

Estimating the Number of People with Intellectual Disabilities in 'Out Of Area' Residential Placements

Jim Mansell, Julie Beadle-Brown, Clare Skidmore, Beckie Whelton, Aislinn Hutchinson, Tizard Centre, University of Kent.

Abstract

Out of area placement of people with intellectual disabilities is a potentially problematic practice. Few data exist on the scale of out of area placement. Every care home in a large English county was surveyed to find the number of people placed by other authorities. Information was cross-checked by asking three placing authorities for information about everyone they had placed in residential care in the county. The survey identified 759 people placed by other authorities in homes in the county. Cross-checking suggested that only about half to two thirds of placements were being identified. Residents included all age groups, a disproportionate number of men and were mainly placed for long-term care. Between 30 and 54 per cent had not been contacted by their care manager for at least a year. It seems likely that between 1,000 and 1,400 people were placed by other authorities in this county, occupying 30 to 40 per cent of all residential placements. This figure does not include placement in health facilities or 'supporting people' placements. The number of people placed by other authorities seems likely to pose a considerable extra demand for health and social care services.

Keywords

Intellectual disabilities, people with learning disabilities, care homes, long term placement, social care provision, care markets, survey.

Introduction

About 44,000 people with intellectual disabilities live in residential care in England (Department of Health, 2004a). The need for accommodation with support is increasing because of demographic changes and there is a growing shortage of places (Emerson & Hatton, 2004). In addition, the distribution of places varies widely between different parts of the country, so that places are particularly scarce in some areas (Emerson & Hatton, 1998).

Where suitable services are not available locally, people with intellectual disabilities may end up in residential homes outside their own local area,

sometimes a long way away. Moving away from their own community is likely to make it more difficult for people to keep in touch with family and friends. Out of area placement may not just reflect a general local shortage of residential care but a shortage of particular kinds of accommodation and support. This is most likely to be an issue where individuals present challenging behaviour. The shortage of good local services to support people in spite of their challenging behaviour has been recognised for some time and concern has been expressed about the quality of alternatives (Department of Health, 1993b).

The policy framework governing out of area placements is complex, inconsistent and risks producing perverse incentives (Mansell *et al.*, 2006). Where residents have moved to a home from another part of the country, they remain the responsibility of the 'sending' social services for funding and care management (Department of Health, 1993a, 2003). They get health services from those in either their old or new home's area, depending on what they need and when the need arises (Department of Health, 2006). Problems of communication and co-ordination have been found in these circumstances (Beadle-Brown *et al.*, 2006; Buckinghamshire County Council, 1998; Pring, 2003; Ritchie *et al.*, 2005).

Out of area placement is, therefore, potentially an important policy issue. However, there are few official data on people placed out of area in England. It is known that there are over 11,000 people supported out of area by local authorities in England (Department of Health, 2004b). This represents 31 per cent of all people with intellectual disabilities supported by local authorities. There is no information on placements by NHS organisations, nor is there information about where people end up. A recent study by Ritchie and colleagues (2005) tracked all the out of area placements made by health and social services agencies in the West Midlands and found 623 placements in 56 different authorities costing £35 million per annum. This paper reports the results of a survey of care homes and analysis of official records to identify the number of people placed in one large English county by other authorities. Thus, it complements the study by Ritchie and colleagues by focusing not on *where* people are sent out of area, but on the impact on a social services authority of placements *made by others*.

Method

The method adopted to estimate the number of people with intellectual disabilities placed in the county was a postal survey of all residential care homes, supplemented by further investigation in relation to three placing authorities (a county and two London boroughs). The county was in the south east of England.

A list of registered care homes was obtained from the (then) National Care Standards Commission. This included 400 homes, providing capacity for 3,484 residents. Every home was asked to provide information about residents placed by other authorities. For each resident, the information requested included name and date of birth, dates of admission, names and contact details of the responsible care manager, date of the last care manager review and the authority responsible for funding the placement. Information about the price of each placement was not requested since this was thought likely to be seen as commercially confidential and likely to prejudice return of the questionnaires. Incomplete returns were followed up by telephone to ensure as complete a set of responses as possible.

Three placing authorities provided lists of the people they recorded as placed in the county. This information was checked against the results of the survey.

