

THE MOVE FROM HOSPITAL: AN EVEN LONGER TERM FOLLOW UP OF CHALLENGING BEHAVIOUR LEVELS

Introduction

Over the last few decades, there has been a major shift in the care of people with learning disabilities away from care in large scale institutions towards smaller more flexible housing options based in the community. This has been supported by both moral and empirical arguments. According to Mansell and colleagues, "The segregation of disabled people in institutions is a human rights violation in itself. Furthermore, research has shown that institutional care is often of an unacceptably poor quality and represents serious breaches of internationally accepted human rights standards. Evidence from research and evaluation of alternatives to institutional care also supports the transition to services in the community. Where institutions have been replaced by community-based services, the results have generally been favourable" (Mansell et al., 2007).

Challenging Behaviour has been defined as "culturally abnormal behaviours of such an intensity, frequency or duration that the safety of the person or others is likely to be placed in serious jeopardy or behaviour that is likely to seriously limit the use of or result in the person being denied access to community facilities" (Emerson, 1995). Challenging behaviours can have a variety of causal and maintaining factors, but it might be expected that there may be higher levels of such behaviour in institutional environments which are often characterised by barren settings,

lacking personal contact or structured activity. However, the evidence is far from convincing that moving people out of such settings into smaller community based residences has an effect on their challenging behaviour levels. Emerson and Hatton (1994) found in their review of deinstitutionalisation that only 5 out of 20 studies that followed up people leaving institutions demonstrated improvements in challenging behaviour levels. In their review of 10 years of deinstitutionalisation outcome studies in the US, Kim et al., (2001) found that although "almost all of the reviewed studies found statistically significant increases in overall adaptive behaviour scores associated with deinstitutionalisation" only "three studies published since 1990 reported statistically significant improvements in challenging behaviour associated with movement to the community, and nine reported no significant differences in challenging behaviour for persons who moved compared with persons who remained in institutions."

Many studies on the outcomes of deinstitutionalisation result from only short term follow ups. Collins and Halman (1996) followed up a sample of 16 people over a two year period after their move from a closed learning disability hospital in 1992 to staffed group home settings. There were some indications of decreases in challenging behaviour levels, with a significant decrease in aggression to other residents being demonstrated. The current paper reports on a further follow up on eight of these individuals

using the same measure as the original paper 15 years after the original baseline.

Method

Participants and settings

Collins and Halman (1996) followed up 16 people who had been resident in a long stay hospital for people with intellectual disabilities. They were also reassessed in 2001. In 2007 as part of a review of residents' needs, eight of these individuals were assessed again on the Brief Challenging Behaviour Scale used in the original study. Since the hospital closure in 1993, the subjects had been living in staffed group homes, which vary in size from four to seven residents. Each was a National Health Service (NHS) staffed residential home in the community, mainly for people with severe challenging behaviour. They were purpose built bungalows and each had a community oriented philosophy, where staff were trained in the management of challenging behaviour.

The cohort had a mean age of 51.4 (range 40 to 73 years). There were seven males (88%) and one female (12%).

The Measure

The Brief Challenging Behaviour Scale was used in all surveys. This scale is based on the Challenging Behaviour Scale (Wilkinson, 1989). The Challenging Behaviour Scale listed 39 challenging behaviours, each of which was rated for its severity and frequency. Behavioural descriptions are given to help clarify the ratings. However, in our original study we found unacceptable low reliability for many items on the scale, and only used 3 items which had acceptable reliability and covered the main areas of challenging behaviour. Therefore

the Brief Challenging Behaviour Scale consists of ratings of Aggression, Self Harm and Destruction. Each of these is rated on a 5 point scale of frequency – from Never, Rarely, Occasional, Often and Very Often and on a 3 point scale of severity: Minor, Moderate or Severe. Each of these points has a behavioural description to aid rating. The scale was used at 5 points in time, 1992, 1993, 1994, 2001 and 2007. The previous paper had statistically compared the 1992 and 1994 data. This paper compares the 2007 data with earlier times, with particular reference to 1992 and 1994 data from the original paper.

