DOES LIVING WITH PEOPLE WHO HAVE CHALLENGING BEHAVIOUR RESULT IN POORER QUALITY OF CARE AND OUTCOMES?

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Introduction

Despite the increasing prominence given in official policy (Department of Health, 2001; Office of the Deputy Prime Minister & Department of Health, 2002) to individualised residential services such as supported living (Allard, 1996; Kinsella, 1993), most people with moderate, severe or profound intellectual disabilities who leave their family home do so to live in groups, usually in staffed group homes in the community. In England in 2001 there were 8,689 homes providing 53,320 places in residential care homes for adults with intellectual disabilities (i.e. mean number of places per home was 6) (Department of Health, 2002). There were 5,164 people with intellectual disabilities in individual supported housing placements in England in 2001 (Joint Centre for Scottish Housing Research, 2001), but the number of these people with substantial intellectual disabilities is probably very small.

Although people live in groups, there has been very little research on the effect of group characteristics on the experience of residents or on how they are treated by staff. Raynes (1980) commented that grouping people with intellectual disabilities who share similar characteristics in residential settings had negative effects on their care. She showed that the most severely disabled residents in her study received more institutional care...
practices, less stimulating speech from staff, less community involvement and poorer physical environment. She argued that these differences were not all functionally related to the nature of resident disabilities but reflected the grouping of residents with similar characteristics together.

A recent study (Mansell, Beadle-Brown et al., 2003) examined the effect of functional grouping on care practices in small group homes in England. This found no significant differences for people who were non-verbal, non-ambulant, had severe social impairment or who were verbal and relatively able. Significant differences were found for people with challenging behaviour, where grouped settings achieved less good results. Regression analysis found that lower adaptive behaviour and grouped settings were predictive of worse care practices for people with challenging behaviour.

This then raises the question whether the detrimental effect of living in a setting where other residents have challenging behaviour extends to those who themselves do not have challenging behaviour. This appears not to have been widely studied in previous research. Mansell et al., (2001) discuss the possible deleterious effects on co-residents of living with people who have serious challenging behaviour and suggest that these might be mitigated by well-organised and resourced staff support, but they present no data on effects.

This study was designed to examine this question, using an existing dataset collected as part of a study of resident characteristics, care practices and outcome in residential care for people with intellectual disabilities (Mansell et al., 2002; Mansell et al., 2003). The first question addressed was whether people who did not have challenging behaviour, but who lived with others who did, experienced worse care practices and worse outcomes. This part of the study also addressed the question of whether particular sub-groups of residents were disadvantaged – those who were particularly vulnerable, because they had sensory impairments or were non-ambulant, or those who were most able, because of the difference between their level of independence and that of more disabled residents. A second part of the study investigated whether it mattered how many people with challenging behaviour lived in the home (i.e. was the effect the same if only one person had challenging behaviour or if many people in the home had challenging behaviour). Third, a stricter definition of challenging behaviour was employed to examine whether frequency and type of challenging behaviour were also important.

Method

Participants and settings

Participants were 303 people with intellectual disabilities living in 68 small homes provided across England by a national charity. These participants were selected from a larger study of 495 people, 95% of the total population of people with intellectual disabilities served by this charity, because they had assessments of their characteristics and also had ratings made by observers of how staff provided support to them.

On average the homes provided 6.5 places (range 2-14). The staff ratio averaged 0.65 (range 0.3-3.1). The length of service of staff averaged 44 months (range 5-104) and staff turnover (defined
as the number of staff leaving the service in the previous year divided by the mean number of staff in post, expressed as a percentage) averaged 47% (range 0-227%). Staff teams had widely varying compositions and training; the percentage of senior staff (Manager, Deputy Manager or Senior Team Member) ranged from 31 to 100%, with an average of 64%. The percentage of the charity’s own management development programme completed by each Service Manager averaged 69% (range 0 to 100%). The percentage of the Manager and Deputy Managers in each service who had attended ‘active support’ training (concerned with care practices designed to promote and facilitate resident engagement in meaningful activity) averaged 70% (range 0 to 100%).

