

People with learning disabilities living in a care home outside of their home area

The Issue

For people with learning disabilities who need a lot of support every day, a placement in a residential home may be chosen to meet the person's needs. Sometimes the residential home they move to is outside of the person's home area, known as an out-of-area placement. Commissioners were interested in the reasons for people moving out-of-area, what this might be like for them compared to people who live in residential settings in their home area and the differences in costs.

What we wanted to find out

What factors lead to people with learning disabilities living outside of their home area? How does living out-of-area affect people's quality of life and how they are supported by health and social care services?

What we did

We searched for relevant reviews, guidelines and research studies that included reasons for, and the impact of out-of-area placements for adults in the UK. We searched Cochrane library, NICE, NIHR, and Essence Project resources, and Medline, Web of Science and SCOPUS databases.

What we found

We found a 2018 NICE guideline on learning disabilities and behaviour that challenges,¹ The NICE guideline includes recommendations that local authorities should have a range of housing and care options and enable adults to live in their home community. NICE based this recommendation on a range of evidence. This included a survey and a non randomised, matched group study comparing placements in-area and out-of-area,^{2,3} a survey and a follow up survey of high cost placements for people with learning disabilities,^{4,5} a cross sectional study of out-of-area placements in one area of Wales,⁶ and a qualitative study of the views people out-of-county placement managers, family members and health professionals.⁷

We also found three papers not included referenced in the NICE guideline: a study of the views of people living in out-of-area placements and their managers,⁸ and a survey and a mixed methods study of out of area placements in Scotland.^{9,10}

What the evidence suggests

Factors that lead to people living out-of-area

People with learning disabilities move out-of-area when there is no local placement that could meet their care and support needs. This includes a setting that is suitable to meet a person's complex care needs,⁸⁻¹⁰ although higher needs are not consistently a factor of living out-of-area.² Between 16%⁸ and 31%⁹ move due to a crisis situation. People are more likely to live out-of-area if they have a mental health or an autism diagnosis (alongside a learning disability)^{5,6}; or they express behaviour that challengesⁱ including injury to self and others,^{2,6} and offending⁵. Being younger² and male⁴ increase the likelihood of people living out-of- area.

A small number of people themselves choose (3%) to live outof-area⁹, and sometimes families choose (25%) for reasons such as, to live nearer family members.⁸ A small study of 30 people found that people who had been living in a long stay hospital or care home experienced a loss of family contact, but location of the placement from an institution was not considered important by professionals arranging the move.⁸

Outcomes for people living out-of-area

We cannot determine with confidence the outcomes for people living out-of-area compared to people living in residential settings in their home area. A small study comparing 76 people, half living out-of-area and half living in-area, found similar outcomes of quality of life measures for both groups.³ The few differences found included:

People living in-area:

- receive more visits from friends.
- take part in more activities in the previous month
- are more inactive and less likely to engage in moderate or vigorous activity.

People living out-of-area:

- are more active.

People living in-area and out-of-area receive a similar number of visits from family members, but the travel costs for families with relatives living out-of-area can be four times more expensive than those visiting relatives in-area.³ Managing behaviour that challenges was similar between the two groups.

With the intention of keeping themselves or other people safe, people with learning disabilities in residential settings are sometimes restrained by care staff. People living out-of-area were more likely to be physically restrained and people living in-area were more likely to be sedated.³

Support from health and social care service

People living in-area and out-of-area have similar levels of lifestyle satisfaction, feeling safe, perceptions of risk of accidents, exploitation or abuse, and access to health and social care services.³ In a small study, two thirds (n=19) of people living out-of-area had access to a care manager or reviewing officer, care managers reported that the distance to visit people out-of-area hindered their work.⁸ Interviews with health professionals identify concerns about being unaware of new residential settings being set up in their area, increased numbers of referrals and difficulties accessing a care manager if they have concerns about a person.^{7,10} Managers of residential settings say they find it difficult to access health specialists for people.¹⁰

Differences in costs of placements in-area and out-of-area

There is limited evidence on costs of placements. Costs of placements out-of-area are higher but not significantly so.^{2,4,5} A survey of 205 people with learning disabilities from London boroughs found a positive correlation between higher cost placements and higher needs of the person.² It should be noted that these studies are based on data from at least 10 years ago.

Quality of the evidence and conclusions

There is limited good quality evidence comparing the impact for people living in-area with those out-of-area. The non-randomised matched group study had a small sample size meaning that results should be treated with caution. The qualitative studies of the views of family members and health and care staff represent a view of a limited number of people.

The NICE guideline is clear that local authorities should enable people with learning disabilities to live close to their family, friends and community unless they choose not to or there is an exceptional reason for the person to live outside of their home area. Local authorities should make sure they have a range of housing and support options available to meet the needs and preferences of people with learning disabilities.

For more information about this briefing, contact

Kate Harris – Evidence Champion, Bristol City Council Kate.Harris@bristol.gov.uk

Lisa Dibsall – Researcher in Residence, University of Bristol Lisa.Dibsall@bristol.ac.uk

References

1. National Institute for Health and Care Excellence. *Learning disabilities and behaviour that challenges: service design and delivery*. NICE;2018.
2. Hassiotis A, Parkes C, Jones L, Fitzgerald B, Romeo R. Individual Characteristics and Service Expenditure on Challenging Behaviour for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2008;21(5):438-445.
3. Perry J, Allen DG, Pimm C, et al. Adults with intellectual disabilities and challenging behaviour: the costs and outcomes of in- and out-of-area placements. *J Intellect Disabil Res*. 2013;57(2):139-152.
4. McGill P, Poynter J. High Cost Residential Placements for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2012;25(6):584-587.
5. Deveau R, McGill P, Poynter JR. Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: a follow-up survey. *Tizard Learning Disability Review*. 2015;20:97-102.
6. Allen DG, Lowe K, Moore K, Brophy S. Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. *J Intellect Disabil Res*. 2007;51(Pt. 6):409-416.
7. Beadle-Brown J, Mansell J, Whelton B, Hutchinson A. People with Learning Disabilities in 'Out-of-Area' Residential Placements: Views of Families, Managers and Specialists. *The British Journal of Development Disabilities*. 2009;55(108):15-31.
8. Beadle-Brown J, Mansell JL, Whelton B, Hutchinson A, Skidmore C. People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research*. 2006;50(11):845-856.
9. MacDonald A. *Coming Home. A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Edinburgh: Scottish Government;2018.
10. Brown M, Paterson D. Out-of-area placements in Scotland and people with learning disabilities: a preliminary population study. *Journal of Psychiatric and Mental Health Nursing*. 2008;15(4):278-286.

ⁱ A comment on the phrase challenging behaviour or behaviour that challenges. Authors note that behaviour that challenges is not innate to the individual, it is a communication of unmet need from a person as a result of where they live and the support they receive⁹.