Results

It was felt important to focus on the most severe challenging behaviours. People were categorised as showing frequent challenging behaviour if it occurred two to three times a month or more (Brief Challenging Behaviour Scale rating "Occasional" or worse) and was rated as having significantly severe challenging behaviour if it was rated as "moderate" or "severe" in intensity on the Brief Challenging Behaviour Scale.

FIGURE 1 shows the numbers of people rated as showing frequent challenging behaviour over the 5 data points.

FIGURE 2 shows similar data for numbers of people showing significantly severe challenging behaviour at the same time points of assessment.

It can be seen that there appears to be a downward trend in both frequency and severity for aggression but this is not so clear for destruction or self injury. To determine if this trend was significant, a chi-square test was carried out to establish the significance of the difference between the numbers of people rated as challenging before the move, at the first follow-up in 1994 and the follow-up in 2007. TABLE I shows that when comparing

FIGURE 1
Numbers of people in cohort showing frequent challenging behaviour between 1992 and 2007

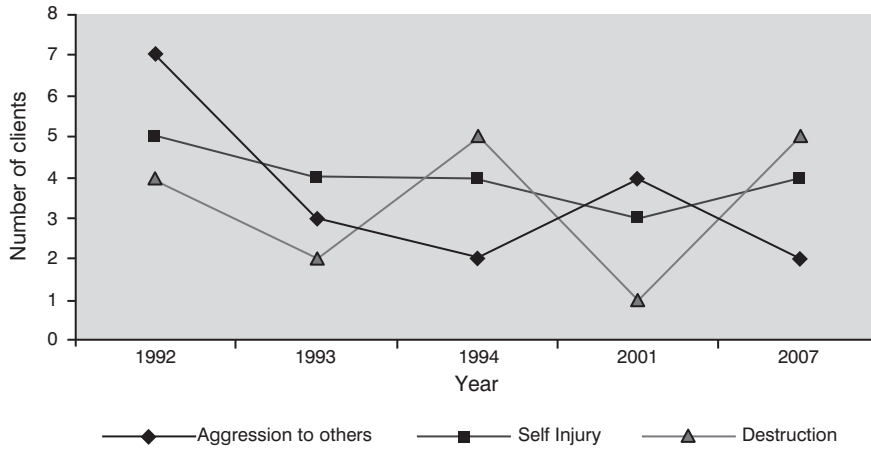
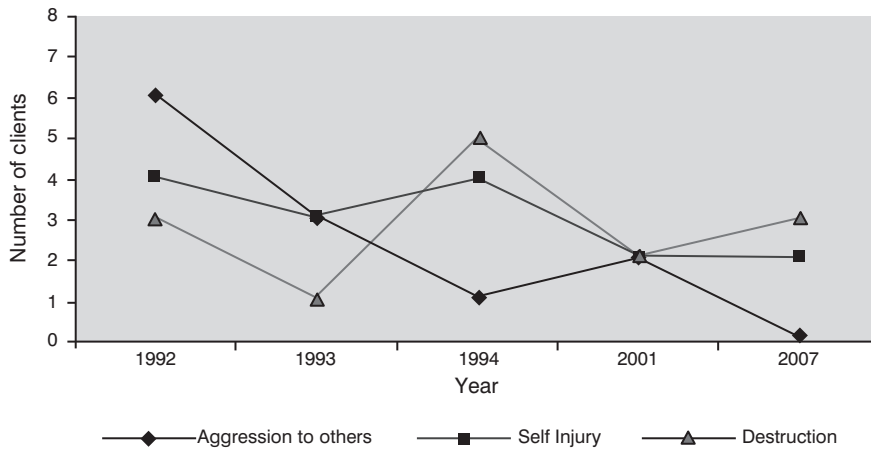


FIGURE 2
Numbers of people in cohort showing significantly severe challenging behaviour between 1992 and 2007



the data between 1994 and 2007, there were no significant changes in frequency or severity of challenging behaviour ratings for aggression to others, self injury or destruction. However, when comparing the data between 1992 and 2007, there were significant reductions in ratings of frequency and severity of aggression to others. There was no significant change in the levels of self injury and destruction.

