

Commissioning person-centred, cost-effective, local support for people with learning disabilities



Commissioning person-centred, cost-effective, local support for people with learning disabilities

Eric Emerson and Janet Robertson

Full author list in Acknowledgements

First published in Great Britain in July 2008
by the Social Care Institute for Excellence

© Lancaster University 2008
All rights reserved

Written by Eric Emerson, Janet Robertson, Helen Dorr, Phillipa Russell, Karen Spencer,
Ian Davies, David Felce, David Allen, James Churchill, Steven Rose, Sarah Maguire,
Chris Hatton, Phil Madden, Richard Mills, Barbara McIntosh, David Congdon.

This report is available online
www.scie.org.uk

Social Care Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB
tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk

Front cover photograph kindly supplied by <http://careimages.com/>

Contents

Acknowledgements	v
Executive summary	vi
1 Introduction	1
2 The extent of out-of-area placements	3
3 The systematic review	8
3.1 Local studies of all people with learning difficulties in out-of-area placements	8
3.1.1 West Midlands	8
3.1.2 Coventry	9
3.1.3 Cumbria and Lancashire	10
3.1.4 Calderdale	10
3.1.5 'I Count' Register data: Lambeth, Sutton and Merton	11
3.2 Local studies of specific out-of-area placements	11
3.2.1 Out-of-area placements for people with challenging behaviour in Wales	12
3.2.2 High-cost services for people with challenging behaviour in London	13
3.2.3 High-cost placements in the North West	13
3.2.4 Complex mental health needs and severe learning difficulties in the West Midlands	14
3.2.5 Complex needs in Hull	14
3.2.6 Assessing the quality of placements made by Lambeth	14
3.2.7 Transition from out-of-area residential schools or colleges in the South West	15
3.3 Forensic and secure care needs	15
3.3.1 Forensic and secure care in the area of the Wessex Consortium	15
3.3.2 National Development Team Tough Times Project	16
3.3.3 Breaking the cycle: better help for people at risk of offending in the North West	16
3.3.4 Learning difficulties and mental health problems in the South West	17
3.4 Research on into-area placements	17
3.4.1 Placed in Kent	17
3.4.2 Implications of into-area placements for psychiatry in Leicestershire	20
3.4.3 Other sources of evidence	20
3.5 Conclusions	21
3.5.1 Characteristics of people placed out-of-area	21
3.5.2 Reasons for out-of-area placements	21
3.5.3 Characteristics and quality of out-of-area placements	21
3.5.4 Issues for people placed out-of-area	22

3.5.5	Issues for placing authorities	22
3.5.6	Issues for receiving authorities	22
3.5.7	Forensic and secure service issues	22
3.5.8	Gaps in the literature	23
4	Undertaking the practice survey	24
4.1	Online consultation	24
4.2	Consultation workshops	24
4.3	Consultation conferences	24
5	The results of the practice survey	25
6	The adverse impact of out-of-area placements	26
6.1	Who is at risk?	28
6.2	Some caveats	29
7	Barriers to commissioning person-centred, cost-effective, local support for people with learning difficulties	31
7.1	Lack of incentives/weak performance management	31
7.2	Policy and regulatory barriers	33
7.3	Unclear responsibilities	34
7.4	Insufficient investment in long-term strategic and joint commissioning	34
7.5	Lack of experience of commissioning person-centred support for people who challenge and risk-averse cultures	36
7.6	Market weaknesses	41
7.7	The drive toward specialisation and congregate care	41
7.8	Insufficient resources	42
7.9	Insufficient safeguards	42
8	Summary of recommendations	43
8.1	The Department of Health should...	43
8.2	The Department for Children, Schools and Families should...	43
8.3	National advocacy agencies should...	43
8.4	Councils with social services responsibilities should...	43
8.5	Provider agencies should...	44
9	Conclusions	45
	References	46
	Resources	49
	Index	51

Acknowledgements

A consortium of researchers and non-governmental organisations undertook the knowledge review. It has been coordinated from the Institute for Health Research at Lancaster University (overseen by Professor Eric Emerson and managed by Dr Janet Robertson).

The full list of authors is: Eric Emerson, Janet Robertson, Helen Dorr, Phillipa Russell, Karen Spencer, Ian Davies, David Felce, David Allen, James Churchill, Steven Rose, Sarah Maguire, Chris Hatton, Phil Madden, Richard Mills, Barbara McIntosh, David Congdon.

The consortium included the following organisations:

- Institute for Health Research, Lancaster University
- Central England People First
- Welsh Centre for Learning Disabilities, Cardiff University
- Unit for Development in Intellectual Disabilities, University of Glamorgan
- National Family Carer Network
- ARC (Association for Real Change)
- Mencap
- National Children's Bureau
- National Autistic Society
- Foundation for People with Learning Disability
- HFT (The Home Farm Trust Ltd)
- Choice Support.

We are also indebted to numerous people and organisations who supported our consortium while undertaking the practice review. In particular we would like to thank the Valuing People Support Team and the Challenging Behaviour Foundation for their support in facilitating particular consultation events.

Executive summary

There are concerns that a substantial number of people with learning difficulties are not receiving support in their local area. Instead they are being supported in 'out-of-area placements'. Some of these placements can be a long way from their families and friends.

The knowledge review was undertaken by a consortium of researchers and non-governmental organisations. It was coordinated from the Institute for Health Research at Lancaster University (overseen by Professor Eric Emerson and managed by Dr Janet Robertson).

The knowledge review looked at what is known about out-of-area placements. This was done by finding out about research on out-of-area placements (the 'research review'). We also spoke to many people about their experiences of out-of-area placements (the 'practice survey'). We asked why people were not supported locally. We tried to find good examples of people with complex needs being supported locally.

This is a summary of the main findings we found from both the research review and the practice survey.

How many people are placed out-of-area?

In 2006 over 11,000 people with learning difficulties were supported in out-of-area placements. This is over a third (34 per cent) of all people with learning difficulties who are supported in residential care homes and nursing homes. Some areas have more people in out-of-area placements than others. For inner London the number is nearly two thirds (63 per cent). For Yorkshire and Humberside it is less than a quarter (24 per cent).

Who is likely to be placed out-of-area?

When the old institutions closed, people moved to new places in the community. Some people did not move back 'home'. They stayed out-of-area. These were mainly older people.

Other people who are more likely to be placed out-of-area include those with:

- challenging behaviour
- autistic spectrum disorders (ASD)
- mental health needs
- complex health needs
- complex epilepsy
- people who might offend (get in trouble with the police)

People with learning difficulties who are parents may have to go to out-of-area assessment units to have their parenting skills looked at.

On the whole people placed out-of-area are fairly young. More men than women are placed out-of-area.

Why are people placed out-of-area?

The main reason for out-of-area placements is that there is nothing available locally. This is also true for those in out-of-area residential schools or colleges. Very few out-of-area placements are made for good reasons, such as being nearer to family, or meeting religious needs. Placements are mainly made for reasons such as local services failing, or people not being satisfied with local services.

Problems for people placed out-of-area

'Of course I wouldn't choose to send my son to live miles away from his family – but when my local authority said there were no services locally to meet his needs, the "choice" was for him to stay at home, his behaviours increase and quality of life decrease, or to move hundreds of miles away and be properly supported with staff and an environment tailored to his needs.'

The main problem with out-of-area placements is that they make it difficult for people to stay in contact with family, friends and their local communities.

People placed out-of-area may find it difficult to become a part of life in the new area. This may be true for community activities and also support such as employment services and advocacy.

Placements might not suit the person's culture, for example someone who speaks Welsh may not want to move to a place where everyone speaks English.

People placed out-of-area do not always receive enough contact from their home authority. This means that not enough checks are made to see if placements are right for the person. This leaves people vulnerable to abuse.

For those placed at out-of-area schools or colleges, being a long way away makes it difficult to plan well when people move on to adult services.

Problems with out-of-area placements

Some out-of-area placements are in services where a lot of people with learning difficulties live together. Some people are concerned that these will develop into new institutions.

There are worries about how good some out-of-area placements are. Not enough people:

- have person-centred plans (PCPs) or health action plans
- have access to psychology, psychiatry and help with challenging behaviour
- are busy in the home
- take part in community activities

Some out-of-area placements are supposed to be 'specialist' but do not provide good support for people with complex needs.

Problems for placing authorities

Out-of-area placements are generally more expensive than locally based services. It is likely that this money could be spent on better local services.

Problems for areas where people are placed

Some parts of the country (for example, Kent) have many people placed into their area. Specialist needs are not always met by the out-of-area placement. Local services may have to provide these people with the specialist help they need. This can lead to much more work for professionals in areas where people are placed. This means that they have less time for people from the local area.

Areas where people are placed are often not told when somebody is placed there from out-of-area. Sometimes they only find out when somebody is referred because they are having a crisis. This makes it difficult for local services to plan for the needs of the people placed there.

When are out-of-area placements okay?

Out-of-area placements are not always a bad thing. Here are some reasons why:

- Someone in an out-of-area placement may live close to their home. They may be 'just over the border'.
- Some people move out-of-area because their family has moved away. They may move to be closer to them.
- Some people choose to move out-of-area, for example they might want to live in an 'intentional community'.
- People may have made friends and be happy and settled in their out-of-area placement.
- If someone has got a very bad 'reputation' locally, a fresh start in a new area may help.

Why are people not supported locally?

We asked why people with complex needs are not supported locally. Here are some of the reasons that we were given and what people think can be done about them.

Lack of incentives

Government policies say support should be local but there are no incentives to make this happen. There is nothing to stop an authority placing everyone out-of-area.

People suggested some ways to tackle this:

- The number of out-of-area placements made by each authority should be measured. It should be seen as part of how well they are doing.
- If someone is being placed out-of-area the authority should have to tell services in the new area.
- The authority placing out-of-area should have to pay for services in the new area.
- New residential services should only be set up if they are to support people from the local area.
- Advocacy organisations should speak out about the problem of out-of-area placements.

Policies and regulations

Some policies and regulations do not help to make sure support is local. For example, continuing healthcare regulations mean that people cannot get direct payments or the Independent Living Fund. This can stop people receiving more personalised support.

The Department of Health needs to look at whether regulations promote local support for people with learning difficulties.

Unclear responsibilities

Sometimes it is not clear whether the local authority or the NHS should pay for support for someone with complex needs. Time and money is wasted trying to work out who should pay. People are hoping that some work currently being done by the Department of Health will make things clearer.

Lack of investment in planning services

Some areas do not have enough information on who needs services now or in the future. This is very true for people moving from children's to adult's services. This means they cannot plan services well.

Some areas do not have a good way of checking the quality of services and seeing if they are value for money. People need to know what makes a good service. They need to see if services are giving people with learning difficulties a good quality of life.

Some people said it was harder to get money for planned new services than it was to get money for an out-of-area placement in an emergency.

To tackle these problems authorities need to collect information on who needs services now and in the future. They need to find a way of seeing if services are giving people a good quality of life. Health and social services should work together to plan and develop local services. They should put their money into a 'pooled budget'.

Lack of experience and avoiding risk

Some areas have little experience in setting up local services for people with complex needs. They end up relying on out-of-area services. They may worry that things will go wrong if people are placed locally and they will get blamed for it. They may see out-of-area placements as less risky.

One way to tackle this is to share examples of how people *can* be supported locally. People need to know about more creative ways of providing support.

Not enough services locally

People think that more services are needed locally to support people with complex needs. There are not enough day supports or supported accommodation services. There is not enough nursing support for people with complex health needs. There are not enough staff with the skills needed to support people who have complex needs.

More money needs to be spent setting up services that can support people with complex needs. More staff need training in how to support people with complex needs.

Services for particular groups of people

There seems to be a trend to set up services for particular groups of people (this is called 'congregate' care). For example, services might be set up just for people with challenging behaviour, or just for people with ASD. Some people think this might lead to more out-of-area placements. It also worries some people because there is evidence that 'congregate' services are poor value for money.

To tackle this authorities should join together to set up services for people with specialist needs. This should be done by developing expertise and skills in supporting people with specialist needs, instead of developing 'congregate' services.

Not enough money

Most people felt that some of the problems that we have talked about here are because not enough money is available for services for people with learning difficulties. They felt that more money is needed before people could be supported locally in good, personalised services. As one person with learning difficulties put it, people end up on out-of-area placements because there are "not enough good services where they have grown up".

Examples of people being supported locally

In the knowledge review we described how three people were provided with support locally. Here are brief summaries of these stories.

Steven owns his own home

Steven has autism, challenging behaviour and epilepsy. When his mother needed support there was nothing available locally and he was sent to a specialist placement, moving to the adult version of it at the age of 19. This was very expensive and meant a 5- to 6-hour journey for his parents to go and visit. His parents wanted something more local and the obvious solution was to buy one of the houses for sale in their area.

The family solicitor helped Steven to appoint his mother as Power of Attorney, which let her manage the process of taking out a mortgage and buying a house. They got a mortgage based on 'Income Support for Mortgage Interest'. The council put down the deposit on the house realising that in the long term this investment would save them money! His support team is paid through direct payments, managed by his brother.

Paul receives direct payments

Paul is a young man of 20 who receives direct payments, lives in his own house, in the middle of a community of which he feels very much a part. Paul has a wonderful, friendly nature, and is a 'people person'. He loves a good joke, and he really enjoys life. The look on his face now mostly says 'I am having a great time'.

Paul has virtually no spoken language, but uses his own signs to communicate. He is a very active, energetic young man who has physical energy to spare. He can also sometimes become very frustrated. This has resulted in some behaviours that challenge those around him.

Paul was just turning 18 when he arrived back home from an out-of-area residential school. He had no transition plan. However, he was lucky in having his mother's backing, a circle of support and staff in the local authority who had arrived with new ideas about supported living and direct payments. He also had a PCP.

After a period of agency support, the circle of support decided to become an 'Independent Living Trust' for Paul, and negotiated a direct payment with the local authority. They employed a broker to help with that process, and to put things in place for the first couple of years. Paul still continued to live at home with his mother for that period, but started the arrangements for moving to his own house. He moved in at the beginning of December, and has just had his first Christmas in his own house.

Ken was part of the 'in Control' project

Ken is thrilled. In July, he moved out of an institution. Ken has had a life of being moved around without having any control over where or when he went. Ken is now 43. He had his first experience of the long-stay hospital system when he was 15. It is true that Ken has lost his temper with staff in the hospitals he has lived in. But in all the years that his friend and advocate Tony has known him, he has never done anything like that outside the hospital.

Tony came up with the idea of Ken being part of the in Control project. Everyone they spoke to said that this was a great idea. Kenny was desperately unhappy where he was living. He longed to move to Essex.

When Ken was on holiday in a cottage with Tony in Essex, he invited Nicola for a cup of tea. Nicola is a social worker. She read the report about Ken but could not match what she had read with the person she saw in front of her. She started looking for somewhere suitable in Essex. This is how Ken came to be where he is now – in his flat, able to organise his life as he chooses.

1 Introduction

At present, social policies in the UK that address the provision of social care emphasise the importance of supporting the inclusion of people within their local communities. This is particularly the case given the recent history of large-scale institutionalisation, for policies relating to the social care of people with learning disabilities. Yet concerns have been expressed by various groups and organisations that current practice lags far behind these aspirations. In particular, concern has been expressed about the number of adults with learning disabilities receiving various forms of supported accommodation services who are living away from the communities to which they belong (ie, are 'placed out-of-area').

In light of these concerns, the Social Care Institute for Excellence (SCIE) commissioned this knowledge review in order to 'bring together knowledge from research and practice on commissioning person-centred, cost-effective, local support for people with learning difficulties who are labelled as having complex needs and/or challenging behaviour'. In the following sections we:

- describe how this work was undertaken
- review what is currently known about the extent, nature and characteristics of out-of-area placements
- report the results of a wide-ranging process of consultation which people with learning difficulties, the families who support them and the professionals and managers who provide services
- make a series of recommendations that we believe would improve future practice and reduce the chances of adults with learning difficulties being placed out-of-area.

Central to these recommendations is the need to strengthen local capacity to provide individualised services for people who present complex challenges. People with learning difficulties and their families are often faced with two options – coping without the right support at home or sending the person far away to a 'specialist' service. For many this is a dilemma and not a choice. Hopefully these recommendations, if implemented, will go some way to ensuring that people with learning difficulties and their families are less likely to have to make such 'choices' in the future.

