Twelve years on: outcomes and costs of deinstitutionalisation for people with mental health problems

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Background

In the mid 1980s the UK's Department of Health sponsored a programme of demonstration projects to establish models of community care for long-stay patients living in institutions, known as the *Care in the Community* programme. A parallel evaluation of costs and outcomes for over 400 people who moved to community services between 1986 and 1987 was undertaken by the PSSRU (Knapp et al., 1992). Here we report on the 12-year follow up of people with mental health problems. (See Cambridge et al., 2002 for results from the study for people with learning disabilities).

Of those users assessed while in hospital, we were able to trace 107 12 years later, of whom 68 (64%) had been assessed nine months after leaving hospital. We also identified 21 former hospital patients who had been discharged but who had not been assessed in the earlier evaluation. Prior to resettlement, these 128 users had been living in the same hospital for an average of 12 years.

Service users' skills and behaviour

Since the initial discharge from hospital, there had been significant reductions in users' mobility, their ability to wash, bathe and dress, and in their appearance. Clarity of speech was thought to have deteriorated, but conversation and social interaction had improved. Ratings of co-operative behaviour had decreased and argumentative behaviour increased. The majority of residents were functioning quite well and had relatively few symptoms and behavioural problems but around a quarter of users were significantly impaired, and 10–15 per cent presented quite serious problems.

There was some evidence of an overall increase in symptoms and behaviour problems since leaving hospital. For example, a greater proportion of users were reported to be awake at night and there were marginally significant increases in the reported incidence of odd gestures and mannerisms, obsessiveness, depression and suicidal preoccupation. There was also a marginally significant increase in the proportion of residents showing a degree of confusion.

Box 1 Characteristics of the sample

- 83% had a primary diagnosis of schizophrenia
- Average age at follow-up was 62 (range 35–93)
- 43% were aged over 65
- 50% were women and over three-quarters were single
- Over 80% were of white British origin

Service users' views

A much higher proportion of users were satisfied with their community accommodation than with hospital, and very few wished to return, although the proportion of satisfied users had decreased a little since the nine-month follow up. There were, however, substantial minorities who were not happy with the degree of privacy offered and only half had positive relationships with neighbours. Relationships with staff were generally positive, but there was room for improvement. Many users in residential and nursing homes did not feel that they had choices in their lives.

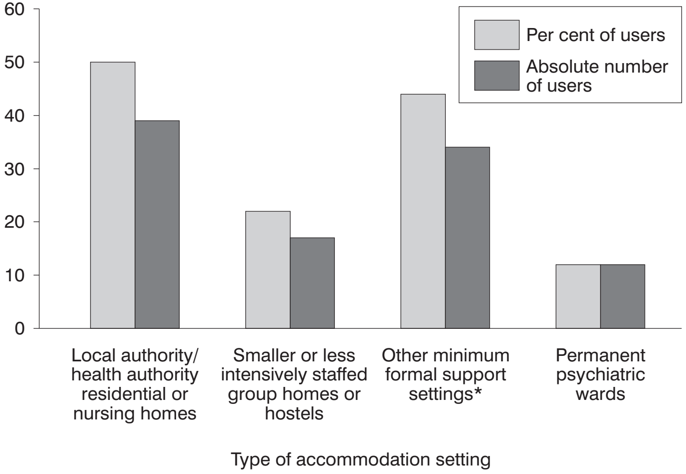
Social networks

The average size of social networks (23 contacts) compared favourably to that reported in other studies but they included mainly staff and other service users. Residents living in hospital or hostels and small group homes had fewer close and confiding relationships than those in other accommodation types. Residents in hostels and small group homes were least frequently in contact with their network members.

Residents living in private and voluntary sector accommodation received less help with domestic tasks, less material aid and less support for decision making compared to people living in accommodation managed by the public sector. They also had fewer confiding relationships. Conversely, they were less likely to be on the receiving end of critical behaviour from their network members.

The costs of community care

Figure 1 Accommodation settings 12 years after leaving long-term inpatient care



* 13 settings were recorded, including adult foster placements, unstaffed group homes, sheltered housing, and independent living in domestic housing.