Results

Of the 400 homes surveyed, responses were received from 325 (81 per cent), in respect of 759 people. Three homes refused to provide information; the remaining 72 failed to return the questionnaire despite prompting.

When checked against information supplied by three placing authorities, substantial discrepancies were found

(see Table 1). Only 53 per cent of the total numbers of people identified by either source were found by both, and the survey only identified 76 per cent of the total. Evidence of missing information is also provided by comparing the total number of residential places recorded by the National Care Standards Commission (3,484) with the number of placements funded in the county by the local social services department (1,815) and the survey results (1,000-1,400). Even allowing for NHS funded placements, privately purchased places, and empty places, this still suggests that there are many more individuals placed from out of county than were identified in the survey.

Table 1: Agreement between survey and placing authorities' data

Authority data	Survey data		
	% Found	% Not found	% Total
% Found	52	24	76
% Not found	22	-	22
% Total	74	24	98

Characteristics of people placed

Seven hundred and fifty-nine people who had been placed by other authorities were identified. Of these, 63 per cent were men and 37 per cent women. Their average age was 41 (range 17-96). There was no significant difference between the age distribution of the population in this study and that reported by Mansell and colleagues (2002) from a study of 99 services located throughout England and provided by one national charity (Mann-Whitney, $Z= 1.732$, $p=0.176$).

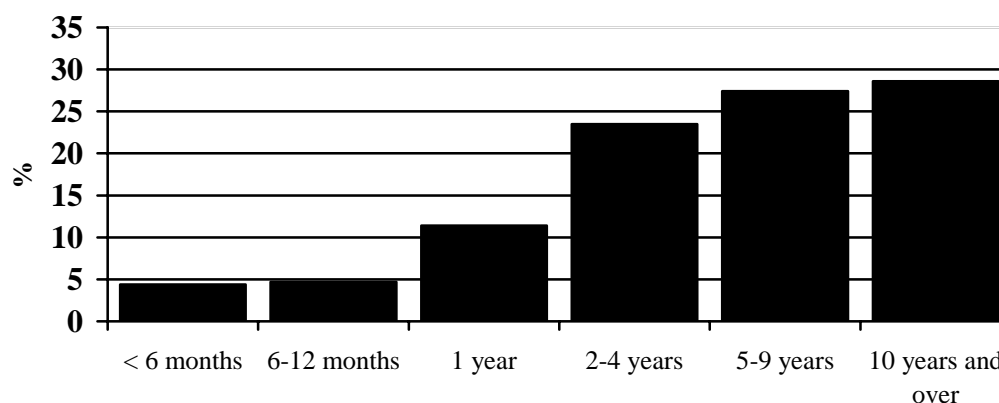
On average, their length of stay was 7 years 10 months (range 1 month to 37.4 years). Figure 1 shows the distribution of length of stay. The overwhelming majority (96 per cent) of placements were described as long-term. The 29 cases classified as short-term had an average length of stay of 3.4 years (range 2 months to 8.1 years). Thirteen of the 29 had been in what were termed short-term residential placements for 4 years or more.

Placing authorities

Ninety-nine authorities had placed people with intellectual disabilities in residential care in the county. The largest number (65) were placed by a neighbouring unitary authority. Sixty two per cent (473 people) were placed by London authorities. The furthest authorities were in Scotland and Wales. The average number of people placed by each authority was 8 (range 1 to 65, standard deviation 12.3).

Details of a care manager were provided in relation to 506 people (67 per cent). On average, the date of the last care manager contact with residents was 9 months before the survey date (range 1 to 124 months). Seventy per cent of residents had received a contact from their care manager in the last year. However, this result needs to be interpreted with caution given that in 253 cases no information was provided. If these cases reflect lack of contact with a care manager then over half the sample would not have had contact in the last year.

The frequency of contact was compared for the group placed by authorities within and beyond the home counties in order to see whether care managers visited less often for people placed by authorities further away. This showed that there was no statistically significant difference ($t=0.854$, $df=504$, $p=0.394$).