2 The extent of out-of-area placements

In order to set the context for the practice survey, we summarise the most recent information available regarding the extent of out-of-area residential placements for people with learning difficulties in England. These data (*Community Care Statistics: Supported Residents [Adults], England*) have been published on an annual basis, originally by the Department of Health and now by the Information Centre for Health and Social Care,^{*} since 2003 at the level of councils with social services responsibilities (CSSRs). The latest data relate to the situation of supported residents as of 31 March 2006.[♦] A CSSR supported resident is a person receiving care in residential or nursing accommodation whose costs are met wholly or partly by a particular CSSR. As such these data may exclude people with learning difficulties in some forms of supported living arrangements and will also exclude all people with learning difficulties whose accommodation is funded solely by the NHS.

In England on 31 March 2006, 11,345 CSSR supported residents aged 18-64 were supported in residential care homes and nursing homes outside of the area covered by the CSSR (that is, in 'out-of-area' placements).[†] This represents just over one third (34 per cent) of all CSSR supported residents in England in this age range. Between 2003 and 2005, the number of adults (of all ages) with learning difficulties who (as supported residents) were supported in residential care homes and nursing homes outside of the area covered by the CSSR rose by 1,425 (14 per cent).[✱]

There are, however, clear regional and local variations in the percentage of CSSR supported residents who were supported out-of-area. Table 1 gives the number and percentage of CSSR supported residents who were supported out-of-area by Government Office Region (with London split into inner and outer London boroughs). Figure 1 illustrates the variation in use of out-of-area placements by CSSR (range four per cent to 90 per cent).[‡] Figure 2 shows the number of people placed out-of-area from 2003–05 for each Government Office Region. For England as a whole, the number of out-of-area placements rose by 10 per cent between 2003 and 2004 by four per cent between 2004 and 2005.

* www.ic.nhs.uk/

♦ www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2006:-supported-residents-adults-england

† These data exclude all people in unstaffed accommodation and adult placements.

✱ In 2006 these data were reported for adults aged 18–64, rather than adults of all ages. As such, it is not possible to compare 2006 data with previous years.

‡ Six CSSRs have been omitted from this figure due to non-reporting or concerns about the reliability of the data.

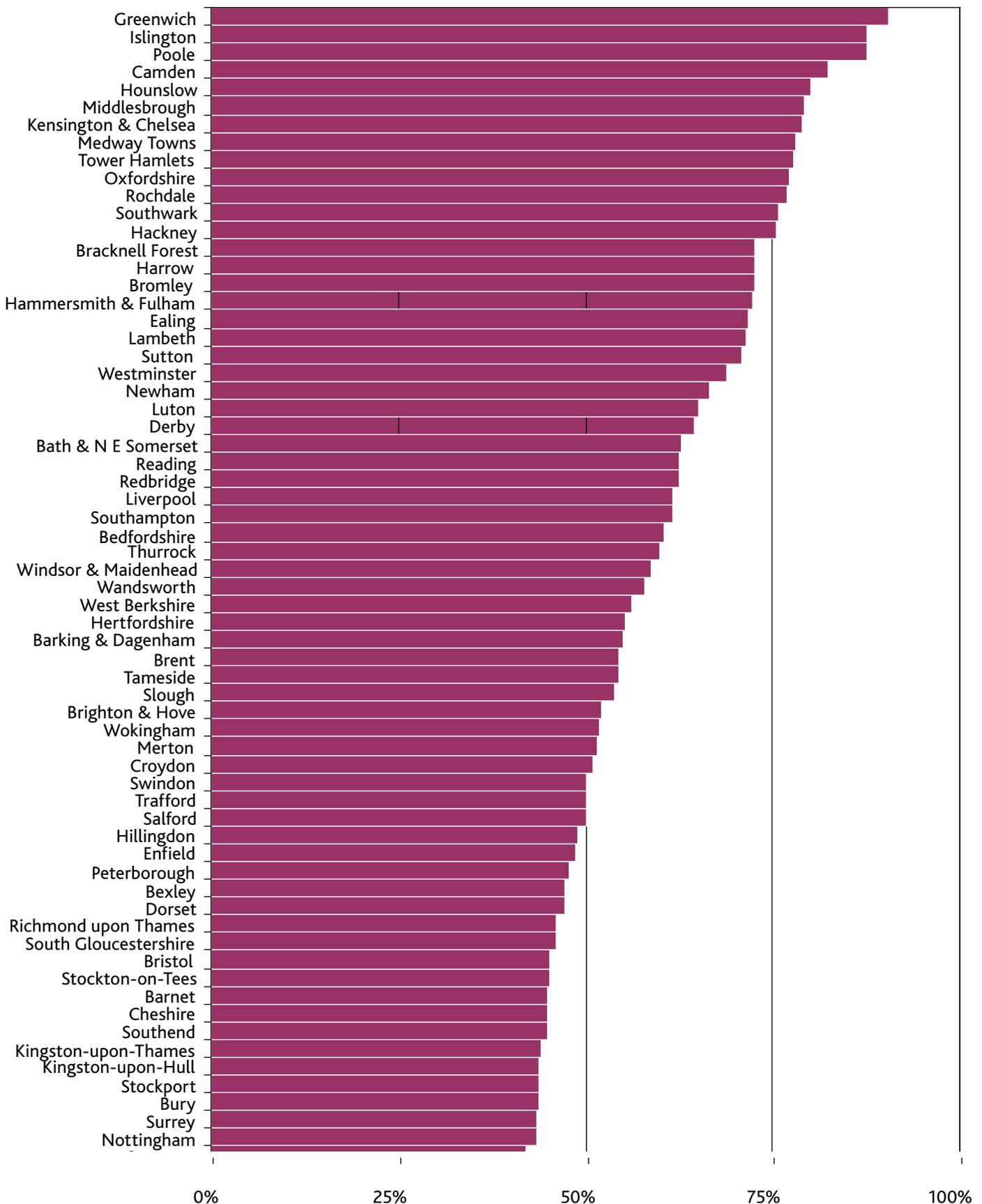
Table 1: Number and percentages of CCSR supported residents aged 18-64 supported 'out-of-area' on 31 March 2006 by Government Office Region

Region	Number	As % of all supported residents
Inner London	1,400	63
Outer London	1,705	49
North West	1,005	38
South East	2,150	36
Eastern	1,180	34
North East	465	27
West Midlands	975	27
South West	1,040	26
East Midlands	765	25
Yorkshire & The Humber	665	24

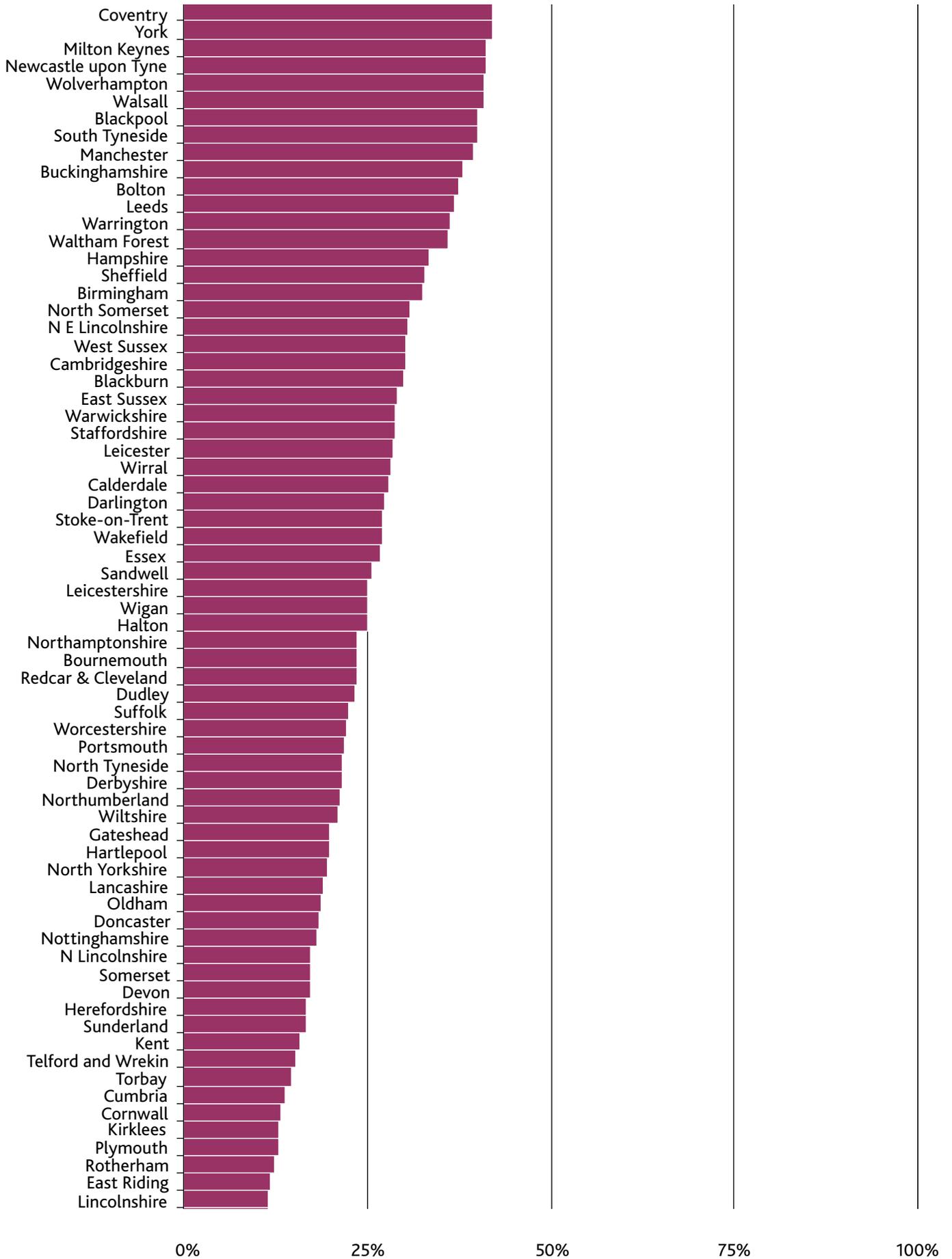
In Wales, the number of out-of-area placements were reported to the Welsh Assembly Government in an audit that accompanied local authority funding applications in response to the *Learning disability strategy section 7 guidance on service principles and service responses*.² There were 354 people placed out-of-county but within Wales and a further 176 people placed out-of-county and outside of Wales. The total of 530 represented about 16 per cent of the people placed in supported living, independent sector or local authority residential, or NHS care. The proportion placed out-of-area varied across local authorities from three per cent to 51 per cent.

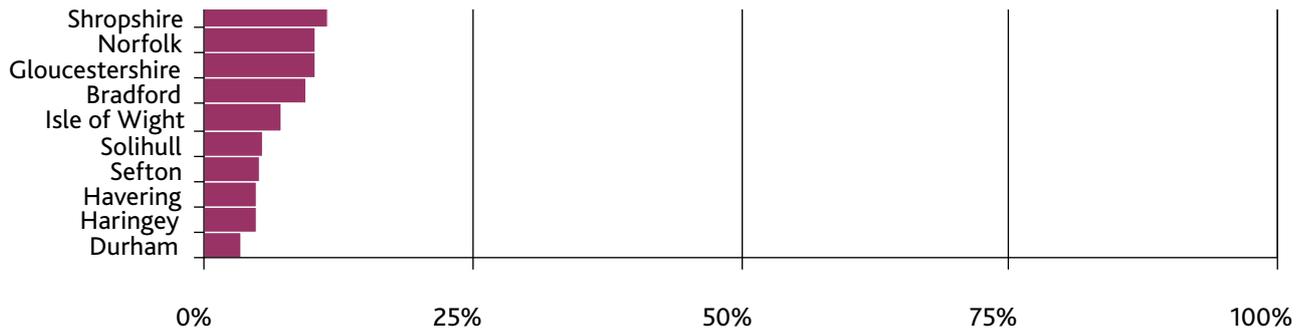
Information is not collected in Northern Ireland on the number of out-of-area placements.³

Figure 1: Percentage of CCSR supported residents aged 18-64 supported 'out-of-area' on 31 March 2006 by CSSR



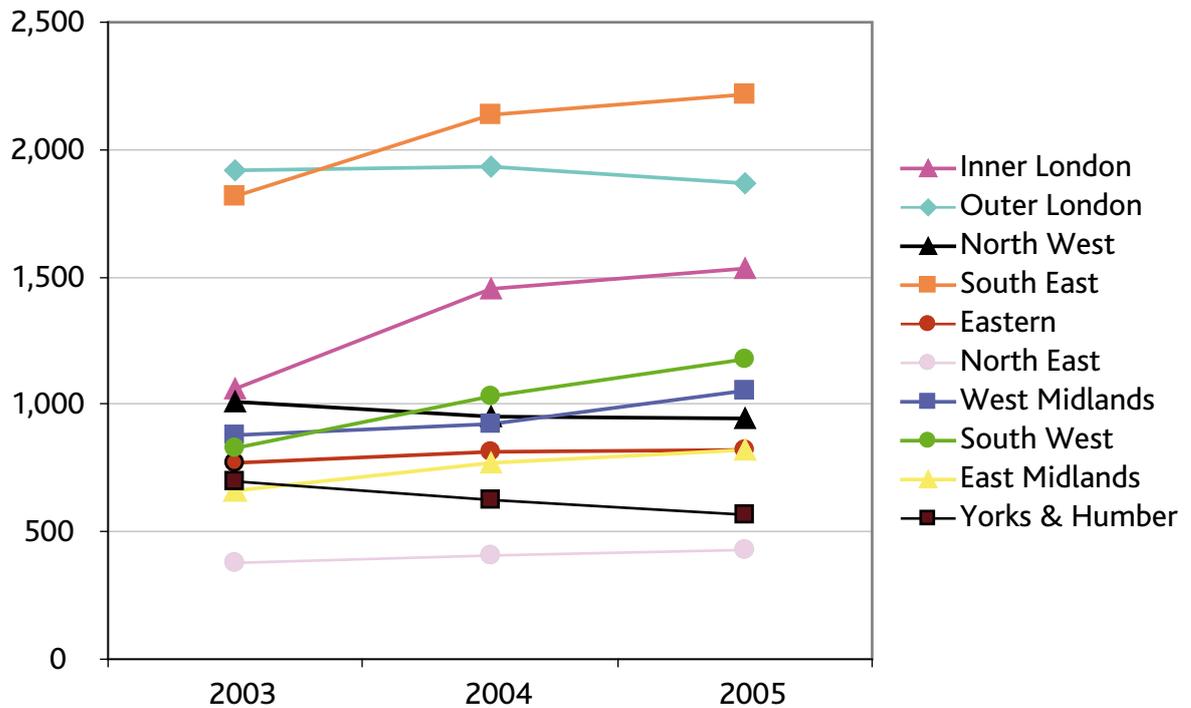
ADULTS' SERVICES





Note: As can be seen, people with learning difficulties living in London, and people with learning difficulties living in nearly one third (32 per cent) of all CSSRs in England are more likely (if they are supported residents) to be living in out-of-area placements than they are to be living in their 'home' area.

Figure 2: Number of adults with learning difficulties aged 18+ placed out-of-area from 2003-05 for each Government office Region



3 The systematic review

This review summarises the existing research on out-of-area placements for people with learning difficulties. The evidence base on this topic is relatively small. The existence of large local variations in the use of out-of-area placements and the different foci of studies (for example, all people in out-of-area placements; people in high-cost placements only; people with challenging behaviour only) makes it difficult to interpret results comparatively. As such, the review summarises the research study by study, enabling the interpretation of findings within the context of the region and study population involved.

The research literature is divided into a number of areas: national data on the scale of out-of-area placements; local studies of all out-of-area placements; local studies of specific out-of-area placements; research involving forensic and secure needs; and research on the impact of out-of-area placements for receiving areas. The conclusions draw out the main themes from the studies reviewed. Details of the procedure for carrying out this review can be found in Appendix One.