Discussion

This study has looked at the severity and frequency of challenging behaviour over 15 years in people with learning disabilities, following their move out of a large hospital in 1993. Only eight people have been able to be followed during the whole of this time. At a previous evaluation (Collins and Halman 1996) statistically significant decreases in aggression were found between 1992 and 1994. The current data show that while no further decreases in aggression have occurred, the current levels are still significantly lower than the hospital baseline. Other types of behaviour were at the same broad levels as at the baseline.

In trying to understand these results, it must firstly be recognised that most of these

residents had been living in institutional care for several decades, many since childhood, and patterns of behaviour learned and reinforced over this timescale can be very resistant to change. The numbers in the study were small which makes significant changes harder to detect. Because the living conditions for the subjects appear to be better now than when they lived in the hospital, it may have been predicted that all challenging behaviour should have decreased. The setting conditions and triggers for challenging behaviour have improved (e.g. smaller group living, own bedrooms rather than dormitories, greater access to day services) and also the conditions for responding appropriately to behaviours and teaching alternatives are better (e.g. better staffing levels, more training for staff). However, many of the destructive and self injurious behaviours are very entrenched, and certain of the setting conditions for them have not changed e.g. periods of lack of engagement in activity, high levels of noise etc.

It is interesting that levels of aggression do seem to have decreased. It can be postulated that this may be due to the very different social environments. The original hospital wards housed between 15 and 30 people, many of whom exhibited very challenging behaviours. Provocation by others was frequent, and aggressive behaviours could often be very

TABLE I
Chi-squared comparisons of numbers of groups whose behaviour was rated as frequent and significantly severe between three different time periods

	1992-1994	1994-2007	1992-2007
Frequency of aggression	6.91 sig p <0.01	0.33 n.s.	6.91 sig p <0.01
Severity of aggression	6.28 sig p <0.05	0.26 n.s.	9.06 sig p <0.01
Frequency of self injury	0.57 n.s.	0.25 n.s.	0.57 n.s.
Severity of self injury	0.56 n.s.	1.06 n.s.	1.06 n.s.
Frequency of destruction	0.44	0.26 n.s.	0.44 n.s.
Severity of destruction	1.25 n.s.	1.25 n.s.	0.26 n.s.

sig - significant; n.s. - not significant

adaptive in maintaining personal safety and the person's place in the social hierarchy. Also, aggression was more tolerated by staff than it would now be in present day settings. The residents all lived at follow up in NHS long stay housing, in groups of between 3 and 5. They enjoyed more individualised treatments and activities, and there were less potential provocations from others. Aggression could be seen to have therefore fewer triggers and be less adaptive in obtaining desired outcomes.

The value of such long term recording of behavioural levels can be in promoting realism in attempts to modify and manage challenging behaviour, adding an appreciation of how long such behaviours have been used by the person to cope with their own circumstances, and what an effort will be required to seriously tackle the issues of understanding them and finding more acceptable alternatives. As Mansell et al., (2007) conclude: "However, experience shows that moving to community-based services is not a guarantee of better outcomes: it is possible to inadvertently transplant or recreate institutional care practices in new services. Developing appropriate services in the community is a necessary, but not a sufficient, condition for better results."

Summary

Data on levels of challenging behaviour were collected on a sample of fifteen people who moved from a learning disability hospital setting to staffed community houses. A previous study had found some evidence of a reduction in frequency of aggression to other residents two years after the move. The current study followed up the behaviour levels fifteen years after the move and indicated that decreases in frequency and severity of aggression had been maintained, while other types of challenging behaviour were unchanged from the hospital days.

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