**Measurement**

**Resident characteristics**

Adaptive behaviour of participants was rated using the American Association on Mental Retardation Adaptive Behavior Scale Part 1 (ABS) (Nihira et al., 1993). The ABS measures independence and adaptive behaviour and has a possible maximum total score of 322. It is divided into ten behaviour domains: physical development, language development, domestic activity, numbers and time, economic activity, independent functioning, vocational activity, self-direction, responsibility and socialisation.

Problem behaviour was rated using the Behavior Problems Inventory (BPI) (Rojahn, 1994). The BPI rates 29 specified problem behaviours in groups relating to self-injurious behaviour, aggression and stereotyped behaviour, with the opportunity to specify additional problems. Problems were rated for frequency (never occurred, less than monthly, monthly, weekly, daily, hourly or more than hourly). Following McGill et al. (2001), frequency of problem behaviours was summed to give a total score (maximum 222) indicating the overall burden represented by each person’s challenging behaviour. Each behaviour was also rated for whether it presented a behaviour management problem for staff, distinguishing between those causing severe management problems (staff had to intervene, upset other residents, marked effect on social atmosphere or unacceptable in public), lesser problems, those not causing a problem and potential problems (where the problem was controlled in the present environment but was likely to reoccur as a severe problem if the environment changed).

Social impairment was rated using a specially constructed Social Impairment Scale (SIS), which comprised 7 items relating specifically to social impairment from the Abnormal Behaviour section of the Handicaps, Behaviour and Skills Schedule HBS (Wing and Gould, 1978). These items related to whether the person made and used eye contact with other people, spontaneous show of affection, their response to age peers, social play, willingness to join in leisure activities and overall quality of social interaction. These items were summed to give a total score, expressed as a percentage, with scores from 0 (profound social impairment) to 100 (no social impairment).

**Care practices**

The nature and quality of staff support was rated for each resident using a 15-item rating scale, the Active Support Measure (ASM) (Mansell and Elliott,
Each item was scored on a scale of 0 (poor, inconsistent performance) to 3 (good, consistent performance). The items were:

1. Age-appropriateness of activities and materials
2. ‘Real’ rather than pretend or very simple activities
3. Choice of activities
4. Demands presented carefully
5. Tasks appropriately analysed to facilitate client involvement
6. Sufficient staff contact for clients
7. Graded assistance to ensure client success
8. Speech matches developmental level of client
9. Interpersonal warmth
10. Differential reinforcement of adaptive behaviour
11. Staff notice and respond to client communication
12. Staff manage serious challenging behaviour well
13. Staff work as a coordinated team to support clients
14. Teaching embedded in everyday activities
15. Specific, written individual programmes in routine use

Engagement in meaningful activity

At the same time that ratings of active support were made, researchers rated the engagement in meaningful activity of residents in each home using a similar four-point scale (0=largely disengaged, 1=engaged less than 50% time, 2=engaged between 50 and 75% time and 3=engaged more than 75% time). Engagement in meaningful activity was defined, after (Mansell et al., 1987) as

1. Interacting with another person
2. Using materials or equipment (not just holding or carrying them), such as a vacuum cleaner or lawnmower or coffee pot
3. Taking part in a group activity such as watching the ball and running after it in a game of football.

Engagement in meaningful activity was distinguished from disengagement:

1. Doing nothing, dozing, just walking around
2. Repeating the same thing over and over again to no purpose
3. Doing something disruptive
4. Being processed – passively allowing someone to do something to you without joining in (e.g. being dressed)

Procedure

The assessment schedules (the ABS, BPI and SIS) were sent to the manager of each home, who was asked to ensure that they were completed by a member of staff who knew the individual resident well. Questions and clarification about the information required were dealt with by the fourth author, who also followed up data collection to obtain the fullest information possible and dealt with queries arising during data processing.