3.1 Local studies of all people with learning difficulties in out-of-area placements

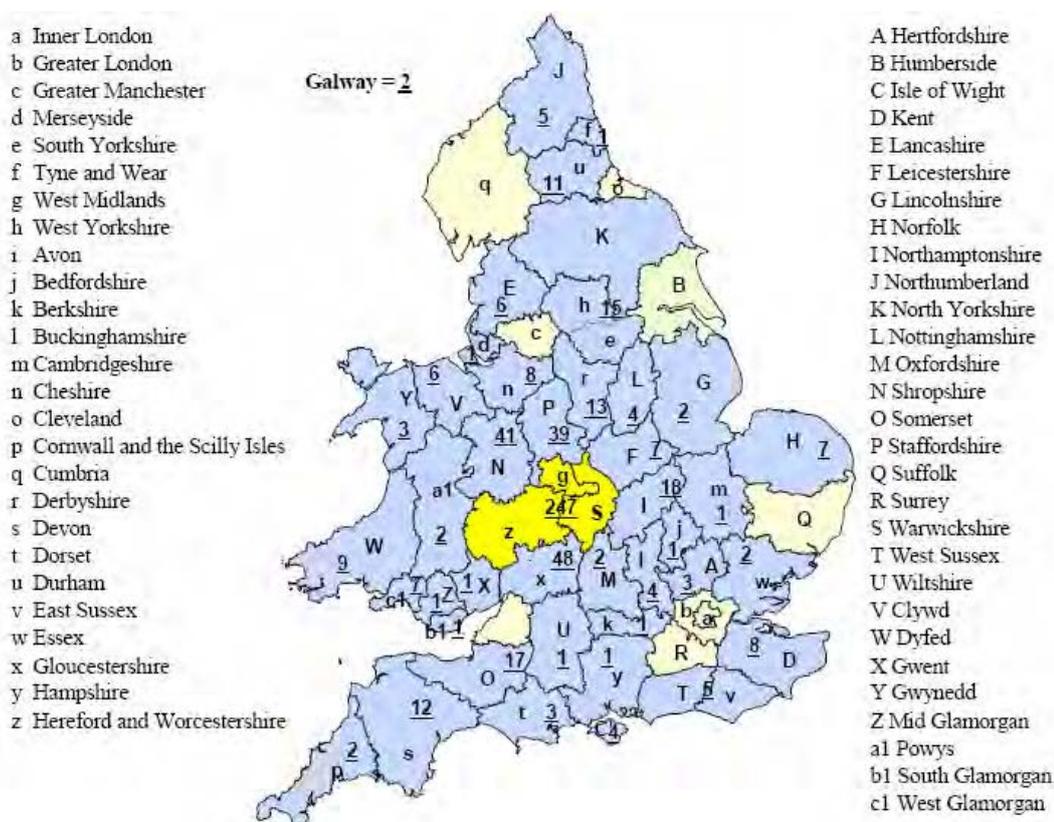
To understand the issues and processes involved in out-of-area placements it is necessary to consider a number of reports that present more detailed data at a local level. Several studies look at out-of-area placements for the total population of people with learning difficulties from a particular local area and these are summarised below.

3.1.1 West Midlands

A study in the West Midlands^{4,5} looked at out-of-area placements made from two strategic health authorities: West Midlands South and Birmingham and the Black Country. Overall, 623 people with learning difficulties were identified as being placed out-of-area. More men were placed out-of-area (405, 65 per cent were male). This may reflect the fact that the main additional diagnoses were challenging behaviour (214) and autism (118). Placements were as far flung as Northumberland and Cornwall (see Figure 3). Of the 526 placements identified, 449 (85 per cent) were independent sector care homes.

More comprehensive information was collected on 111 people who were identified as priorities for visiting by commissioners. Only 17 per cent (19) moved for a positive reason such as to access specialist services or to be closer to family, and 83 per cent (92) moved for negative reasons such as placement breakdown or inadequate local services.

Information on the 111 people raises concern about service quality. Specifically, 76 per cent of people did not have a person-centred plan; 87 per cent did not have a health action plan; the number of visits where engagement in home activities

Figure 3: Out-of-area placements from the West Midlands⁶

appeared poor was 32 per cent; the number of visits where community activities appeared poor was 29 per cent (with challenging behaviour and staffing levels being seen as the main reasons for this); and risk assessments and management of challenging behaviour were varied (with at worst, only general rather than individual risk assessments in place and, at best, good behavioural strategies).

There was no knowledge of contact from the district of origin for 42 per cent. Such lack of contact highlights the issue of authorities failing to visit the vulnerable people they have placed out-of-area regularly. Such failures have been blamed for leaving people vulnerable to abuse.⁷ The difficulty of monitoring out-of-area placements is a recurring theme in the literature.

3.1.2 Coventry

A recent survey follows on from the West Midlands study.⁸ This survey was carried out to determine the characteristics of adults placed out-of-area by Coventry authorities. Over a 15-year period, 89 people had been moved by statutory services from the greater Coventry area to other areas within the UK, 48 of whom had moved out-of-area since 2000. Ages ranged from 17–66 and 66 per cent were male. The majority of placements were in registered care homes (79 per cent), five per cent were in registered nursing homes, three per cent were in supported living projects and 14 per cent were in other forms of accommodation (for example, National

Health Service or independent hospitals). Sixty-four per cent were over 50 miles away and 40 per cent were over 150 miles away.

The survey revealed three main groups who were placed with specialist providers out-of-area: people with autistic spectrum disorder (ASD); people with challenging behaviour; and people with sensory impairments. It was also found that 10 per cent of those placed out-of-area left the city immediately after ceasing full-time education. It was noted that this situation should be preventable with adequate transition planning which should allow time to develop local service provision. Only a small number (three per cent) were noted to have moved to be near significant others (mainly parents) who had relocated.

3.1.3 Cumbria and Lancashire

Cumbria and Lancashire Strategic Health Authority (SHA) commissioned a census of out-of-area placements.⁹ A total of 310 people with learning difficulties were placed out-of-area out of a total of 3,277 made (that is, about 10 per cent). The reasons for the original placement were: assessment, 18 per cent; forensic, 8 per cent; high-risk behaviour, 10 per cent; breakdown in care network, 14 per cent; do not know, 27 per cent. Positive reasons included being nearer family, one per cent; and faith and culture, one per cent. Only 30 per cent of the sample were subject to the care programme approach (CPA), or other planning processes such as person-centred planning (PCP).

The age profile of the sample showed that most were relatively young, with 64 per cent aged under 40, and 20 per cent under 25. Despite a high number of people from the Asian population in some parts of Lancashire, a small number of people from an Asian or Asian British background were placed out-of-area or out of sector (just 5 of the 335). It is unclear whether this reflects good practice in people from Asian families staying in their locality, or Asian families simply not accessing services. Previous research suggests that there is evidence of low uptake of residential services by people from South Asian communities.¹⁰

In terms of diagnoses, 22 per cent of the sample were reported to have ASD. Over half of the sample had a dual diagnosis, these being: (most common) learning difficulties and challenging behaviour (16 per cent); learning difficulties and mental health problems (12 per cent); learning difficulties and physical health problems (12 per cent); learning difficulties and forensic needs (10 per cent); learning difficulties and personality disorder (one per cent); and learning difficulties and substance misuse (one per cent).

3.1.4 Calderdale

Calderdale Council¹¹ examined the processes involved in people moving to out-of-area placements. The study identified a total of 48 people in out-of-area placements out of a population of 682 people with learning difficulties (seven per cent). A significant number were placed due to breakdown of placements in local provision. Overall, there were three main groups for whom out-of-area placements were arranged: people with challenging behaviour ($n=11$); autism and challenging behaviour

($n=12$); and mental health problems and challenging behaviour ($n=10$). There were also five people with offending behaviour and mental health problems.

The total cost of the placements to social services and the primary care trust (PCT) was £3,758,573 pa. For people with autism, the average weekly cost was £1,929 (£101,000 pa); challenging behaviour £1,679 (£87,000 pa); challenging behaviour and mental health £2,010 (£105,000 pa); and offending and mental health £1,181 (£62,000 pa). The people in out-of-area placements were a relatively young group (for example, 7 of the 12 people with autism were aged 18–30) and, therefore, will continue to need support for the foreseeable future.

Information was also collected from the out-of-area placements, with all being contacted and 11 being visited. Many of the out-of-area placements were classed as 'specialist' placements because of a claimed ability to meet the needs of people with autism, challenging behaviour, and/or mental health problems. However, the author [name?] noted that:

... on closer examination it is more difficult to determine the nature of this "specialist" support. For example, in many cases people in out-of-area placements do not have direct access to services such as psychology through the provider organisation. In such cases service users would access psychology and other specialist services through their GP as any other member of the community would. (p 16)

Only 3 out of 10 people with challenging behaviour and mental health problems had direct access to psychiatry, and only 3 out of 11 people with challenging behaviour had direct access to psychology. This reliance on local services for specialist input by 'specialist' placements is one of the recurring issues in the literature on out-of-area placements.

3.1.5 'I Count' Register data: Lambeth, Sutton and Merton

Data on out-of-area placements has been obtained from the 'I Count' Register for three London boroughs.¹² Lambeth was responsible for a total of 791 people with learning difficulties and 261 (33 per cent) were placed out-of-area: 66 per cent had challenging behaviour (compared to 45 per cent in-area) and 48 per cent had a psychiatric problem (compared to 37 per cent in-area). Merton placed 143 people out of a total of 549 people with learning difficulties (26 per cent) out-of-area: 73 per cent had challenging behaviour (compared to 48 per cent in-area) and 43 per cent had a psychiatric problem (compared to 32 per cent in-area). Sutton placed 202 people out of a total of 807 people with learning difficulties (25 per cent) out-of-area: 70 per cent had challenging behaviour (compared to 50 per cent in-area) and 49 per cent had a psychiatric problem (compared to 36 per cent in-area).

3.2 Local studies of specific out-of-area placements

A number of studies have adopted a specific population focus in looking at placements made outside the area. These include: people with challenging behaviour; people in high-cost placements; people with mental health needs; and people with

complex needs. Several studies have looked specifically at the issue of forensic and secure needs and these studies are reviewed separately in Section 5 below.

3.2.1 Out-of-area placements for people with challenging behaviour in Wales

Allen et al (2007) looked at out-of-area placements for people with learning difficulties and challenging behaviour from the territory served by Bro Morgannwg NHS Trust Learning Disabilities Directorate. The work was part of a total population study of the epidemiology of challenging behaviour in that area.¹³ The area has a network of community support teams, and specialist services for people who present a challenge to services, including four specialist behavioural teams, three eight-bed acute admission units, and eight NHS-run five-bed continuing healthcare facilities. Despite the availability of such local services, it was found that 107 of 1,458 people identified in the survey (7 per cent) were supported in out-of-area placements. The combined health, social service and educational costs for the 107 out-of-area placements was £11.2 million at 2002/03 prices. The mean placement cost was £96,000 pa. The mean cost of local, specialist NHS residential care in the five-person community bungalows was £97,000 pa.

Allen et al (2007)¹³ compared the characteristics of those placed out-of-area and in-area. Comprehensive data was available on 901 people, 97 of whom were placed out-of-area. Out-of-area placement was predicted for 90.8 per cent of the sample by: history of detention under the Mental Health Act; presence of mental health problems; formal diagnosis of autism; higher adaptive behaviour scale score; behaviour that led to physical injury to the participant themselves (repeated incidents and usual consequence) and their exclusion from service settings. In short, out-of-area placement could be accurately predicted by user mental health status, higher ability, diagnosis of autism and impact of challenging behaviour.

The study also compared the characteristics of the in- and out-of-area placements themselves. The most common placements in-area were family homes (27 per cent) and staffed homes (55 per cent). The most common out-of-area placements were staffed housing (34 per cent) and 'other' types of accommodation (52 per cent), which mainly consisted of larger-scale, more institutional provision.

Access to and frequency of contact with psychology support and care management was noticeably higher out-of-area, as was input from psychiatrists. However, information was not collected on whether psychology or psychiatry services provided out-of-area were supplied directly by the receiving care organisations or whether organisations were availing themselves of services provided by the public sector locally. It is noted that: 'If the latter, out-of-area placements would serve to further deplete resources available to local service users' (p 8).

Finally, it was noted that it would be logical to assume that out-of-area placements would offer higher levels of expertise and quality of service than those in-area in view of their rationale and costs. However, over 37 per cent of those placed out-of-area had no behavioural support plan, almost 50 per cent had no access to psychology and over 40 per cent no access to psychiatry. If services were commissioned on the basis of their expertise in supporting challenging individuals, it

might be expected that everyone would be receiving these services. It was concluded that:

Taken together, these findings raise serious concerns. Having successfully achieved a closure programme for our public institutions, there is a suggestion that failing to plan effectively for the needs of people who challenge is resulting in a de facto policy of rebuilding of these institutions within the private sector. (p 8)

3.2.2 High-cost services for people with challenging behaviour in London

A project on high-cost services (defined as over £70,000 pa) for people with challenging behaviour in five London boroughs has been reported in three publications.¹⁴⁻¹⁶ Forensic services were excluded. In total, 205 people with learning difficulties and challenging behaviour were identified in services costing over £70,000, representing five per cent of the total population of adults with learning difficulties. Sixty-five per cent of these were placed out-of-area. Service users placed out-of-area were significantly younger. Of those detained under the Mental Health Act, 14 (87.5 per cent) were placed out-of-area. Service users with a higher severity of challenging behaviour tended to be placed out-of-area.

In total £21,148,081 pa was spent on supporting the 205 service users; £14,197,641 pa was spent supporting the 134 people in out-of-area placements. Mean annual cost overall was £103,000 (range £70,000–£258,000). Mean cost within borough ($n=71$) was £98,000 (range £70,000–£195,000) and out of borough ($n=134$) was £106,000 (range £70,000–£258,000). There were 22 continuing care placements (part funded by health) and these were significantly more expensive than the rest. Service users with mental health problems and/or autism were placed in significantly more expensive facilities. Costs correlated significantly with level of assessed need.

In an earlier study¹⁷ all people over the age of 19 who were known to use learning difficulty services in three London boroughs were surveyed. Agencies were asked to identify clients with challenging behaviour. The total number of individuals identified was 448, 90 of whom were placed in out-of-borough residential services. The results suggested that out-of-borough placement was related to: aggressive and damaging behaviours; the borough in which the subject lived; and being male, being black or being younger.

3.2.3 High-cost placements in the North West

A census by the North West Centre of Excellence^{18, 19} looked at high-cost placements for people with learning difficulties or physical disabilities (defined as costing more than £1,000 per week). The census covered the entire North West. A total of 410 high-cost out-of-area placements for people with learning difficulties were identified. The reason for continuing the placement was not known in 45 per cent of cases; it was due to a lack of appropriate provision within the authority in 43 per cent; it arose from service user choice in four per cent; and it was due to the person having meaningful links in the area in one per cent of cases.

3.2.4 Complex mental health needs and severe learning difficulties in the West Midlands

A study in the West Midlands²⁰ looked at out-of-area placements for people with complex mental health needs and people with severe learning difficulties. There were 189 adults with complex mental health needs placed out-of-area (39 per cent) and 291 in-area (61 per cent); 210 adults with severe learning difficulties (28 per cent) placed out-of-area and 532 in-area (72 per cent). There was a young age structure to those being placed out-of-area with the majority of clients (74 per cent) placed out-of-area being in the 19–45 year age range.

Most out-of-area placements for those with complex mental health needs were in the private sector (81 per cent). The average annual cost for those with complex mental health needs placed out-of-area was £98,000, compared to an average in-area cost of £75,000. The average out-of-area cost for those with severe learning disabilities was £47,000 and the average in-area cost £43,000. The study indicated that there were examples of clients of all degrees of complexity being successfully placed in local services more cost-effectively.

3.2.5 Complex needs in Hull

A study in Hull looked at services for people with complex needs.²¹ The study mapped services available in Hull and provided an in-depth description of 15 people with learning difficulties and complex needs (this included five young people aged under 18 placed out-of-area). The study group could be divided broadly into two main sub-groups: those with profound multiple impairments and additional health needs; and those with challenging behaviour and autism or mental health difficulties. The needs of the first sub-group were relatively well met by services in Hull. People with learning difficulties and challenging behaviour posed a greater challenge. There were shortages of short-break and long-term provision. The majority of individuals living in out-of-area placements or high-cost placements had challenging behaviour and autism or mental health needs. Decisions to place these people were frequently made in a situation of crisis.

