of amenities by the most severely mentally handicapped people can be accepted and even welcomed. While aggressive outbursts were not observed, other inappropriate behaviours were evidenced showing that a certain level of aberrant behaviour can be tolerated. Kastner, Reppucci and Pezzoli (1979) demonstrated a discrepancy between stated attitudes and actual behaviours with regard to the acceptance of the principle of community integration. However, they and Lubin, Schwartz, Zigman and Janicki (1982) showed that community opposition may change following actual experience of local services. This study supports these findings. Whatever the hypothetical attitudes of the community at large, those people with first-hand experience were tolerant and accepting; respondents did not take the opportunities given during the interview to enlarge on problems or untoward incidents.

However, it is important to recognise the specific conditions under which these subjects have gained a favourable attitude from the local community and to avoid over generalisation. Effort has been given to the subjects having a beneficial appearance both in terms of the quality and adult-appropriateness of clothing and hairstyle. While the appropriateness of their behaviour cannot be guaranteed, staff were seen as responsible for its management and as efficient and competent. Use of community amenities has been by small numbers of subjects together, conforming with the desired group-size. Moreover, the subjects are genuine customers contributing in a similar way to others to the local economy. Certain organisational features of the residential settings facilitate these conditions. Staff:client ratios need to be sufficient to allow staffed small group outings to the community while preserving adequate staffing to those residents remaining in the house. Arrangements need to be made which permit the spending power of the household to be associated with the subjects and directed locally (in this case a fully devolved cash budget). Were service organisation to result in the revenue expenditure being diverted away from the community, the response of proprietors and staff might be different from that found generally to be true here.

This study has examined the extent of adaptive activity and contact with the public of a group of severely and profoundly mentally handicapped adults using community amenities with staff support. While the data do indicate some measure of achievement, they also show that the subjects' social integration is still essentially limited. Improvements in this area and in gaining increased substantive participation might be derived from intensive concerted teaching of the type documented in recent literature (Aeschleman and Schladenhauffen, 1984; Marholin, O'Toole, Touchette, Berger and Doyle, 1979; Trace, Cuvo and Criswell, 1977).

SUMMARY

The study addressed the question of social integration and participation in activity of severely and profoundly mentally handicapped adults when in the community in the company of staff. Using a momentary time sampling procedure, 10 severely and profoundly mentally handicapped adults were observed in local shops, cafés and pubs. Results show engagement in normative purposeful activities for all subjects, interactions with members of the public for nine subjects and some inappropriate behaviour. A questionnaire survey of the businesses visited ascertained the general acceptability of this level of integration given the small size of group who used the amenities at a time, and showed largely favourable views concerning the appearance and behaviour of the subjects.

Reference notes

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APPENDIX

A QUESTIONNAIRE ON THE USE OF LOCAL AMENITIES BY MENTALLY HANDICAPPED ADULTS WHO LIVE IN THE COMMUNITY

This section to be completed by the interviewer in advance.

Setting:-

- a. Supermarket
- b. Large store
- c. Small shop
- d. Café
- e. Public house
- f. Other

Position:-

- a. Owner
- b. Manager
- c. Shop assistant
- d. Cashier
- e. Waiter/waitress
- f. Receptionist/clerk

1 How often do the mentally handicapped people who live in the residential homes usually come here? (to the place where you work)

- a. Daily
- b. A few times a week
- c. Once a week
- d. Less than once a week
- e. It varies a lot
- f. Don't know for sure

2 From the point of view of the business do you think this frequency

- a. Is about right
- b. Could be more often
- c. Would be better if it were less

Allow the respondent to answer Q3 in their own words and match the response with one of the categories.

3 How many mentally handicapped people come here usually (to the place you work) at a time?

- a. Usually one at a time
- b. Usually one or two together
- c. Usually two at a time
- d. Usually two or three together
- e. Usually three or more
- f. Usually four or more

4 What number in a group suits you best?

5 Do the mentally handicapped customers appear to be joining in (e.g. with the choosing/shopping/paying) when they come here (to the place where you work?)

- a. The mentally handicapped people are nearly always involved
- b. The mentally handicapped people are rarely involved as it is usually done by the staff
- c. It is usually about half and half
- d. Don't know

6 On the occasions when there is communication or actual contact with you and other members of staff, such as paying, taking goods from you, giving goods to you and ordering, how often does the mentally handicapped person join in?

- a. The mentally handicapped people are nearly always involved
- b. The mentally handicapped people are rarely involved as it is usually done by the staff
- c. It is about half and half
- d. Don't know

7 Do you think that the mentally handicapped people could join in more?

- a. Yes, staff could involve the mentally handicapped person more often
- b. No, the mentally handicapped people are involved as much as they can be
- c. Definitely not, I am very impressed by how much the mentally handicapped people do

Arising from the contact you have had with these mentally handicapped customers, I would like to now ask you how noticeably different, if at all, they are from other customers.

8 In your view, do these customers stand out from the others?

- a. Considerably
- b. Moderately
- c. Little
- d. Not at all

If the answer is a or b then ask what features make them noticeable?

9 On the whole would you say that the appearance (clothing, hairstyle and tidiness) of the people from the residential homes is generally

- a. As presentable as the average customer
- b. Less presentable than the average customer
- c. More presentable than the average customer

If the answer is b, how do you think the appearance could be improved?

10 On the whole would you say that the behaviour of the mentally handicapped people is generally

- a. Similar to other customers
- b. Reasonable considering the handicap
- c. Needs improvement

If c is the answer then ask:-

in what ways does it need improvement?

11 Have there ever been any incidents, concerning the mentally handicapped people from the residential homes, which are different to the general behaviour of other customers?

- a. Nothing important
- b. Yes

If the answer is b, could you explain what happened in each incident?

How were they dealt with?

Was this satisfactory -

- a. Yes
- b. No

If no, how would you like to have seen them dealt with?

12 Do you have any concerns about these customers coming to the place you work/here?

- a. No concerns
- b. A few small concerns
- c. Substantial concern

If the answer is b or c - Could you tell us what the concerns are?

13 Have any other customers ever made positive comments to you about the mentally handicapped people coming here?

- a. Yes
- b. No

If yes - please could you say what they were?

14 Have other customers ever made negative comments to you about the mentally handicapped people coming here?

- a. Yes
- b. No

If yes - please could you say what they were?

15 Are there any benefits from these customers using the place where you work?

- a. For you
 - a. Yes
 - b. No

If yes - what do you think they are

- b. For the business

- a. Yes
- b. No

If yes - what do you think they are

- c. For other customers

- a. Yes
- b. No

If yes - what do you think they are

- d. For the mentally handicapped customer

- a. Yes
- b. No

If yes - what do you think they are

16 Can you think of anything that would make it easier for you and the other people here to serve mentally handicapped people?

17 Have you any other comments?

Thank you very much for taking part in this study.