People lived in a range of different accommodation types (see figure 1) and drew on a wide range of community services and supports. There were, therefore, many organisations involved in supporting people but there was little evidence to suggest that organisations worked together to create support packages. For example, people with mental health problems living in social services managed accommodation rarely used services provided by NHS Trusts.

The average weekly total cost per resident remained lower than the long-stay hospital costs. However, the range was considerably wider, suggesting a greater diversity of support arrangements. After standardising for users' skills and behaviour problems, costs in supported accommodation were significantly lower than expected and costs for people living permanently in hospital were somewhat higher than expected.

The support costs could not be predicted from users' characteristics as measured in hospital 12 years earlier. There was no evidence of a relationship between cost and changes in skills, and only weak evidence to suggest that the more a person's behaviour had deteriorated over the 12-year period, the more costly is their package of care.

Organisational issues

The study assessed the wider organisational aspects of community care, including care management. This was a requirement of the original pilot projects, and in mental health has developed through the implementation of the care programme approach (CPA). A key finding was that 12 years on, the CPA was poorly or rarely integrated with care management and many users were not included in the CPA arrangements. Common criticisms of the CPA included lack of psychiatric input and that the process was dominated by form filling.

Although joint working had developed considerably since the inception of the pilot projects, funding had become increasingly uncertain and lines of accountability were often fractured. Services that were best placed to respond to changing local and national management and policy environments were generally part of wider local service strategies for their client group. The most isolated services were those provided by voluntary and independent sector agencies.

One of the most pressing service development issues was the changing resource, support and service coordination demands associated with an ageing clientele. Difficulties in staff recruitment, particularly in London and the south east of England were also identified.

Conclusion

This evaluation demonstrates that in essential respects, community care is working for people with mental health problems with most users adequately supported and satisfied with their lives and accommodation. There was no evidence of changes in skills and only weak evidence of a small increase in symptoms and behaviour problems, suggesting that the long-term clinical and social outcomes were at least satisfactory. Overall, the care costs were lower than while users had lived in hospital or at the nine-month assessment. However, it is worrying that despite having lived away from hospital for over a decade, people were still interacting predominantly in a community within a community.

Acknowledgement

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Papers currently available from this research project

Beecham, J., Hallam, A., Knapp, M. et al. (2003) Twelve Years On: service use and costs for people with mental health problems who left psychiatric hospital, in preparation.

Cambridge, P., Carpenter, J., Beecham, J., Hallam, A., Knapp, M., Forrester-Jones, R. and Tate, A. (2002) Twelve Years On: the long-term outcomes and costs of deinstitutionalisation and community care for people with learning disabilities, *Tizard Learning Disability Review*, 7, 3, 34–42.

Carpenter, J., Cambridge, P., Tate, A., Forrester-Jones, R., Coolen-Schrijner, P., Beecham, J., Hallam, A., Knapp, M. and Wooff, D. (2003) Twelve Years On: the social and clinical outcomes of community care for people resettled from psychiatric hospitals, submitted for publication.

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M. and Beecham, J. (2002) The quality of life of people twelve years after resettlement from long-stay hospitals: users' views on their living environment, daily activities and future aspirations, *Disability and Society*, 17, 741–758.

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Mental health law in Scotland

Angela Hallam, a former colleague at PSSRU and CEMH, now works in the Health and Community Care Research Team in the Health Department at the Scottish Executive. Her role is to develop a long-term programme of research into the operation of mental health law. The programme aims to evaluate the operation and impact of the Mental Health (Care and Treatment) (Scotland) Act, once it has come into effect.

The broad aims of the research programme are as follows:

- To provide information to support the implementation of the new legislation
- To contribute baseline information to understand the operation of the Mental Health (Scotland) Act 1984
- To evaluate the operation and impact of the new legislation
- To evaluate whether the aims of introducing the new legislation have been achieved, taking account of the expectations of all stakeholders.

A process of consultation in summer 2003 allows stakeholders to have a say in the development of the research programme. For more information about the programme or the consultation process, please email Angela.Hallam@Scotland.gsi.gov.uk.