3.2.6 Assessing the quality of placements made by Lambeth

One study looked specifically at the quality of out-of-area placements that were referred for assessment by care managers from the Lambeth Partnership on the basis of urgency of need.²² The study was based on the assessment of 13 out-of-area placements, five in residential homes and eight in a private hospital. Service quality was assessed on a scale of 0–4, based on a point for the presence of each of the following processes: assessments had taken place; both proactive and reactive interventions for challenging behaviour were used; outcome measures were taken; and PCP was used. The scores for the residential home placements averaged 1.8 (range 1–3) and for the private hospital placements 3.1 (range 0–4). (The person in the placement that scored 0 was subsequently moved.)

Functional assessments and analyses of individual challenging behaviour had not taken place in any of the residential homes, and only 50 per cent of the private

hospital settings. Only one out of five residential homes and six out of eight private hospitals used PCP. The authors acknowledged that the data concerned such a small sample that generalisation was not possible. They noted that 'one must be very critical of the lack of functional assessments and implementation of PCP in the residential settings' (p 17).

3.2.7 Transition from out-of-area residential schools or colleges in the South West

The Help To Move On Project worked with five local authorities in the South West of England.^{23, 24} It aimed to explore, promote and support the implementation of better pathways and options for young people at transition to adulthood. The particular focus of the project was young people with learning difficulties living away from home at an out-of-area residential school or college. Fifteen young people took part in the research. All were in their final or penultimate year at an out-of-area residential school or college. They were interviewed twice, a year apart, as were members of their family and up to five professionals they named as being helpful to them at transition.

In terms of young people being out-of-area in the first place, most parents said that they had looked at residential schools because there was no other suitable local educational provision.²³ Good transition planning onwards from the out-of-area residential school or college was often hampered by distance. Professionals from the 'home' area were less likely to be able to take the time to travel and attend transition planning meetings a long way away. This distance also meant that 'home' professionals did not feel that they really knew the young person concerned and what their own views or hopes for the future were.

3.3 Forensic and secure care needs

The Department of Health issued a policy clarification note²⁵ which emphasised the need to ensure that people with 'forensic' needs or challenging behaviour were not placed many miles from home out of a need for specialist help. This section reviews research in relation to out-of-area placement of people with forensic or secure care needs.

3.3.1 Forensic and secure care in the area of the Wessex Consortium

A study in the catchment area of the Wessex Consortium²⁶ did a needs assessment and resource mapping exercise which revealed an almost total lack of any level of secure provision for people with learning difficulties and severe challenging behaviour within the territory. The needs assessment showed a large unmet demand for long-stay low-secure care. This needs assessment was updated²⁷ to provide a more recent assessment of the numbers and characteristics of individuals with learning difficulties who required a secure service in the area. A total of 35 people with learning difficulties needing secure care were identified (29 male, 6 female). The majority (19) were in private secure settings many miles distant from the consortium area. Twenty-seven of the 35 people identified were in out-of-area placements (six in NHS secure care and two in high to secure care).

3.3.2 National Development Team Tough Times Project

The issue of providing more local services to meet the needs of people at risk of offending has been the subject of the recently completed Tough Times Project by the National Development Team.²⁸⁻³² This project aimed to help partnership boards to devise local services that could support people with learning difficulties at risk of offending, so that those who were placed in secure services out-of-area could return to their communities. All reports can be found via www.ndt.org.uk/projectsN/TTFactS.htm

The work included details of two recent national studies that have started to quantify the use of secure settings within the independent sector for adults with learning difficulties.³⁰ The Healthcare Commission completed the first study. A census was conducted of all independent mental health hospitals registered to provide care and treatment for people with a learning difficulty as of 31 March 2004. There were 46 hospitals registered within this category, providing a total of 968 beds. Twenty-six per cent of the patients within these settings were detained under criminal provisions of the Mental Health Act; 41 per cent were detained under civil provisions; and 33 per cent were 'informal' patients (that is, not formally detained but kept in locked environments).

The second study was by Selby and York PCT. They looked at NHS expenditure on medium and low secure forensic services commissioned from the independent sector as at 28 February 2005. They received information on 22 different independent providers offering 144 places to patients diagnosed as learning disabled. The NHS was spending in excess of £20.2 million pa on the identified 144 patients. The most expensive 'bed' recorded cost £875 per day, £319,000 pa.

The Tough Times Project presents recommendations to change the situation of people with learning difficulties at risk of offending (see NDT, 2007, for details of all recommendations). First, it is recommended that a 'forensic needs analysis' should be done which includes information on people from the local area who are placed in secure care, or who are at risk of offending, and their support needs. Examples of areas where such a forensic needs analysis has been undertaken are given.²⁹ Secondly, it is recommended that areas should have a 'forensic learning disability strategy' based on the forensic needs analysis. This should document what services are available locally and what new services are needed locally to support people at risk of offending. Again, examples of areas where such a strategy has been developed are given.²⁹ Examples are also given of services that have succeeded in providing local support for people at risk of offending.³²

3.3.3 Breaking the cycle: better help for people at risk of offending in the North West

A report by the North West Training and Development Team (2007) provides a comprehensive strategy to improve support for people with learning difficulties who are at risk of offending in the North West. The report suggests that once community-based services do fail for people at risk of offending, the person often transfers directly to overly supportive provision, usually secure services, which may be over-restrictive.

3.3.4 Learning difficulties and mental health problems in the South West

A study in the South West focused on services for people with learning difficulties and mental health problems.³³ A retrospective two-year census of 348 case files of adults with a dual diagnosis of learning difficulties and mental illness was carried out. There was a small (just 20 examples over the two years) but continuing flow of individuals out-of-area, triggered by a combination of placement collapse, a lack of specialist provision, and in some instances, the very complex needs of the individuals. All but two of the people placed out-of-area had been either involved with the criminal justice system or detained under the 1983 Mental Health Act. Interviews with providers indicated that there was widespread concern that the lack of local specialist provision was continuing to lead to out-of-area placements that might have been avoided.

The audit also revealed that over 80 people were placed *into* the region. Interviewees expressed a very different set of concerns about into-area-placements. There was a widespread criticism of poor placement practice, leading to a lack of continuity in providing adequate care. Most service providers saw the net inflow as a major problem. Their perception was that the additional workload was not reflected in the resourcing of services, leading to increased pressures and diluting their capacity to meet the needs of local people.

While there was recognition that some very good independent sector provision existed, there was also considerable concern about the willingness of some providers to 'import' individuals with complex needs without the capacity to provide effective support. Several interviewees expressed the concern that services which were not seen as competent by local purchasers were more likely to import people from elsewhere to make up for 'lost' business.

3.4 Research on into-area placements

The study of people with learning difficulties and mental health needs in the South West begins to outline some of the issues for areas that *receive* people placed out-of-area. While some of the concerns about out-of-area placements, such as the quality of such placements, is shared by both placing and receiving authorities, a range of other issues have been highlighted for receiving authorities. Research relevant more specifically to receiving authorities is reviewed in this section.

3.4.1 Placed in Kent

Data from a survey of into-area placements in Kent are contained in the main report of the project³⁴ and in a number of related publications.³⁵⁻³⁹ The survey covered all 400 residential care homes in Kent, providing capacity for 3,484 residents. Homes were asked for a list of residents identifying which were people placed from outside Kent.

Responses were received from 325 homes (81 per cent) regarding 759 people. However, on checking against information provided by two placing authorities large discrepancies were found and it was estimated that the actual number placed in Kent

was substantially more than this. It was estimated that Kent fund about 1,500 of the 3,484 residential places in Kent. Hence, somewhere in the region of 1,000–2,000 may be out-of-area placements, constituting 30 per cent – 50 per cent of all learning difficulty placements in the county.

The study gives some characteristics of people placed in Kent. Fifty-one per cent were under 40 years of age. The average length of stay was 7 years 10 months (range 1 month to over 37 years) and 96 per cent of placements were described as long term. In total, 99 authorities placed people in Kent with the highest placing authority (Medway) placing 65; 62 per cent (473 people) were placed by London authorities. The furthest placing authorities were in Scotland and Wales.

Of those for whom care manager details were given, 30 per cent had not had contact in the last year, and for a further 33 per cent care manager details were not known. The authors noted that the absence of care manager information may reflect lack of contact with the care manager. If so, over half the sample would have had no contact in the last year.

The average number of people from out-of-area placed at the same address was four (range 1–30). Organisations tended to receive placements from particular placing authorities. There was uneven geographical distribution with more places in East than West Kent, and a tendency for congregation in coastal towns (see Figure 4). For example, there were more people placed in Dover from other authorities than there were placed from Kent. The authors conclude that:

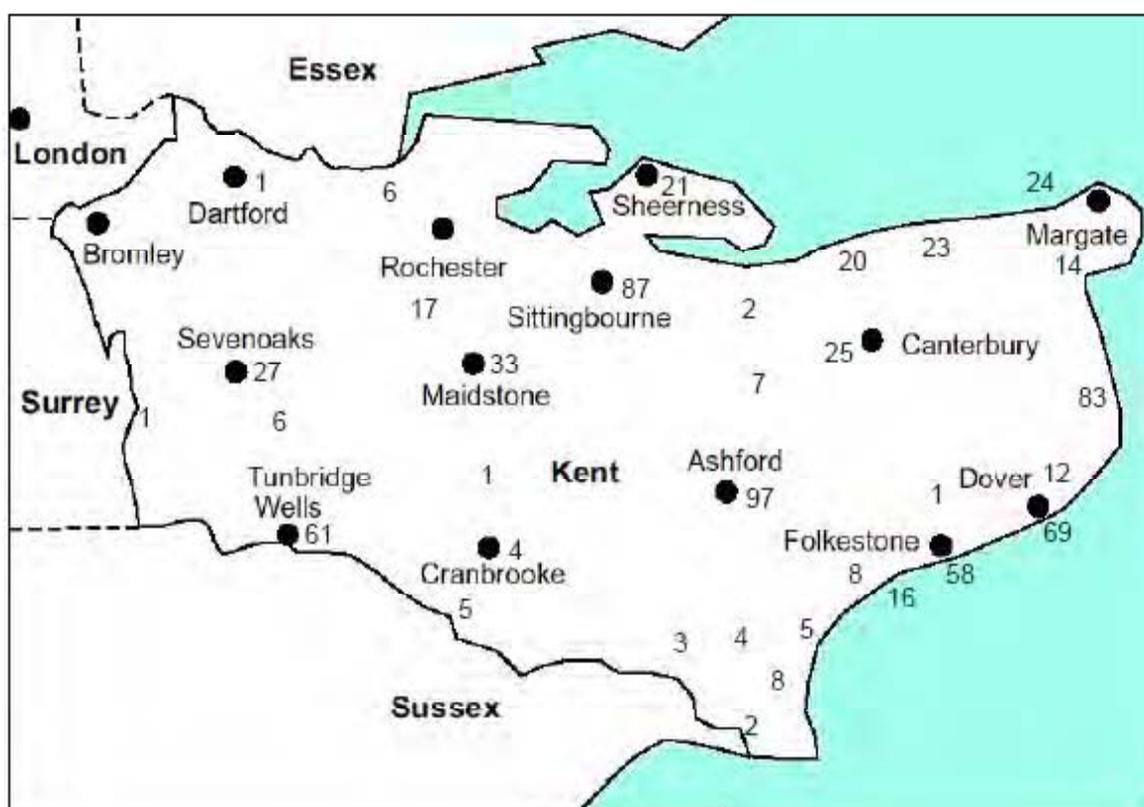
There is, therefore, a *prima facie* case that the number of people placed in Kent by other authorities pose a considerable extra demand for health and social care services. (p 19)

In-depth information was collected on a sample of 30 people placed in 30 different homes. While the sample was small, the 30 people appeared, as a group, to be less socially impaired, have more language ability and be more challenging than other people with learning difficulties in residential care in Britain. They also appeared to include a higher proportion of people from black and minority ethnic groups.

The authors note that two main themes explained why people had been placed away from their home area: (a) because of lack of sufficient services locally, either because they were not of acceptable quality, or because they were unable to support people with higher needs for support (for example, because of challenging behaviour); and (b) because locality was not thought to be important (for example, for those people who were in long-stay institutions). The first reason was an important factor in respect of three quarters of participants.

Two thirds of homes specialised in the needs of the residents served: 11 of the 30 homes specialised in challenging behaviour or mental health problems, sometimes in addition to autism; four specialised in physical disabilities and learning difficulties; four in autism and learning difficulties; and one in older people with learning difficulties. Fifty-nine per cent of homes had more than half their residents placed from out-of-area, and in 22 per cent every resident was placed from out-of-area.

Figure 4: Distribution of people placed in Kent [34]



Half the managers said that the only referrals they received were from out-of-area. The authors suggested that there was often a financial incentive to accept referrals from out of Kent, either because other authorities paid higher fees or because they accepted poorer quality.

The study also looked at the quality of homes. Inspection reports were available for 27 of the 30 homes. These indicated whether national minimum standards were met in respect of 43 standards in eight areas. Overall, the mean number of standards met was 31 (range 11–43). Five homes met 50 per cent of standards or fewer. There was no statistical relationship between whether the home was specialised or how much it cost and the percentage of national minimum standards met.

On the basis of interviewing 15 family members, the study found that: (a) a third of families said they had no say in the choice of placement; (b) some felt that they had had to fight hard to find and fund the right placement for their relative; (c) the distance involved and transport problems caused some families problems in visiting their relative and taking part in review meetings; (d) some families were very anxious about criticising the care received by their relatives for fear that their relative might be asked to leave; and (e) almost all thought that their relative was happy but some had concerns about basic levels of care.

In relation to coordination and liaison the study found that: (a) almost half the home managers reported problems contacting care managers from the placing authority; (b) all care managers identified distance as a disadvantage for them (in terms of providing care management and monitoring); (c) nearly half the care managers said that they would not normally inform Kent of the placement being made; and (d) members of community learning disability teams said that they were not usually informed in advance of people placed in their area with referrals to them for help typically being made when people were in crisis.

Community learning disability teams reported that the effects on them of out-of-area placements were increased workload, fewer resources for local people, more difficulties in coordination and liaison with care managers and lack of information about people moved into their area.

3.4.2 Implications of into-area placements for psychiatry in Leicestershire

The research in Kent suggested that there is a prima facie case that receiving authorities face an increased strain on local services. Supporting evidence for such a case comes from a survey on the implications of out-of-area placements for psychiatric services in learning difficulty.⁴⁰ The active out-patient caseload of one consultant psychiatrist was surveyed from May 2000 for one year. People from outside Leicestershire who were placed in residential homes in the area were identified and case notes scrutinised. A total of 29 patients were in out-of-area placements, 72 per cent of whom were male. All were placed in private residential homes. The vast majority (93 per cent) were known to specialist health services even before placement, with a mean length of contact of 13 years.

The authors reported the following professional involvement with these patients: psychiatrist (100 per cent); community psychiatric nursing team (97 per cent); assertive outreach team (41 per cent); clinical psychologists (31 per cent); speech and language therapists (17 per cent); and occupational therapists (seven per cent). Overall, a mean of three professionals from different health disciplines were involved with each patient. Patients had a mean of five out-patient appointments a year. In summary, it was clear that these patients needed significant professional input. However, there was very little contact and discussion from the placing area health team. Formal handover arrangements were seriously deficient and consultation with specialist health services prior to the placement being made was almost non-existent. Often the first that specialist health services knew about someone moving into an out-of-area placement was a referral from a GP about three months after the placement was made.

3.4.3 Other sources of evidence

While it is not clear how the local data were collected, Pring⁷ noted that 570 people from out-of-county were placed in Lincolnshire, which placed a drain on local resources when funding was only received for its own 1,900 clients. At one large residential home, all but one of 40 or so residents were from out-of-county. In one rural area of Wales, approximately 50 people are placed into an area with a local population of people with learning difficulties of 168.⁴¹

Forsyth and Winterbottom (2002) suggested that out-of-area placements are often used where higher levels of specialist services are needed (implying greater health needs). They argued that the receiving area ends up funding future mental health needs unless service level agreements are arranged. This can mean that the health burden of such placements is high for the receiving area, and they anecdotally suggested that this was the experience in their area of Gloucestershire.

3.5 Conclusions

The following section presents some emerging themes from the review of research on out-of-area placements.