Figure 1: Average length of stay for participants

There was a weak correlation between time since the last care manager visit and both length of stay ($r=0.094$, $n=499$, $p=0.035$) and resident age ($r=0.089$, $n=505$, $p=0.045$). Older people, or people who had been resident in the county for longer, tended to have a longer gap since the last care manager visit. This result needs to be interpreted with caution, given the large number of cases in the correlation.

Residential homes used

Placements were made in 197 different homes, provided by 104 organisations. The average number of people from out of area placed at the same address was 4 (range 1-30).

There appeared to be an association between the placing authority and the organisations receiving placement; that is, the same organisations tended to receive placements from particular placing authorities. Among the 13 authorities placing more than 20 people in the county, seven placed more than 8 people with the same care provider. These seven authorities were placing, on average, 34 per cent (range 23-48 per cent) of their clients with providers serving more than 8 people from that authority. In six cases, these placements were with one provider; in the other, two providers were used. Half the

placements were in the eastern of three administrative areas of the county, especially in the coastal towns. In one district, for example, there were more people with intellectual disabilities placed from other local authorities than there were from the county itself.

Discussion

Since this study was of out of area placements made in one county, caution should be exercised in generalising the results. The rather poor agreement between the survey results and the returns provided by three placing authorities would benefit from further investigation. Many home managers seemed unsure about funding arrangements when questioned. Therefore, it seems likely that mistakes will have been made by some homes when providing this information. Similarly, there were practical problems extracting information from official record systems and it is likely that this was also a source of error.

It would also be useful to replicate the survey for people placed in NHS and private health care facilities. Although it might be expected, if official guidance had been followed, that the local authorities providing social care to these individuals (whether they were the placing authority themselves or whether

their local primary care trust had made the placement) would have them on their list of people placed out of area, this may not have been the case.

Similarly, people in *Supporting People* placements were not included in the survey. This kind of placement is significant because under these arrangements, residents sign a tenancy agreement for their home, which makes them ordinarily resident in the area in which their home is located, and thus entitled to local social services support should they need it (and should they fit the local eligibility criteria). It also means they lose any rights to future housing support in their 'home' area.

If the information from either the survey or the local authority records is correct it suggests that a more accurate estimate of the number of people with intellectual disabilities placed by other authorities in this county would be at least 1,000 people. If all the people identified from either source were included, this suggests a total number of people placed of approximately 1400 people. These estimates are both likely to underestimate of the true figure of all out of area placements, because the survey excluded NHS, private healthcare, or *Supporting People* placements. This level of placement from out of area represents 30 per cent to 40 per cent of all intellectual disability placements in this county. They include people of all age groups, with 51 per cent under 40 years old, so this is not a historical phenomenon reflecting past patterns of service provision but an ongoing practice. Compared with other recent studies of populations of people with intellectual disabilities in residential care (Mansell *et al.*, 2002; Mansell and Beadle-Brown, 2004) there are more men than would be expected. This may reflect the disproportionate use of out of area placements for people with

challenging behaviour, which is reported more frequently among men (Emerson, 2001 p25).

Seventy per cent of residents have lived in their current placement for more than three years and the great majority are deemed to have been placed for long-term care. Authorities tend to place people in the same homes, and placements are concentrated in particular areas such as coastal towns. Sixty two per cent are placed by authorities in London. Between 30-54 per cent have not been contacted by their care manager for at least a year.

The number of people placed in this county by other authorities is so large that it seems reasonable to expect that it poses a considerable extra demand for health and social care services. This is over and above the effects on individuals and their families that we have reported elsewhere (Beadle-Brown *et al.*, 2006 advance access). Although social care services should be provided by the placing authority, this survey suggests that care management arrangements could be potentially problematic in a significant proportion of cases. If problems result in emergencies or in adult protection alerts (Department of Health, 2000) then it is the receiving social services authority that is likely to bear the brunt of the work. In so far as people placed out of area tend to be those with more complex needs, especially with challenging behaviour (Mitra and Alexander, 2003), they will place demands on local health services which are not reflected in funding allocations. These matters are the subject of a further study.

Acknowledgements

The authors would like to thank the local authorities and home managers involved for their willingness to provide information for the survey.