Care practices and resident engagement in meaningful activity were assessed by direct observation in each home. Observations were made over a 3-4 hour period around a meal time because this seemed likely to provide many opportunities to see staff providing support.
Reliability

The reliability and validity of the ABS, BPI and the HBS (from which the SIS was drawn) have been studied and reported as acceptable by their authors. Reliability was measured in the study of which this was part by asking the same member of staff to repeat the rating a few weeks after initial data collection (i.e. the measure was of pre-test/post-test reliability). Pairs of ratings were made for 4% of the population studied (19 residents for the ABS and 21 for the BPI and the SIS). Pearson product-moment correlation coefficients were calculated for pairs of total scores on each measure and were 0.96 for the ABS (p<0.001), 0.75 for the frequency score of the BPI (p<0.001), 0.79 for the BPI severity score (p<0.001) and 0.85 for the SIS (p<0.001).

For 38 residents of six homes (selected quasi-randomly), a second rater made independent assessments on the ASM and engagement in meaningful activity. Inter-rater reliability was assessed using Cohen’s kappa (Cohen, 1960). For all but two items on the ASM, kappa values exceeded 0.6 (ranging from 0.64 to 0.96) and were therefore judged acceptable (Bakeman and Gottman, 1986). For ‘Differential reinforcement of adaptive behaviour’ kappa was 0.55. For ‘Staff manage serious challenging behaviour well’ too little challenging behaviour was observed to assess inter-rater reliability and this variable has been excluded from further analysis. For resident engagement in meaningful activity, kappa was 0.953 (p<.001).

Analysis

For each set of analyses described below, differences were examined in resident characteristics (ABS and SIS), care practices (ASM items) and engagement in meaningful activity.

First, the effect of the number of people with severe or potentially severe challenging behaviour (using the severity item on the BPI and recoded into quartiles) was examined using a Kruskall-Wallis non-parametric analysis of variance. This analysis was completed for all those people who did not have severe or potentially severe challenging behaviour themselves, and for three sub-groups: those who were non-ambulant (ABS item 28a=0), had major sensory impairments (ABS item 25 or 26 <2), or who were the most able (those having scores in the top quartile on the ABS).

Next, Mann-Whitney tests were undertaken to determine the effect of living with people with challenging behaviour on anyone who did not have challenging behaviour (irrespective of what other characteristics they had) in two situations:

1. homes where no-one with severe or potential challenging behaviour lived compared with homes where anyone had severe or potential challenging behaviour
2. homes where 75% or fewer people in the home had severe or potential challenging behaviour versus those where more than 75% had severe or potential challenging behaviour

Finally, this analysis was repeated using a more stringent definition of problem behaviour, which included only severe and frequent (weekly or more) aggression.

Since analysis involved a large number of comparisons, only those results significant at p<0.01 are reported.
Results

Resident characteristics

The average age of residents in this study was 39 years (range 16-78). 60% of participants were men and 95% were white. Mean total score on Part One of the ABS was 130 (range 12-298). Average total frequency score on the BPI was 13 (range 0-96). 31% of residents were rated as presenting a lesser management problem, 12% as presenting a potentially severe problem and 34% a severe problem. The average score on the SIS was 50 (range 0-100).

Effect of living with other people who have challenging behaviour

There were 162 people who did not show severe or potential challenging behaviour; 22 had sensory impairments, 59 were non-ambulatory and 43 of them had ABS scores in the top quartile. There were no differences in the Kruskal-Wallis analysis for any of the variables for any of these four groups.

There were 35 people living in homes where no-one had severe or potentially severe challenging behaviour and 127 in homes where someone had such behaviour. Analysis using Mann-Whitney tests found no significant differences in resident characteristics, care practices or engagement in meaningful activity.

There were 156 people living in homes where less than 75% of residents had severe or potentially severe challenging behaviour and 6 in homes where 75% or more had such behaviour. Analysis using Mann-Whitney tests found no significant differences in resident characteristics, care practices or engagement in meaningful activity.