3.5.1 Characteristics of people placed out-of-area

The main groups found to be placed out-of-area are those with: challenging behaviour; autism; mental health needs; complex health needs; and forensic needs. Information on the age of people placed out-of-area indicates a relatively young group who will require support for the foreseeable future^{9, 11, 14, 17, 20} Those placed out-of-area are also more likely to be male.^{6, 8, 17, 27, 40} This is consistent with an increased prevalence of autism and challenging behaviours among men.⁴²

There is some evidence that people placed out-of-area may be more able.^{34, 43} They may show challenging behaviour that is more severe or has a more severe impact.^{14, 17, 43}

Information on ethnicity gives a mixed picture, with some studies suggesting that people from minority ethnic groups are over-represented in out-of-area placements^{17, 34} but one study suggested that people from an Asian background are under-represented in out-of-area placements.⁹ This mirrors research conducted in the 1990s that found an over-representation of people from black and minority ethnic communities and an under-representation of people from South East Asian minority ethnic communities in residential services.¹⁰

3.5.2 Reasons for out-of-area placements

The main reasons for out-of-area placements, including out-of-area residential schools or colleges, relate to the lack of available local services. Out-of-area placements are made for predominantly negative reasons such as placement breakdown and dissatisfaction with local services as opposed to positive reasons such as being nearer to family, or meeting religious or cultural preferences.^{6, 8, 9}

3.5.3 Characteristics and quality of out-of-area placements

Most out-of-area placements are in the independent sector and in many cases within large settings.^{6, 43} There have been no direct comparisons of the quality of out-of-area placements with locally based services. However, the evidence points to shortcomings in the quality of some out-of-area placements. Concerns with the quality of out-of-area placements include: low numbers with PCPs or health action plans;^{6, 22} low levels of access to psychology, psychiatry and appropriate behavioural

support for people with challenging behaviour;^{22, 43} lack of engagement in the home and in community activities;⁶ and lack of effective support for people with complex needs.³³

3.5.4 Issues for people placed out-of-area

A recurring theme in the literature is the lack of contact with people placed out-of-area by placing authorities with some evidence that contact decreases the longer people are placed out-of-area.^{6, 7, 34} Hence, vulnerable people who are placed away from their families may be left in a situation where the quality and appropriateness of their placement is subject to inadequate monitoring. Distance also hampers good transition planning for those placed at out-of-area schools or colleges.²³

3.5.5 Issues for placing authorities

The financial cost to placing authorities of funding out-of-area placements can be high. Where comparative data is available, out-of-area placements are generally more expensive than locally based services.^{14, 20} The use of expensive out-of-area placements has a negative impact on local investment, contributing to a situation where lack of local services leads to high expenditure on out-of-area placements, taking away resources which could be invested in developing better local services.

3.5.6 Issues for receiving authorities

The pattern of out-of-area placements is such that particular areas of the country have substantial numbers of people placed into their area. Even within a county these placements may be concentrated in particular areas. The need for specialist professional input is often met through local services rather than through specialist provision made by placement providers. This has led to considerable concern in some areas that into-area-placements have diluted services available to those from the local area. Receiving areas are not generally informed in advance of an into-area-placement. The first knowledge they have of someone being placed into-area is often a referral when people are in crisis.^{6, 40} This makes it difficult for local services to plan for the needs of the people placed into-area.

3.5.7 Forensic and secure service issues

Evidence suggests that people with forensic and secure needs are something of a 'hardcore' of out-of-area placements, with most people with such needs being placed out-of-area.²⁷ Where an area has very few out-of-area placements, the few that exist are likely to be for forensic and secure needs.³³ Placements are extremely expensive. As noted in the Tough Times Project,³⁰ the fact that about a third of people in independent secure services are 'informal' patients is a particular concern as these placements may be viewed as unlawful in light of the recent European Court of Human Rights decision in the Bournemouth case (*HL v the United Kingdom*).

3.5.8 Gaps in the literature

There are at least three groups of people at risk of out-of-area placement for whom there appears to be no research: people with complex medical needs; people with severe epilepsy; and people with dual sensory impairments. For example, in the North West, the David Lewis Centre offers specialist support to people with epilepsy, with over 200 people living on the site from the age of seven upwards. As a national centre, it is likely that the majority of people living there will be placed a long way from home. The lack of research on out-of-area placements for these groups is reflected in the paucity of practice examples and emerging solutions for them in the practice survey element of this knowledge review.

4 Undertaking the practice survey

The aim of the practice survey was to consult as widely as possible. In an attempt to achieve this, the practice survey included three distinct components each utilising a different method: online consultation, consultation workshops and consultation conferences. We believe that such an approach would have been more likely to achieve the overall aims of the project than a traditional survey.

4.1 Online consultation

Online consultation was undertaken through establishing a Google group to which information could be disseminated and commented on across the UK. Links to the group were established on the SCIE website and advertised through various activities undertaken by consortium members, including an article published in *Community Connecting*. Thirty-six participants signed up to the group. We did not collect information on the background or location of participants.

4.2 Consultation workshops

We also organised a number of workshops, most of which were undertaken in the context of existing meetings and conferences organised or attended by members of the consortium. The aim of these workshops was to provide a forum for the identification of barriers and potential solutions to commissioning local personalised support for people with learning difficulties who are at risk of exclusion from local services. These workshops/meetings included meetings with:

- All Wales Community Living Network
- South West Adult Learning Disability Commissioning Forum
- social care commissioners of South Wales Learning Disability Commissioning Partnership Boards
- London Learning Disability Network
- the East Midlands regional meeting of partnership board representatives with learning difficulties
- ARC (Action for Real Change) members meeting
- a specific workshop for carers run jointly by the National Family Carer Network and National Children's Bureau

4.3 Consultation conferences

Finally, we organised three one-day consultation events (London, Pontypridd and Accrington)[♦] that enabled us to share initial findings and road-test emerging solutions with participants and solicit further examples of good practice and relevant 'grey' literature. Delegates included people with learning difficulties, parent carers, advocacy organisations, commissioners and service providers.

♦ Organised jointly with the Valuing People Support Team.

5 The results of the practice survey

The following sections highlight the key issues that arose during the consultation process. In summarising these issues we decided it would not be appropriate to attribute comments to specific individuals or organisations. Nor have we taken 'head counts' of how many people agreed with particular issues and themes. We have, however, striven to ensure that our summary captures the prevailing consensus among the different stakeholder groups and have ensured, where appropriate, that 'dissenting' views are aired. We have also included a bibliography of position papers, guidance and reports that are relevant to these issues.

Participants made a number of recommendations about how practice could be improved. We report these recommendations later in the body of this report and summarise them in a later section. It must be kept in mind, however, that these are recommendations made to us during the consultation process. They are not necessarily endorsed either by members of the consortium who undertook the consultation or by SCIE.

Throughout the consultation process we sought to identify examples of better practice. Almost all of the examples that were given related to the experience of particular individuals, rather than examples of better practice at the level of organisations or systems. We have placed these examples throughout the following text to illustrate the general themes raised during the consultation. In order to preserve anonymity, we have omitted the names of the areas and changed the names of individuals. What is noticeable is that many of the individual 'successful stories' often appear to be driven by the commitment of families and friends who have the time, energy and commitment to 'take on and do battle with service orthodoxies'.

6 The adverse impact of out-of-area placements

There was almost universal agreement among people who participated in the consultation that the current extent and pattern of out-of-area placements in England and Wales was, overall, detrimental to the quality of life of people with learning difficulties and their families. It was also seen as being detrimental to the development of high-quality comprehensive services for people with learning difficulties in both the placing and receiving authority areas. As noted above, no information was available on the extent of out-of-area placements in Northern Ireland. In addition, while current policy documents stress the importance of deinstitutionalisation and the development of inclusive local services,⁴⁴ they make no mention of out-of-area placements being an issue of concern. Neither did we receive specific comments during the consultation process to suggest that the issue of out-of-area placements was an issue of concern in Northern Ireland.

The primary disadvantages of out-of-area placements were seen in terms of the disruption that they may cause to relationships between the person, their families and their friends. Such disruptions were considered to be particularly problematic:

- for people who are placed at a considerable geographical distance from their family and friends
- for friends and relatives who themselves have learning difficulties
- for elderly parents
- for relatives and friends who may have difficulty in travelling

When my son was nine, the local special school admitted they were unable to meet his complex needs. Initially, to try to contain him, they strapped him to a chair and sandbagged it to the floor. He has Cri du Chat syndrome, severe learning disabilities and very challenging behaviour. At home, he was pulling his curtains down, ripping his mattress open and eating the stuffing, or banging his head against the wall – and our family life was disintegrating. Fortunately, we managed to find a school that specialised in helping children like my son. Within months of starting at his new school, he was sitting in a chair on his own and making eye contact. Instead of pushing the table over when he had had enough food, he now made a sign for 'finish'. Unfortunately, the school was over 250 miles away, and for the next 10 years any visit to see my son meant a 500-mile round trip. While happy that he was making such good progress at his new school, I was NOT happy that a 500-mile round trip was required each time I wanted to see him, and I started to ask why we couldn't have a specialist service for him nearer to home. He is now 21 years old. He lives less than five miles from our family home. His new service, which provides accommodation, support and a Further Education college course, was the product of a great deal of hard work and effort.

Indeed, there was a widespread concern that out-of-area placements could within a relatively short period of time lead to people becoming isolated from their friends, local communities and in some instances their families.

There was also a parallel concern that people, once placed out-of-area, could all too easily be forgotten by the placing authority.

Additional concerns were raised with regard to:

- the person's choice and self-determination (given that most people with learning difficulties do not appear to be actively choosing to move away from their families, friends and local communities)
- difficulties in promoting the social inclusion of people who are placed out-of-area
- difficulties for the person who is placed out-of-area in accessing appropriate non-residential support and services (for example, employment services, advocacy and self-advocacy)
- the relatively high costs of many out-of-area placements and the impact that this has on the often constrained budgets of the placing authority
- the lost opportunity for placing authorities in investing in and developing local capacity and expertise
- the difficulty for professionals in monitoring long distance placements, both in terms of the well-being of service users and service quality
- the cultural inappropriateness of placing people in areas in which support in the person's preferred language is unlikely to be available (a particular issue for Welsh-speaking people with learning difficulties and people from minority ethnic communities).

A number of concerns were expressed regarding the quality of many out-of-area placements, especially those provided in larger-scale, more institutional settings. Given the risk that once placed people could all too easily be forgotten by the placing authority, there was a very real concern that the current pattern of out-of-area placements could give rise to a new wave of (private sector-dominated) institutionalisation.

Finally, significant concerns were also expressed about the impact of out-of-area placements on the areas to which people have been relocated (the 'receiving' area). For example, a significant amount of inward migration has been reported from London to areas in South West and South East England (for example, Kent). This was described as a significant urban to rural drift, driven primarily by financial incentives related to the relative cost of property (especially for larger homes) and the availability of direct support staff. This trend has been exacerbated as independent sector providers have no statutory duty or responsibility to relate to the locality in which their services are located. It has been suggested that these trends may lead to a disproportionate build up of people with learning difficulties (especially people with more complex support needs) relative to local population. One consequence of this would be increased demands on locally provided NHS care, and possibly increased demands on other professional services, the provision of day and employment services, educational provision for adults with special needs as well as a possible impact on the more general infrastructure (for example, transport). In areas in which

pooled budget arrangements exist, any additional resource demands on the NHS were seen to have a secondary impact on resource availability for social care. People we consulted were unclear whether new Healthcare Commission guidance on the responsibility for providing specialist healthcare would have an impact on these issues.

6.1 Who is at risk?

It was clear that the risk of being placed out-of-area varied over time, people and localities. In particular, the running down and closure of NHS-operated institutions for people with learning difficulties over the past three decades appeared, in some areas of the country, to drive the development of out-of-area placements. While some agencies (for example, the old regional health authorities) developed and implemented specific policies that encouraged people to be resettled to their 'areas of origin', others did not. As a result, there exists a continuing legacy of (now older) people with learning difficulties who were originally placed 'out-of-area' as a result of institutionalisation, but who never returned 'home' when resettled into more community-based options.

Other factors that were suggested as being associated with increased risk of out-of-area placements included:

- placement in out-of-area residential special schools and/or colleges
- not having strong family or other advocacy
- having a family that actively requests a long distance placement due to fears about dependency and risk
- living in an area with high property costs
- living in an area with a tradition of placing people with more challenging needs out-of-area'

In particular, current decisions with regard to out-of-area placements appear to primarily reflect the perceived or actual lack of capacity (or willingness) to support people with more complex needs locally.

The characteristics and needs of people with learning difficulties that place them at risk of out-of-area placements include (but are not necessarily limited to):

- people with challenging behaviours, significant mental health needs or 'personality disorders'♦
- people with ASD
- people who are at risk of offending
- people with complex epilepsy
- people with continuing and complex health needs, including those who are dependent on complex medical technology to support life
- people with inappropriate sexual behaviours

♦ For example, there are no secure facilities for people with learning difficulties in Northern Ireland. As a result, people deemed in need of such facilities are detained in Scotland.

- people with learning difficulties who are parents who may be subject to court-ordered assessments of their parenting skills in residential out-of-area assessment units

6.2 Some caveats

While there was a strong overall consensus that the current extent and pattern of out-of-area placements was detrimental to the quality of life of people with learning difficulties and their families, there were also a number of important caveats made to qualify this general view.

- Out-of-area placements may represent the best option for particular individuals at that point in time *due to the lack of appropriate local services and supports*. As one parent put it “Of course I wouldn’t choose to send my son to live miles away from his family – but when my local authority said there were no services locally to meet his needs, the ‘choice’ was for him to stay at home, his behaviours increase and quality of life decrease, or to move hundreds of miles away and be properly supported with staff and an environment tailored to his needs”.
- Basing definitions of who is placed ‘out-of-area’ simply on administrative boundaries (for example, of CSSRs) could, in certain contexts, be unhelpful and misleading. For some people being placed ‘out-of-area’ did not necessarily mean that they were living a significant distance away from their home communities. It could, in fact, mean that they were living closer to their home communities than would be the case for some ‘within-area’ placements.
- Some out-of-area placements have arisen as a result of people with learning difficulties moving to be closer to their families who have moved to a different area. This may arise, for example, when parents have separated and moved to different areas.

Geraldine is 38 years old. She has high support needs and uses a wheel chair. In Geraldine’s area the local education authority said that they could not provide an education but that they were willing to fund it. As a result, Geraldine went to school in another county until she was 19. Her family believed that this was the best decision at the time. After trying several alternatives, she then went to live at a service several hundred miles from her home. She was very unhappy there. Her parents moved and built a bungalow on adjoining land for Geraldine, where she now lives in and maintains herself with considerable support from her family. She now has her own staff team, provided by a registered provider. The provider is developing a bank of people who can work with her. This currently costs £79,000 for 1:1 24/7 support, which is estimated would cost £107,000 in residential care.

- Some people may actively choose (and some families may actively choose on behalf of their offspring) placements in preferred settings elsewhere (for example, intentional communities or specialist provision for people with ASD). It was noted that many intentional communities are run by national organisations, have national catchment areas and that dialogue with local authorities is underdeveloped.

- It was also noted that parental choice of an out-of-area school or college placement may contribute to risk of out-of-area placement as an adult.
- Some people have been living away from their communities of origin for many years. In such cases the appropriateness of moving people back to their home communities needs to be carefully considered.
- Some people may wish to move to another area (for example, because of housing availability or costs, if the person concerned wished to move towards independent living). Families pointed out that non-disabled people can (and do) move to different areas and people with learning difficulties should have the same option.
- Any development in policy that seeks to reduce out-of-area placements needs to ensure that it does not encourage the development of poor quality local placements or lead to people becoming trapped in their area of origin. As such, there is a need to consider carefully the extent to which any regulations and guidance involving notions of a person's 'home locality' could act as a barrier to the freedom of movement of people with learning difficulties.
- For a small number of people who have acquired significant local 'reputations', a fresh start in another locality may be of benefit.
- The term 'out-of-area' placements covers a wide variety of arrangements including:
 - residential education or training (usually specialist and time-limited);
 - specialist but time-limited placements (for example, for rehabilitation following surgery or a head injury or for specific behaviour management or therapy programmes)
 - short breaks/respite care – usually very short because of competition on resources, but sometimes sequential or longer-term, for example in family illness
 - residential provision (could be planned or crisis intervention)
 - supported/independent living scheme where the person is still funded by their home authority (for example, the person might move out-of-area in order to access appropriate housing, because family moved or for some other elective reason)
 - arrangements covering all or some of the above, often for a particular impairment such as ASD, where the local authority does not believe it has the capacity to make provision and automatically seeks out-of-area placements.