References

- Beadle-Brown, J., Mansell, J., Whelton, B. & Hutchinson, A. (2006 advance access). People with learning disabilities in 'out of area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research*. doi:10.1111/j.1365-2788.2006.00848.x.
- Buckinghamshire County Council (1998). *Independent Longcare Inquiry*. Aylesbury: Buckinghamshire County Council.
- Department of Health (1993a). *Ordinary residence*(LAC(93)7). London: Department of Health.
- Department of Health (1993b). *Services for people with learning disabilities and challenging behaviour or mental health needs: Report of a Project Group (Chairman: Prof J L Mansell)*. London: Her Majesty's Stationery Office.
- Department of Health (2000). *No Secrets: Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse*. London: Department of Health. <http://www.dh.gov.uk/assetRoot/04/07/45/40/04074540.pdf>.
- Department of Health (2003). *Establishing the Responsible Commissioner: guidance for PCT commissioners on the application of the legal framework on PCT's secondary care commissioning responsibilities*. London: Department of Health.
- Department of Health (2004a). *Health and Personal Social Services Statistics for England*. London: The Stationery Office.
- Department of Health. (2004b). *Statistical Bulletin: Community Care Statistics 2004 Supported Residents (Adults), England (No. 2004/19)*. London: Department of Health.
- Department of Health (2006). *Establishing the Responsible Commissioner: Guidance for PCT Commissioners on the Application of the Legal Framework on PCT's Secondary Care Commissioning Responsibilities*. London: Department of Health.
- Emerson, E. (2001). *Challenging Behaviour: Analysis and Intervention in People with Severe Intellectual Disabilities*. Cambridge: Cambridge University Press.
- Emerson, E. & Hatton, C. (1998). Residential provision for people with intellectual disabilities in England, Wales and Scotland. *Journal of Applied Research in Intellectual Disabilities*, 11 (1): 1-14.
- Emerson, E. and Hatton, C. (2004). *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England*. Lancaster: Institute for Health Research, Lancaster University.
- Mansell, J., Ashman, B., Macdonald, S. & Beadle-Brown, J. (2002). Residential care in the community for adults with intellectual disabilities: needs, characteristics and services. *Journal of Intellectual Disability Research*, 46 (8): 625-633.
- Mansell, J. and Beadle-Brown, J. (2004). *Implementation of 'person-centred active support' in residential services for people with intellectual disabilities*. Canterbury: Tizard Centre.
- Mansell, J., Beadle-Brown, J., Skidmore, C., Whelton, B. & Hutchinson, A. (2006 advance access). People with learning disabilities in 'out of area' residential placements: 1. Policy context. *Journal of Intellectual Disability Research*. Doi: 10.1111/j.1365-2788.2006.00849.x.
- Mitra, I. & Alexander, R. (2003). Out of area placements: implications of psychiatric services in learning disability. *Psychiatric Bulletin*, 27 (10), 382-385.

Pring, J. (2003). *Silent Victims: The Longcare Scandal and Britain's Continuing Failure to Protect Society's Most Vulnerable*. London: Gibson Square Books.

Ritchie, F., Goodman, N., Nix, J. & Bowyer, A. (2005). *'Out of area, out of sight?' Review of out of area placement arrangements made by Social Services and Health for people with learning disabilities from the West Midlands*. Birmingham: Birmingham and The Black Country Strategic Health Authority and West Midlands South Strategic Health Authority.

Address for correspondence:

Professor J L Mansell
Tizard Centre
University of Kent
Beverley Farm
Canterbury
Kent
CT2 7LZ
Email: j.mansell@kent.ac.uk

Notes on contributors

Jim Mansell is Professor of the Applied Psychology of Learning Disability in the Tizard Centre at the University of Kent, England. He is a Fellow of the British Psychological Society and a Chartered Psychologist. He has been involved in the research and development of community-based intellectual disability services in England and Wales since 1970. Julie Beadle-Brown is Senior Lecturer in Learning Disabilities and a Chartered Psychologist. She has convened the postgraduate taught courses in intellectual and developmental disabilities at the Tizard Centre and played a lead role in research projects focusing on quality of care and quality of life of people with intellectual disabilities. Clare Skidmore is a Telecare Project Manager at Kent County Council and was a researcher on the out of area placement study. Beckie Whelton and Aislinn Hutchinson were researchers on the project.