Using the more stringent definition of challenging behaviour similar results were found. There were 170 people living in homes where no-one had severe and frequent aggression and 93 living in homes where someone had such behaviour. No significant differences in resident characteristics, care practices or engagement in meaningful activity were found. No-one lived in a home where 75% or more of the residents had severe and frequent aggression.

Discussion

This study found that there was no effect on outcomes or care practices experienced by people who did not have challenging behaviour themselves, of living in homes where other residents had severe or potential challenging behaviour. This was also true for those groups that might be considered more vulnerable (those who were non-ambulant or who had sensory impairments) and for those people who were considered more able. There were no differences between those people living with no-one with challenging behaviour, compared to those living with at least one other person with challenging behaviour, and no differences between those people living in homes where less than 75% of the residents had challenging behaviour compared to those where 75% or more had challenging behaviour. Finally, there was also no effect detected when a narrower definition of challenging behaviour as severe and frequent aggression was used.

This is a surprising result and, since this issue has been the subject of so little research, it should be treated with caution. There are several possible explanations, which should be considered:
the measures of engagement and staff practices may be insufficiently sensitive to pick up differences that do exist between the groups studied. However, the same measure was used in Mansell et al. (2003) and differences were detected between mixed and grouped settings, implying that it is sensitive to the effects being examined here.

(ii) The ASM measures mainly quality of interaction and it is possible that the effect of living with other people who have challenging behaviour is experienced in the amount of interaction. Emerson et al. (1992), in a study of a specialised unit for people with challenging behaviour in houses on the edge of a hospital campus, found that the most disturbed residents received disproportionately more staff attention and contact.

(iii) People with the most severe challenging behaviour, whose presence might affect co-residents, may already have been excluded from the services provided by the national charity. However, this sample does include individuals with multiple, severe problem behaviours comparable with the group identified by Lowe et al. (1998) as having the most severe challenging behaviour in Wales.

(iv) It may be that, in these relatively well-staffed services (compared with staffing in the institutions they have replaced), staff are effective in individualising care practices, so that those without challenging behaviour are not disadvantaged.

The implications of these findings are twofold. First, it is clear that more research in this area is needed in order to understand more about the effects of people living in grouped settings, in particular to understand in what ways are staff differentiating between care of those with challenging behaviour and those without. Taken together with the findings of Mansell et al. (2003), this study raises the question, why are care practices worse for those with challenging behaviour living in grouped settings but not for people without challenging behaviour?

Second, these findings counsel caution in assuming that people will have poorer outcomes or receive worse treatment if they live in settings with people with challenging behaviours. It may be that, as Mansell et al. (2001) suggest, sufficient skilled staff support can avoid the presumed disadvantages of settings which mix resident characteristics. At the same time, it must be acknowledged that for the most part these people did not choose where to live and that, given that choice, people might not opt to live with those who have challenging behaviour. This argument applies equally, of course, to people who have challenging behaviour.

**Summary**

Following earlier findings that people with intellectual disability and challenging behaviour received poorer care when they lived in a grouped setting (75% or more residents also having challenging behaviour), this study aimed to investigate whether people without challenging behaviour also experienced different care or lower engagement in meaningful activity when living with people with severe or potentially severe challenging behaviour. Kruskal-Wallis analysis revealed no effect of living in homes where residents had challenging behaviour, ei-
ther on care practices or on engagement in meaningful activity. This was also true for sub-groups selected because they might be more vulnerable. Further Mann-Whitney analyses revealed no differences between those living in homes where no-one had severe or potentially severe challenging behaviour compared to those living in homes where anyone had challenging behaviour, and no differences between those people living in homes where less than 75% of the residents had challenging behaviour compared to those where 75% or more had challenging behaviour. Using a narrower definition of challenging behaviour, as severe and frequent aggression, also produced no significant effects. Possible explanations for these somewhat surprising results are discussed and suggestions for future research are presented.

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References