7 Barriers to Commissioning person-centred, cost-effective, local support for people with learning disabilities

The vast majority of the people we consulted were clear about and supportive of the direction set by current policies and the values (rights, self-determination, social inclusion, independence) that underlay them. The existing pattern of out-of-area placements was seen by most as a reflection of historical processes (for example, patterns of deinstitutionalisation) and a symptom of the continuing failure of local agencies to commission person-centred local support for people who, for whatever reason, challenge services. People suggested that this failure of effective person-centred commissioning was due to a number of interrelated factors:

- lack of incentives and weak performance management
- policy and regulatory barriers
- unclear responsibilities
- insufficient investment in long-term strategic and joint commissioning
- lack of experience of commissioning person-centred supports for people who challenge and risk-averse cultures
- market weaknesses
- the drive toward specialisation and congregate care
- insufficient resources

7.1 Lack of incentives/weak performance management

As noted above, the vast majority of the people consulted were clear about and supportive of the direction set by current policies and the values (rights, self-determination, social inclusion, independence) that underlay them. However, a number of people argued that existing policies and value statements lack teeth, appearing to have little impact in controlling a market dominated by largely pragmatic and supply-driven decision-making processes. In short, it was argued that there were few, if any, effective external incentives or penalties that would encourage local agencies to support people with more complex needs locally. It was pointed out that the issue of out-of-area placements was not being addressed within current national performance management systems operating within education, health or social care. This led some contributors to question the actual strength of expressed real policy commitments to the provision of comprehensive, person-centred and local services.

These problems are compounded by local and regional variations in economic development and the supply of care staff. Thus, for example, it was suggested that provider organisations find it easier to obtain planning permission (especially for larger facilities) in more economically deprived areas (which are also likely to have a greater supply of entry-level care staff and lower property prices). These factors can contribute to the development of areas with very high densities of residential care

and nursing homes supporting significant numbers of people with learning difficulties placed out-of-area. It was therefore recommended that:

- The Department of Health should consider introducing effective incentives to support local provision and effective penalties to discourage *new* out-of-area placements into their performance management of CSSRs. (For many participants, the key priority in addressing out-of-area placements was the prevention of new placements for people who challenge services, rather than addressing the historical legacy of out-of-area placements that arose during the era of deinstitutionalisation, especially given the damage that another move could do to people's social networks. There was also a concern expressed that any penalties should be reserved for placements that clearly posed a significant problem for the person in maintaining contacts with family and friends.)
- Given the historical legacy of out-of-area placements, the Information Centre for Health and Social Care should modify form SR1 (the form currently used to collect information from CSSRs on out-of-area placements) to collect information on *new* admissions to out-of-area placements of people with learning difficulties and this information should be summarised in the annual Community Care Statistics reports at the level of CSSRs. In addition, the Information Centre for Health and Social Care should monitor the number of out-of-area placements of people with learning difficulties in receiving CSSRs and separate out information on people with learning difficulties aged 65 and over.
- The Department of Health should consider imposing a duty to consult on placing authorities and incoming provider organisations. This would, in effect, give some powers to CSSRs to prevent the development of services by providers who intend to accept the placement of service users from other areas.
- Applications for planning permission for the establishment of residential care and nursing homes should take into account the extent to which these developments reflect local need.
- Authorities placing out-of-area should be required to pay a per capita fee or 'bursary' for local health and social care services.
- Given that educational placements in out-of-area residential special schools appear to lead to out-of-area residential placements for adults, the Department for Children, Schools and Families should act to reduce the number of children with learning difficulties educated out-of-area in residential special schools. In addition, there should be greater investment in transition planning for those young people with learning difficulties who are educated out-of-area. Indeed, the Audit Commission report on *Out of authority placements for special educational needs* (2007) states that: 'Councils and their partners, including health trusts, should take a more strategic approach to the joint commissioning of support for pupils with complex needs. This commissioning strategy should take account of the costs and benefits of local and out of authority provision and seek to address the shortcomings in respite care, therapies and mental health support identified in this study and others'.
- National advocacy agencies should use their political influence to raise the profile of the extent and unacceptability of the existing pattern of out-of-area placements.

7.2 Policy and regulatory barriers

Some of the existing policy frameworks and regulations were considered to present barriers to the control of out-of-area placements:

- The commissioning mechanisms associated with Supporting People were seen as focusing on schemes rather than individuals with provider organisations leading their development. This arrangement involved no disincentives whatsoever to prevent or discourage provider organisations from 'importing' people from other areas. In addition, concern was expressed regarding the inability to refuse Supporting People funding for people being 'placed' locally from outside the local area.
- In relation to housing, social housing grant regulations and housing allocation systems were considered by some to constitute a barrier to moving people back from out-of-area placements.
- While it was generally agreed that there are clear criteria/practice precedents for engaging health to use continuing healthcare funds to support out-of-area placements, it was reported to be significantly more difficult to get the same funding to make local community arrangements. As such, the existence of the current criteria/practice precedents could act as a perverse incentive to encourage the development of out-of-area placements.
- It was argued that restrictive and burdensome procurement regulations impeded the capacity of NHS organisations to respond competitively to market pressures, thereby opening up the field to private companies who are less constrained by such regulations. As one participant described it, "you can't get out of bed in the NHS these days without developing a five case business model and tendering via the Official Journal of the European Communities".
- Concerns were also raised with regard to problems accessing capital funding to develop supported living environments that were appropriate for people with complex needs. For example, it was suggested that, while some registered social care landlords would be willing to develop accommodation, housing benefit rates would not cover the development costs, particularly if new-build was required. Similarly, the long lead-in time for securing capital funding (for example, through the Strategic Housing Grant), did not match the need 'on the ground' to act speedily.
- It was reported that the arrangements around continuing healthcare (which prevented people from accessing direct payments and the Independent Living Fund) were unhelpful and, in certain instances, had led to the cessation of more personalised packages of support.

It was, therefore, recommended that:

- The Department of Health and related regulatory bodies review the extent to which current regulations relating to the funding and operation of supported accommodation services for people with learning difficulties take into account whether proposed service developments meet local requirements (that is, whether proposed developments are needed to meet needs in the local area).

7.3 Unclear responsibilities

There continues, at least in many parts of England and Wales, to be a lack of clarity with regard to the funding responsibilities of local authorities and the NHS in supporting people with learning difficulties who have more complex needs. In particular, there remains a lack of clarity with regard to the definition and identification of people in need of continuing healthcare. One consequence of this lack of clarity is inefficient use of resources and time lost as the respective agencies seek to clarify their respective responsibilities for each individual with complex needs for whom additional investments are required. There was some hope expressed that work currently being undertaken by the Department of Health to clarify these issues would be helpful in resolving this issue.

7.4 Insufficient investment in long-term strategic and joint commissioning

It was widely acknowledged that there was a significant shortfall in current capacity for adopting a more strategic approach to commissioning services and support for people with learning difficulties. While there was clear variation in local practice, far too many localities appeared to be characterised by underdeveloped systems for:

- mapping current and anticipating future need (especially at the point of transitions)
- evaluating the costs and outcomes of placements (especially out-of-area placements)
- developing joint protocols, service specifications and other mechanisms for delivering more sophisticated commissioning responses in light of this need.

It was also argued that, at present, there was a real shortage of readily available quality indicators and service specifications for determining what makes an effective high-quality service for people that present a challenge to services. There was a clear consensus that effective commissioning required much more robust information on what services were (or were not) delivering for people. That is, monitoring needed to move from counting 'how many' (for example, how many plans have we done? how many bed spaces do we have?) to looking at the quality of life of people receiving services.

In some areas the perceived failures of strategic commissioning were contrasted with increasing investment of resources in contract monitoring teams and operational teams undertaking micro-commissioning. While capacity in micro-commissioning was seen as essential to any system commissioning person-centred local support, there was a general consensus that, in a market dominated by the achievement of short-term goals and dominated by existing providers, micro-commissioning all too often descended into spot purchasing.

A number of comments were also made regarding:

- the disjunction in the time required to develop strategies which would comprehensively match the needs of the local population (especially people with

complex needs) and the pressure on operational teams and care managers to find solutions for people in crisis

- the difficulty of securing funding to support planned development (including capital funding) compared with the often ready availability of money to fund emergency (and often out-of-area) placements
- the failure to support effective transition planning that would enable people to move out of their family home in an appropriate way or enable children who were being educated out-of-area to move back
- the failure to provide effective support to families caring for a relative with learning difficulties.

I am a parent of a severely autistic predominantly non-verbal 18-year-old son and also of a 19-year-old son with Asperger syndrome. My ex-husband and I set up and ran a National Autistic Society support group for eight years. I am also a learning disability nurse. I am now speaking as a parent: my son, although in a specialist out-of-county placement since the age of eight, has never to my knowledge (and I presumably should have been told!) had anyone doing any specific work on his transition, although I have asked for it. He has recently moved off his school site to an eight-bedded house (this is a newly developed placement for those aged 16-24 years from the same school) while we await whether our funding will come through for July 2008 when he is due to leave education. We have little contact with the transition worker and have made formal complaints to the Director of Social Services in the past, which were upheld. In fact the transition worker or a council representative did not attend his April review or send any statements as to progress!! I read in my journals about some people having specific communication work carried out and I have offered to do a PCP and ELP for my son, but my offer was not taken up. My ex-husband and I are wondering whether to bring in an independent advocate as we are often just given the brush off, I sense as 'interfering parents' the same goes within the profession. Parents seem to get in the way of organisations routines and procedures!.

The result of these trends were summarised in terms of a focus on ad hoc commissioning (or spot purchasing), driven by the pressures to identify the cheapest (or only available) placement. The failure in some areas to develop a clear strategy for supporting at-risk groups (for example, people with challenging behaviours) was considered to both reflect and exacerbate these types of problems.

In addition to capacity issues relating to taking a more strategic view of the commissioning process, concerns were raised in some areas with regard to the continuing failure to develop effective joint commissioning between PCTs and CSSRs reflected in continuing disagreements over agency responsibilities and the prospect of cost shunting with associated squabbling between health and social services (see above).

It was noted that the Healthcare Commission, Commission for Social Care and the Mental Health Act Commission have undertaken to carry out a joint programme of work in 2008–09 to assess the quality of commissioning of services for people with high support needs. They will pay particular attention to the use of high-cost, out-of-area placements both in terms of the quality of outcomes for people and the

effective use of resources. The decision to undertake this work reflected concerns highlighted by the commissions through their work to date. Their intention is to establish what it is like to be a person with learning difficulties with high support needs requiring support in a place where services are commissioned on their behalf, such that they are able to assess the effectiveness of those commissioning arrangements through the organisations responsible for delivering them.

In light of these shortcomings and developments it was recommended that:

- CSSRs enhance their strategic capacity through the development of robust information systems that are capable of:
 - identifying the need profiles for all people with learning difficulties for whom they are responsible
 - have the capacity to anticipate future changes in need and demand by collating information from children's services
 - evaluating/monitoring/driving performance in terms of long-term efficiency in achieving outcomes related to the quality of life of people with learning difficulties (as opposed to the short-term management of costs).
- There should be continued investment and encouragement of partnership working with housing providers and joint risk assessment.
- Effective long-term strategic joint commissioning should seek to develop the local provider market. This would itself be supported by:
 - geographic co-terminosity between agency boundaries
 - the use of pooled budgets
 - the adoption of a more collaborative approach that sought to use provider expertise in an attempt to expand local capacity.
- There should be a greater emphasis on improving cross-border working, an issue that was considered to be particularly relevant in London.
- There should be a greater emphasis on investing in support (from childhood on) for people and their families to reduce crises and thus the demand for rapid response that so often results in out-of-area placement.

7.5 Lack of experience of commissioning person-centred support for people who challenge and risk-averse cultures

In those areas with a significant lack of experience in commissioning individualised local services for people who challenge (and who as a result were often over-reliant on out-of-area placements), the lack of experience itself presented an additional barrier, particularly in organisations that were considered 'risk averse'. It was suggested to us that commissioners in some areas were unwilling to sign off risk assessments for people who challenge to be placed locally, with out-of-area placements being seen as less 'risky'. These problems appeared to be exacerbated in areas that lacked local service resilience (the capacity to cope in the short term and solve problems in the longer term).

The issue of risk-averse practices was also raised in the context of an increasing 'blame culture'. It was argued that sometimes the emphasis seems to be on why things cannot happen rather than how and why they can. It was also suggested that health and safety policies and risk assessments often mean that people were not

enabled to take life risks and have opportunities to experience new things. It was suggested that, until a shared responsibility replaces the feeling that if anything goes wrong social workers and health professionals would be blamed for it, they would constantly avoid doing things in the community and instead put people in out-of-area placements that seem much safer.

It was also argued that insufficient information is readily available at a local level with regard to different options about housing. As such, it was suggested that there is a need to share examples of good practice and increase awareness of more creative ways of providing support, including direct payments, individual budgets and the In Control programme.[♦] There is much hope that the more widespread use of funding mechanisms that support the personalisation of services will serve to reduce the rate of out-of-area placements. To date, however, this proposition has not been empirically evaluated.

It was, therefore, recommended that:

- There is a need to develop commissioning knowledge (including in contract monitoring teams), particularly an understanding of how to provide to meet more complex needs.⁴⁵
- CSSRs should develop explicit protocols regarding 'reasonable risk'.

It was also clear, however, that there is a growing wealth of expertise regarding the development and maintenance of individualised community-based supports for people who are at risk of being placed out-of-area. Some of the personal stories that reflect this growing expertise are shared below.

Direct payments, circles of support and PCP

Paul is 20, receives direct payments and lives in his own house, in the middle of a community of which he feels very much a part. A typical day will see him looking out of his window to greet the postman with an enthusiastic 'thumbs up' sign. He may then meet up with his older brother who lives down the road, and take the dog for a walk over the fields. Paul has virtually no spoken language, but uses his own signs to communicate. He is a very active, energetic young man who has physical energy to spare. These two things, taken together, mean that he can sometimes become very frustrated. This has resulted in some behaviours that challenge those around him.

♦ For more information on these initiatives see
www.in-control.org.uk/home.php www.housingoptions.org.uk/gi_home.html
www.dh.gov.uk/en/Policyandguidance/SocialCare/Socialcarereform/Personalisation/Directpayments/index.htm
www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10016128
<http://individualbudgets.csip.org.uk/index.jsp>

Paul's recent past life has not been straightforward. He was excluded from his special school when 14½, at which point the local authority sent him out-of-county to a residential school. Paul was just turning 18 when he arrived back home, with no transition plan in place, and no idea of his future life from the local authority or the school. However, he was lucky in having his mother's continued backing, a circle of support, a long-standing PCP and new senior staff in the local authority who knew about supported living and direct payments.

After a period of agency support, the circle of support decided to become an Independent Living Trust for Paul, and negotiated direct payments with the local authority. They employed a broker to help with that process, and to put things in place for the first couple of years. Paul still continued to live at home with his mother for that period, but started the arrangements for moving to his own house. This was bought by Golden Lane Housing Association, and Paul has a shared ownership. He moved in at the beginning of December, and has just had his first Christmas in his own house. The support Paul buys in with his direct payments now consists of a team of support workers, with a coordinator, who give him 2:1 support every day, and 1:1 support at night. The coordinator has remained with Paul through all the changes in his life, and his relationship with Paul is excellent.

However, in addition to individual stories there has been a marked growth over the past two decades in organisations which are specifically attempting to enhance the capacity of commissioners and providers to explore innovative models of housing,[♦] to develop local capacity for basing commissioning and provision on individual budgets.⁺

Home ownership

Steven is autistic and had been placed in residential schools and colleges since he was 14. At age 21, he was due to leave and his family wanted him back home, near them, but not living with them. Working with the social work department, they worked out how he could live in his own home with a team of support staff, and incorporating the family into these arrangements. The total cost (£78,000 per annum) £40,000–£50,000 a year less than the type of specialist establishment that could support him. His support team is paid through direct payments, managed by his brother.

However, this could only work if Steven was able to get the right sort of house – detached or semi-detached with good sound insulation, with a garden because gardening is one of his favourite activities, and with rooms that allow separation of activities (a room only for sleeping, a room only for computer equipment). He also needed bedrooms for one live-in carer and to allow sleepovers by others. After

♦ www.housingoptions.org.uk/gi_home.html

+ www.ndt.org.uk/servicesN/SPCBH.htm <http://www.in-control.org.uk/home.php>

some thought about availability of care staff, they settled on a small town within easy reach of his parents. However, the social rented sector could not supply the house type and environment needed.

The family solicitor helped Steven to appoint his mother as Power of Attorney. Ownership Options helped with brokering a mortgage based on Income Support for Mortgage Interest; the social work department offered a grant (with the logic that a one-off capital contribution would enable long-term revenue savings); and Communities Scotland offered a Special Needs Capital Grant.♦

in Control

Ken is thrilled. In July at last, he moved out of the institution. He moved there six months ago after spending three years at another institution 200 miles from his home town. It was supposed to be a temporary stay. Ken's life has been marked by being moved around without having any control over where or when he went. Ken is now 43. He has been in just about every hospital in East Anglia. He had his first experience of the long-stay hospital system when he was 15.

Ken's friend and advocate, Tony, have known each other for many years. Tony who came up with the idea of Ken being part of the in Control project, with a view to moving to supported living and a place of his own. Everyone they spoke to said that this was a great idea. But where would the £3,000 a week come from for Ken to move into his own place? Anxiety among staff mounted. They had never done this before. It would all take time to sort out. Meantime, Ken was desperately unhappy where he was living. He longed to move home.

So it was decided to do a half-way plan. When Ken was on holiday in a cottage with Tony, he invited Nicola for a cup of tea. Nicola is a social worker. She read the report about Ken but could not match what she had read with the person she saw in front of her. She was undeterred by the report and started looking for somewhere suitable. This is how Ken came to be where he is now – in his flat, able to organise his life as he chooses.+

There is also (in some localities) growing experience in strategic joint commissioning of services for people at risk of being placed out-of-area, and of small-scale providers specialising in the provision of personalised support to people at risk of being placed out-of-area.

♦ Extract from *'Mind the gap: Evaluation of owner occupation for disabled people in Scotland, 2004*, Communities Scotland (DTZ Piedad Consulting).

+ Taken from Poll, Duffy, Hatton and Sanderson and Routledge, 2006, *A report on In Control's first phase 2003-2005*, London: in Control.

The Liverpool Joint Investment Management Group

In Liverpool health and social care have set up ways of working together. They have created a local system that supports people with complex needs to return home. It lets commissioners 'buy' care for people based on their essential lifestyle plan. People can live in residential care homes or be given support to live in a place of their own. Liverpool has used five different support services to help people come back to their community.

Approximately 100 people have received a service through this process in the last 11 years. This amounts to a contribution of about £7 million from each authority. The type of service needs which have been met include young people coming through transition with severe autism and associated challenging behaviour, offenders who have been in regional medium secure units, people who were placed out-of-area in residential care, people with a long history of 'failing' when placed in existing services and, in the early days, people who had been wrongly placed in Ashworth and Rampton. Most people now live alone in their own tenancies with 24-hour support, but there are some people who were placed on section under the Mental Health Act for their offending behaviour who now only have a few hours floating support each week. They also support a young woman with 3:1 staffing which is slowly being reduced. There was often not an alternative, existing service for these people, especially in the case of those with very challenging behaviour but even if there was, they were generally more expensive than the bespoke services. This approach has also enabled them to work with local providers to develop their expertise and person-centred approach to such services.

Partners for Inclusion ...

Partners for Inclusion supports 45 people with 45 different types of service. Everyone is supported to live in their own home, or with their family. Its PCP process brings people together, gathering information about what kind of life would make sense for the person and what would not, reflecting his or her gender, age and culture. It looks to strengthen, establish and integrate natural supports within communities.

Most of the people supported by Partners for Inclusion have very high support needs, and in previous settings have attracted a range of 'challenging' labels. These tend to lead to a commissioner's expectation that at least 2:1 (or more) support is required, with consequent costs. In every situation, after a short time of being supported by Partners for Inclusion, the ratio has reduced to 1:1 support.

John is one example. He has spent most of his life in hospital. When stressed he harms himself and others – cutting and stabbing. This and other behaviour can put him and the community at risk if not managed properly.

Partners for Inclusion supports John with an average 60 hours of support a week, at a cost of £58,000 per annum. The design of the service has been individualised. A key element is that the level of support is not the same from week to week; it

is arranged flexibly to respond to how John is feeling so that, for example, he can be supported to take regular breaks away to reduce his stress. The most likely alternative support service would be in a specialist medium secure environment, at an estimated annual cost of £120,000–£150,000.

7.6 Market weaknesses

As a result of these weaknesses in commissioning (and the limited range of expertise and choice of providers), many commissioners suggested that the current situation could be characterised as being a provider-led rather than commissioner-led market. Indeed, it was considered doubtful by many commissioners whether the capacity currently existed to implement the recommendations of current and previous Department of Health guidance related to providing comprehensive local services for people with complex needs.

These capacity issues were reflected in a lack of local infrastructure, including a lack of:

- providers of personalised day supports or supported accommodation for people who challenged
- flexible and appropriate clinical and nursing support for people with complex needs (for example, clinical psychology, psychiatry, nursing)
- skilled care staff with appropriate knowledge of supporting people with complex needs (for example, knowledge of positive behavioural support).

In part, these infrastructure problems reflected a failure to adopt a more strategic approach to workforce development in relation to people with learning difficulties that would ensure an adequate supply of appropriately skilled support and professional staff. For example, it was reported that commissioning training places for professional staff rarely, if ever, sought to ensure that the supply of such staff met the needs of particular 'specialities' such as learning difficulties.

It was therefore recommended that there needed to be increased investment in:

- enhancing provider competence
- ensuring the supply and retention of appropriate numbers of appropriately trained support and professional staff who are fit to practice in services supporting people with learning difficulties with complex needs
- providing support staff with a level of remuneration commensurate with their responsibilities and competitive within the local economy.

7.7 The drive toward specialisation and congregate care

A number of participants suggested that there appeared to be an increasing tendency to commission services (including regional or sub-regional services) for people grouped on the basis of a shared common 'need' (for example, services for people with ASD and severe challenging behaviour; services for people with sensory impairments). It was argued that acceptance of the 'logic' of meeting low incidence

complex needs through congregate care provision would actively encourage the development of out-of-area provision, particularly in a climate in which decisions appear (to many participants) to be based on consideration of service costs rather than outcomes for the people supported. Concern was also expressed regarding the lack of evidence supporting the cost-effectiveness of such congregate care services.

It was therefore recommended that:

- there should be greater collaboration between neighbouring authorities to develop provision to meet specialist needs
- but that this collaboration should focus on developing expertise and an appropriately skilled workforce, rather than on developing highly specialised congregate care residential services.

7.8 Insufficient resources

Numerous people who participated in the consultation drew attention to the importance of the recurrent under-funding of services for people with learning difficulties in underpinning many (but not necessarily all) of the issues described above. Particular concerns were expressed about the long-term consequences of the under-funding of commissioning functions (and especially strategic commissioning) and workforce development functions. Unsurprisingly, numerous people who participated in the consultation suggested that increasing the funding available to services for people with learning difficulties would be a pre-requisite for achieving the long-term goals of ensuring that people with learning difficulties would be supported in high-quality personalised services within their local communities.

As one person with learning difficulties put it, people end up in out-of-area placements because there are “not enough good services where they have grown up”.

7.9 Insufficient safeguards

Finally, it was argued that people are more likely to get placed out-of-area (and/or remain there) due to an absence of effective advocacy. For many people, families were seen as their most effective (and often only) advocates. Indeed, in many of the personal stories that were offered during the consultation, families often played key roles in fighting against out-of-area placements and in developing local services so that people could return from out-of-area placements. In other instances, however, families were instrumental in arranging and arguing for out-of-area placements. There was hope expressed that the use of independent mental capacity advocates (IMCAs) as mandated under the Mental Capacity Act 2005 may give people with learning difficulties greater protection against placement out-of-area.

8 Summary of recommendations

8.1 The Department of Health should...

- Introduce effective incentives to support local provision and effective penalties to discourage *new* out-of-area placements into their performance management of CSSRs.
- Request the Information Centre for Health and Social Care to modify form SR1 to collect information on *new* admissions to out-of-area placements of people with learning difficulties and this information should be summarised in the annual Community Care Statistics reports at the level of CSSRs.
- Request the Information Centre for Health and Social Care to monitor the number of out-of-area placements of people with learning difficulties in receiving CSSRs and separate out information on people with learning difficulties aged 65 and over
- impose a duty to consult on placing authorities and incoming provider organisations.
- Require authorities placing out-of-area to pay a per capita fee or 'bursary' for local health and social care services.
- Review the extent to which current regulations relating to the funding and operation of supported accommodation services for people with learning difficulties take into account whether proposed service developments meet local requirements (that is, whether proposed developments are needed to meet needs in the *local* area).
- Ensure the supply of appropriate numbers of appropriately trained support and professional staff who are fit to practice in services supporting people with learning difficulties with complex needs.

8.2 The Department for Children, Schools and Families should...

- Act to reduce the number of children with learning difficulties educated out-of-area in residential special schools.
- Support investment in transition planning for those young people with learning difficulties who are educated out-of-area.

8.3 National advocacy agencies should...

- Use their political influence to raise the profile of the extent and unacceptability of the existing pattern of out-of-area placements.

8.4 Councils with social services responsibilities should...

- Enhance their strategic capacity through the development of robust information systems that are capable of:
 - identifying the need profiles for all people with learning difficulties for whom they are responsible
 - having the capacity to anticipate future changes in need and demand by collating information from children's services

- evaluating/monitoring/driving performance in terms of long-term efficiency in achieving outcomes related to the quality of life of people with learning difficulties (as opposed to the short-term management of costs)
- increasing investment and encouraging of partnership working with housing providers and joint risk assessment
- developing effective long-term strategic approaches to joint commissioning that seeks to develop the local provider market
- improving cross-border working, an issue that was considered to be particularly relevant in London
- developing explicit protocols regarding 'reasonable risk'
- developing commissioning knowledge (including in contract monitoring teams), particularly in understanding of how to provide to meet more complex needs
- recognising that there should be a greater emphasis on investing in support (from childhood on) for people and their families to reduce crises and thus the demand for rapid response that so often results in out-of-area placement.

8.5 Provider agencies should...

- Provide support staff with a level of remuneration commensurate with their responsibilities and competitive within the local economy.

9 Conclusions

There was almost universal agreement among people who participated in the consultation that the current extent and pattern of out-of-area placements was, overall, detrimental to the quality of life of people with learning difficulties and their families. This conclusion was also consistent with the results of the literature review. It was also seen as being detrimental to the development of high-quality comprehensive services for people with learning difficulties in both the placing and receiving authority areas.

The existing pattern of out-of-area placements was seen by most as a reflection of historical processes (in particular policies on resettlement adopted during the phase down and closure of the old 'mental handicap hospitals') and as a symptom of the continuing failure of local agencies to commission person-centred local support for people who, for whatever reason, challenge services. People suggested that this failure of effective person-centred commissioning was due to a number of interrelated factors:

- lack of incentives and weak performance management
- policy and regulatory barriers
- unclear responsibilities
- insufficient investment in long-term strategic and joint commissioning
- lack of experience of commissioning person-centred support for people who challenge and risk-averse cultures
- market weaknesses
- the drive toward specialisation and congregate care
- insufficient resources
- insufficient safeguards

One key message arising from the final stages of the consultation process was that our 'findings' were not news. It was generally felt that the problems associated with out-of-area placements (which were at times referred to as a scandal) had been known and talked about for years. Indeed, many of the issues highlighted in the consultation had been highlighted nearly 15 years previously in Department of Health guidance (the 'Mansell report') and repeated at frequent intervals in numerous reviews and reports including the 2005 review of Valuing People and, more recently, by the Audit Commission report on out-of-area education for children with special educational needs. It appears likely that they will yet again be aired in forthcoming Department of Health guidance ('Mansell Two').

There was a widespread belief that the lack of progress reflected political inertia. Out-of-area placements do not grab media headlines. They do, however, damage the life opportunities of thousands of people with learning difficulties (over 10,000 of whom are currently placed 'out-of-area') and provide a litmus test of our enduring failure to provide personalised high-quality support to a very vulnerable group of people.

References

- 1 SCIE (Social Care Institute for Excellence) (2006) *Commissioning person centred, cost-effective, local support for people with learning disabilities*, London: SCIE.
- 2 Welsh Assembly Government (2004) *Learning disability strategy Section 7 Guidance on service principles and service responses*, Cardiff: Welsh Assembly Government.
- 3 DHSSPS (Department of Health, Social Services and Public Safety) (2007) *Community care statistics 1st April 2007–31st March 2007*, Belfast: DHSSPS.
- 4 Goodman, N., Nix, J. and Ritchie, F. (2006) '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', *Tizard Learning Disability Review*, vol 11, no 1, pp 35–43.
- 5 Ritchie, F., Goodman, N., Nix, J. and 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*, Redditch: West Midlands South Strategic Health Authority.
- 6 Ritchie, F., Goodman, N., Nix, J. and 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*, Redditch: West Midlands South Strategic Health Authority.
- 7 Pring, J. (2004) 'The frequency and potential consequences of the failure to visit learning-disabled adults in out-of-area placements', *Tizard Learning Disability Review*, vol 9, no 2, pp 35–42.
- 8 Perry, D.W., Shervington, T., Mungur, N., Marston, G., Martin, D. and Brown, G. (2007) 'Why are people with intellectual disability moved "out-of-area"?', *Journal of Policy and Practice in Intellectual Disabilities*, vol 4, no 3, pp 203–9.
- 9 Mental Health Strategies (2006) *Census of out of area and out of pathway learning disability placements: Report prepared for North West Strategic Health Authority (Cumbria and Lancashire)*, Manchester: Mental Health Strategies.
- 10 Emerson, E. and Hatton, C. (1998) 'Residential provision for people with intellectual disabilities in England, Wales and Scotland', *Journal of Applied Research in Intellectual Disabilities*, vol 11, pp 1–14.
- 11 Mason, R. (2007) *Learning disability out of area placements*, Calderdale: Calderdale MBC Health and Social Care Directorate, Learning Disabilities Services.
- 12 Bowman, A. (2007) *Data for Social Care Institute of Excellence review on out of area placements of people with learning disabilities from Lambeth, Merton & Sutton 'I Count' Registers as at 9 March 2007*, Carshalton: 'I Count' Register Services.
- 13 Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K. and James, W. (in press) 'Challenging behaviours: prevalence and topographies', *Journal of Intellectual Disability Research*, in press.
- 14 Hassiotis, A., Jones, L., Parkes, C., Fitzgerald, B., Kuipers, J. and Romeo, R. (2006) *Services for people with learning disabilities and challenging behaviour from the North Central London Strategic Health Authority Area: Full report of the findings from the scoping project*, London: North Central London Strategic Health Authority, p 68.
- 15 Hassiotis, A., Parkes, C., Jones, L., Fitzgerald, B. and Romeo, R. (in press) 'Service provision and expenditure on challenging behaviour for adults with learning disabilities: a case for review', *Journal of Applied Research in Intellectual Disabilities*.

- 16 Hassiotis, A., Parkes, C., Jones, L., Fitzgerald, B. and Romeo, R. (2006) 'Services and costs for challenging behaviour in 5 London boroughs', *Journal of Applied Research in Intellectual Disabilities*, vol 19, no 3, pp 234–34.
- 17 Joyce, T., Ditchfield, H. and Harris, P. (2001) 'Challenging behaviour in community services', *Journal of Intellectual Disability Research*, vol 45, no 2, p 130.
- 18 Bellis-Jones, S. (2007) *High cost placements project: Report and recommendations*, North West: North West Centre of Excellence.
- 19 Ryan, T. (2006) 'High cost placements for people with learning disabilities or physical disabilities in the North West: A census study from September 2006. Full presentation of data', PowerPoint presentation, North West Centre for Excellence.
- 20 Pritchard, A. and Roy, A. (2006) 'Reversing the export of people with learning disabilities and complex health needs', *British Journal of Learning Disabilities*, vol 34, no 2, pp 88–93.
- 21 Carlin, J., Stanley, N. and Manthorpe, J. (2004) *Meeting complex needs: A study of decisions, services and perceptions*, Hull: Social Work Department, University of Hull.
- 22 Becker, P. (2006) 'Assessing the quality of service provision for people with challenging needs placed out of borough', *Tizard Learning Disability Review*, vol 11, no 4, pp 12–18.
- 23 Heslop, P. and Mallett, R. (2007) *Help to Move On: Transition pathways for young people with learning disabilities in residential schools and colleges*, Bristol: Norah Fry Research Centre and HFT Family Carer Support Service.
- 24 Heslop, P. and Abbott, D. (in press) 'School's out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges', *Journal of Intellectual Disability Research*.
- 25 Department of Health (2004) *Commissioning services close to home: Note of clarification for commissioners and regulation and inspection authorities*, London: Department of Health.
- 26 Vaughan, P. (1999) 'A consortium approach to commissioning services for mentally disordered offenders', *Journal of Forensic Psychiatry*, vol 10, no 3, p 553.
- 27 Vaughan, P. (2003) 'Secure care and treatment needs of individuals with learning disability and severe challenging behaviour', *British Journal of Learning Disabilities*, vol 31, no 3, pp 113–17.
- 28 NDT (National Development Team) (2006) *Supporting people to return home from secure care or out of area placements* (www.ndt.org.uk).
- 29 NDT (National Development Team) (2006) *Telling people about solutions to bring adults with learning disabilities back home from secure (locked) care units: Accessible learning sheet 3*, NDT.
- 30 NDT (National Development Team) (2005) *The Tough Times Project from the National Development Team: Raising the profile of adults with learning disabilities 'stuck' in the secure care system: Learning Sheet 1* (www.ndt.org.uk).
- 31 NDT (National Development Team) (2006) *The Tough Times Project from the NDT: Raising the profile of adults with learning disabilities 'trapped' in the secure care system*, NDT.
- 32 NDT (National Development Team) (2007) *The Tough Times Project: Telling people about the difficulties that keep adults with learning disabilities in secure (locked) care units*, Manchester: NDT final report on Tough Times Project.

- 33 Simons, K. and Russell, O. (2003) *Lines in the sand: A summary of findings from 'Crossing the Line': A research project on the interface between mental health and learning disability services funded by South West Regional NHS R&D Directorate*, Bristol: Norah Fry Research Centre.
- 34 Beadle-Brown, J., Mansell, J.L., Whelton, B., Hutchinson, A. and Skidmore, C. (2005) *Too far to go? People with learning disabilities placed out of area*, Canterbury: Tizard Centre, University of Kent.
- 35 Mansell, J.L., Beadle-Brown, J., Whelton, B., Hutchinson, A. and Skidmore, C. (2006) 'People with learning disabilities in "out of area" residential placements: 1. Policy context', *Journal of Intellectual Disability Research*, vol 50, no 11, pp 837–44.
- 36 Mansell, J.L., Beadle-Brown, J., Whelton, B., Hutchinson, A. and Skidmore, C. (2006) 'Estimating the number of people with intellectual disabilities in "out-of-area" residential placements', *Research Policy and Planning*, vol 24, no 1, pp 53–9.
- 37 Beadle-Brown, J., Mansell, J.L., Whelton, B., Hutchinson, A. and Skidmore, C. (2006) 'People with learning disabilities in "out-of-area" residential placements: 2. Reasons for and effects of placement', *Journal of Intellectual Disability Research*, vol 50, no 11, pp 845–56.
- 38 Beadle-Brown, J., Mansell, J.L., Whelton, B., Hutchinson, A. and Skidmore, C. (2006) 'Too far to go: out-of-area placements for people with intellectual disabilities', *Tizard Learning Disability Review*, vol 11, no 1, pp 24–34.
- 39 Beadle-Brown, J., Mansell, J.L., Whelton, B., Hutchinson, A. and Skidmore, C. (submitted) 'People with learning disabilities in "out-of-area" residential placements: views of families, managers and specialists', *Health and Social Care in the Community*.
- 40 Mitra, I. and Alexander, R. (2003) 'Out-of-area placements: implications of psychiatric services in learning disability', *Psychiatric Bulletin*, vol 27, no 10, pp 382–5.
- 41 McGuinness, S. (2007) Personal communication to Janet Robertson on into-area placements in a rural area of Wales.
- 42 Mansell, J. et al (2001) 'Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behavior', pp 245–98.
- 43 Allen, D., Jones, E., Brophy, S., Moore, K. and James, W. (2007) 'Predictors, costs and characteristics of out of area placements for people with intellectual disability and challenging behaviour', *Journal of Intellectual Disability Research*. Online Early.
- 44 The Bamford Review of Mental Health and Learning Disability (Northern Ireland) (2007) *Promoting the social inclusion of people with a mental health problem or a learning disability*, Belfast: Bamford Review of Mental Health and Learning Disability (Northern Ireland).
- 45 Royal College of Psychiatrists, BPSaRCoSALT (2007) *Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*, London: Royal College of Psychiatrists.

Resources

- Audit Commission (2007) *Out of authority placements for special educational needs*, London: Audit Commission.
- Bamford Review of Mental Health and Learning Disability (Northern Ireland) (2007) *Promoting the social inclusion of people with a mental health problem or a learning disability*, Belfast: Bamford Review of Mental Health and Learning Disability (Northern Ireland).
- Challenging Behaviour Foundation (www.thecbf.org.uk/).
- Department of Health (1993) *Services for people with learning disabilities and challenging behaviour or mental health needs* (The Mansell Report), London: The Stationery Office.
- Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century*, London: Department of Health (<http://valuingpeople.gov.uk/dynamic/valuingpeople8.jsp>).
- Department of Health (2005) *The story so far... Valuing People: A new strategy for learning disability for the 21st century*, London: Department of Health (<http://valuingpeople.gov.uk/dynamic/valuingpeople6.jsp>).
- Department of Health website for direct payments (www.dh.gov.uk/en/Policyandguidance/SocialCare/Socialcarereform/Personalisation/Directpayments/index.htm and www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10016128).
- Department of Health website for the Individual Budgets pilot programme (<http://individualbudgets.csip.org.uk/index.jsp>).
- Housing Options (www.housingoptions.org.uk/gi_home.html).
- Learning and Skills Council (2006) *Learning for living and work :Improving education and training opportunities for people with learning difficulties and/or disabilities*, Coventry: Learning and Skills Council (http://readingroom.lsc.gov.uk/lsc/National/Learning_for_Living_and_Work_Complete_2.pdf).
- National Development Team (www.ndt.org.uk/servicesN/SPCBH.htm).
- Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M. (2006) *A report on in Control's first phase 2003–2005*, London: in Control (www.in-control.org.uk/home.php).
- Review of Mental Health and Learning Disability (Northern Ireland) (2005) *Equal lives: Review of policy and services for people with learning disabilities in Northern Ireland*, Belfast: Review of Mental Health and Learning Disability (Northern Ireland).
- Royal College of Psychiatrists (2005) *Out of area placements and commissioning services for adults with learning disabilities*, London: Royal College of Psychiatrists.
- Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*, London: Royal College of Psychiatrists (www.rcpsych.ac.uk/files/pdfversion/cr144.pdf).

Index

A

- adverse impacts of out-of-area placements 26–30
 - family relationship concerns 26–7
 - quality concerns 27–8
- advocacy services 32, 35, 42
 - key recommendations 43
- Allen, D. et al 12–13
- ARC (Association for Real Change) 2
- Audit Commission (2007) 32

B

- Beadle–Brown, J. et al 17–20
- Becker, P. 14
- Bellis–Jones, S. 13
- Bournewood case (*HL V THE UNITED KINGDOM*) 22
- Bowman, A. 11

C

- Calderdale out-of-area placements 10–11
- Carlin, J. et al 14
- CCSR (Community Care Statistics: Supported Residents [Adults], England) data 3–7
- Central England People First initiative 2
- Challenging Behaviour Foundation 2
 - challenging behaviour and learning difficulties 12–15, 28–9
 - characteristics of individuals placed out-of-area 21, 28–9
 - complex needs provisions 14
 - cost implications 11, 12, 13, 14, 16
 - forensic and secure care needs 15–17
 - into-area implications 17–21
- Choice Support 2
- commissioning effective local services
 - barriers 31–42
 - insufficient investment 34–6
 - lack of experience and knowledge 36–41
 - lack of incentives 31–2
 - market weaknesses 41
 - policy and regulatory issues 33
 - resource deficits 42
 - safeguard deficits 42
 - specialisation drivers 41–2

- unclear responsibilities 34
- recommendations 43–4
 - on incentives and performance management 32
 - on long-term strategic investment 36
 - on specialist care provisions 42
 - on training and knowledge development 37
- complex medical needs 23
- complex mental health needs and learning difficulties 14
- cost implications
 - challenging behaviour care 12, 13
 - complex mental health needs 14
 - for into-area authorities 20–1
 - for secure care 16
- Coventry out-of-area placements 9–10
- Cumbria and Lancashire out-of-area placements 10

D

- Department for Children, Schools and Families, key recommendations 43
- Department of Health
 - key recommendations 43
 - policy guidance reports 45
- direct payments 37–8

E

- Emerson, E. 2
- Emerson, E. and Hatton, C. 10
- England
 - local council out-of-area placements 5–7
 - regional out-of-area placements 4
- epilepsy service provisions 23
- European Court decisions 22
- executive summary v–xi

F

- forensic and secure care needs 15–17, 22
 - costs involved 16
 - needs analysis 16
- Forsyth, B. and Winterbottom, P. 21
- Foundation for People with Learning Disabilities 2

G

Gloucestershire, cost implications of into-area placements 21
 Goodman, N. et al 8–9

H

handover arrangements (local teams-out-of-area teams) 20
 Hassiotis, A. et al 13
 Healthcare Commission
 on quality of commissioning 35–6
 on use of secure settings 16
 The Help To Move On Project (South West) 15
 Heslop, P. and Abbott, D. 15
 Heslop, P. and Mallett, R. 15
 HFT (The Home Farm Trust Ltd) 2
 high-cost services (challenging behaviours)
 London 13
 North West region 13
 home ownership solutions 38–9
 Hull, complex needs placements 14
 human rights issues 22

I

'I Count' Register data (Lambeth, Sutton and Merton) 11
 In-Control programme 37, 39
 independent mental capacity advocates (IMCAs) 42
 'informal' patients 16, 22
 Institute for Health Research (Lancaster University) 2
 institutional care 13
 into-area placements 17–21
 Kent 17–20
 key issues 22
 Leicestershire 20
 investment concerns 34–6

J

Joyce, T. et al 13

K

Kent into-area placements 17–20
 knowledge review study
 background and study rationale 1, 2
 consortium members 2
 context 3–7

the systematic review 8–23
 the practice survey 24, 25
 findings and discussion 26–42
 recommendations and conclusions 43–5
 summary v–xi

L

Lambeth
 out-of-area placements 11
 quality of placements 14–15
 Lancashire out-of-area placements 10
 learning difficulties and challenging behaviour 12–17
 key characteristics of individuals placed out-of-area 21, 28–9
 complex needs provisions 14
 cost implications 11, 12, 13, 14, 16
 forensic and secure care needs 15–17
 into-area implications 17–21
Learning disability strategy section 7 guidance (Welsh Assembly Government 2004) 4
 Leicestershire into-area placements 20
 Liverpool Joint Investment Management Group 40
 local authorities, key recommendations 43–4
 local services
 commissioning barriers 31–42
 insufficient long-term investments 34–6
 lack of experience and knowledge 36–41
 lack of incentives 31–2
 market weaknesses 41
 policy and regulatory issues 33
 resource deficits 42
 safeguard deficits 42
 specialisation drivers 41–2
 unclear responsibilities 34
 impact of into-area placements 17–21
 key recommendations 43–4
 on incentives and performance management 32
 on long-term strategic investment 36
 on policy and regulatory changes 33
 on specialist care provisions 42
 on training and knowledge development 37
 local studies of out-of-area placements 8–15
 'all people' data 8–11
 'specific populations' data 11–15
 London boroughs

- high-cost services (challenging behaviour) 13
 out-of-area placements 4, 5–7, 11
- M**
 McGuinness, S. 20
 Mansell, J.L. et al 17–20
 Mansell Report (DoH 1993) 45
 Mason, R. 10–11
 Mencap 2
 mental health services
 impact of into-area placements 20
 private sector provisions 14
 quality concerns 17
 Merton out-of-area placements 11
 Mitra, I. and Alexander, R. 20
- N**
 National Autistic Society 2
 National Children's Bureau 2
 National Development Team, Tough Times Project 16
 National Family Carer Network 2
 North West Training and Development Team 16
- O**
Out of authority placements for special educational needs (Audit Commission 2007) 32, 45
 out-of-area placements
 background and study rationale 1, 2
 by specific types of care 11–15
 challenging behaviour 12–13
 high-cost/complex needs care 13–14
 quality issues 14–15
 secure care and forensic provisions 15–17
 transition care management 15
 by study area
 Calderdale 10–11
 Coventry 9–10
 Cumbria and Lancashire 10
 'I Count' Register data (Lambeth, Sutton and Merton) 11
 West Midlands 8–9
 financial costs 11, 12, 13, 14, 16, 22
 impact on individuals and families 26–30
 impact on receiving authorities and services 17–21
 key characteristics of 'cared-for' people 21, 28–9
 key concerns and issues 22
 local council data 5–7
 as a 'positive choice' for families 29–30
 quality and type of placements 21–2, 27–8
 reasons for placement 21
 regional data 4
 scope of placements 30
 survey of 'adverse impacts' 26–30
 variation in use 3
- P**
 Partners for Inclusion 40–1
 PCP (person centred planning) arrangements 15, 37–8
 Perry, D.W. et al 9–10
 policy barriers 33
 the practice survey 24, 25
 findings and discussion 26–42
 recommendations and conclusions 43–5
 Pring, J. 9, 20
 Pritchard, A. and Roy, A. 14
 private sector provisions 13, 14
 provider agencies, key recommendations 44
 psychiatric services, into-area implications 20
 psychological support services 12–13
- R**
 recommendations for service improvements 43–4
 on incentives and performance management 32
 on long-term strategic investments 36
 on policy and regulatory changes 33
 on specialist care provisions 42
 on training and knowledge development 37
 regions
 comparisons of out-of-area placements 4
 increase over time of out-of-area placements 7
 resource deficits 42
 Ritchie, F. et al 8–9
 Robertson, Dr Janet 2
 Ryan, T. 13
- S**
 school-adult transition management 15, 32, 35

secure care *see* forensic and secure care needs
 Selby and York PCT 16
 sensory impairment service provisions 23
 Simons, K. and Russell, O. 17
 South West
 school–adult transition management 15
 service provisions 17
 specialisation issues 41–2
 SR1 form 32
 supported resident, defined 3
 Sutton out-of-area placements 11
 the systematic review 8–23
 material covered
 local studies of people with learning
 difficulties in out-of-area placements 8–11
 local studies of places 11–15
 research on into–area placements 17–21
 secure units and forensic care needs 15–17
 summary and conclusions 21–3
 subsequent findings and discussion 26–42
 summary of recommendations and
 conclusions 43–5

T

The Tough Times Project (National
 Development Team) 16
 training in commissioning 41
 experience needs and information deficits
 36–41
 transition management (school–adult services)
 15, 32, 35

U

Unit for Development in Intellectual
 Disabilities (University of Glamorgan) 2

V

Valuing People Support Team 2
 Vaughan, P. 15

W

Wales, out-of-area placements 4, 12–13
 Welsh Centre for Learning Disabilities
 (Cardiff University) 2
 Wessex Consortium, secure care provision
 levels 15
 West Midlands out-of-area placements 8–9
 complex mental health needs 14

Commissioning person-centred, cost-effective, local support for people with learning disabilities

Concern has been expressed about the number of adults with learning disabilities receiving various forms of supported accommodation services who are living away from the communities to which they belong (ie, are 'placed out-of-area').

This knowledge review brings together knowledge from research and practice on commissioning person-centred, cost-effective, local support for people with learning disabilities who are labelled as having complex needs and/or challenging behaviour.

All SCIE publications and resources are free.

This publication is available in an alternative format upon request.

Social Care
Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB

tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk
Registered charity no. 1092778
Company registration no. 4289790