

Voluntary  
Organisations  
Disability Group

V O D G

an umbrella group of voluntary  
sector providers of support  
services to disabled people

# No Place Like Home:

**Ordinary Residence,  
Discrimination and  
Disabled People**



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Report of research  
conducted on behalf of the  
Voluntary Organisations Disability Group  
(VODG)

**by Roger Blunden and Angie Ash**

July, 2007

No place like home



## The Voluntary Organisations Disability Group

The Voluntary Organisations Disability Group (VODG) is an umbrella group of national voluntary sector providers of social care support to disabled people. The group is pan-disability through its membership. It was set up in 1992 in response to the implementation of Community Care legislation.

The VODG is a confederation of national voluntary organisations, both large and small, all of whom provide social care support services on a contractual basis to a million disabled people each year. Its membership has grown significantly since 1992.

The VODG aims to facilitate and promote an environment in which its membership can provide high quality services based on the prime motivation of promoting the independence of disabled people.

The VODG:

- seeks to address with Government those issues that affect its members' ability to deliver high quality services to disabled people, using the breadth of members' experience and exposure to illustrate issues pragmatically;
- offers Government and other bodies a means by which the providers of support services to disabled people can be consulted in a structured way;
- seeks to lead the sector both in terms of the quality of the services that its members provide and through the strength of their coherent voice;
- promotes, conducts and engages in research to the benefit of its members and disabled people.

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## Foreword

This report by the Voluntary Organisations Disability Group raises important issues affecting the rights of disabled people. It demonstrates that hundreds of people each year are prevented from moving home because of bureaucratic delays introduced by local authorities and Primary Care Trusts that dispute who should pay for a person's care. These disputes cause untold distress to the people concerned and millions of pounds of public money are wasted. The report provides a clear account of the issues and the human and financial costs involved. It calls for action which the Department of Health should take without delay to address this bureaucratic muddle that infringes the human rights of disabled people and is, in effect, discriminatory.

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## Executive Summary

Hundreds of disabled people are prevented from moving home or moving from residential care to independent living each year because of bureaucratic delays and disputes about who should pay for their care.

Every citizen enjoys a fundamental and countrywide entitlement to education and General Practitioner and other health services. However, there is no universal entitlement to social care. Each local authority has a duty to assess the individuals living in its locality and decide on what support if any should be provided.

Crossing County or Borough boundaries is fraught for people who need social care support. Disputes arise when local authorities and/or Primary Care Trusts (PCTs) disagree over the definition of the person's place of residence and refuse to pay for their care and may even refuse to assess their needs.

The root cause of these problems is the definition of someone's place of **ordinary residence**. This is a means by which local authorities and PCTs determine which authority has responsibility for financing care services for people who live in their area.

Guidance on the definition of ordinary residence for local authorities and PCTs makes it clear that, apart from people placed out of area in long term residential care, a person should be considered a resident in the area in which they live. It also states clearly that the provision of services or treatment should not be refused or delayed because ordinary residence is in dispute.

However local authorities and PCTs use disputes over the person's ordinary residence as a device to delay or avoid paying the costs of care. In some cases, people are caught in a Catch-22 situation of being unable to move until an assessment has been made, but being unable to receive an assessment until they have moved.

Large sums of money are wasted in administrative and legal costs in seeking to resolve such disputes and in some cases people are prevented from moving into cheaper forms of care or independent life-styles. These disputes cause untold distress and the waste of millions of pounds of public money. Yet solving these problems need not cost the taxpayer a penny; indeed money could well be saved. This is unthinking discrimination against disabled people by various elements of state bureaucracy and is an infringement of their human rights.

## **The size of the ordinary residence problem**

There are at least 500 people at any one time affected by ordinary residence disputes, although the true figure is likely to be substantially higher. The Government Information Centre states that there are nearly 20,000 adults placed in residential care out of County in England. All could potentially be disadvantaged by an ordinary residence dispute if they chose to move from residential care into community-based accommodation. Such disputes could deny many thousands of disabled people the opportunity of achieving the independence they have worked towards and are acting in direct contravention of stated Government policy

## **Resolving ordinary residence issues**

This report investigates the problems and recommends solutions. Updated guidance is needed, reflecting 21st-century policies. The Government has promoted forward-thinking policies which promote disabled people as full citizens, but the implementation of these policies is being seriously disrupted. This does not require extra resources, all that is required is a clarification of which authority is responsible for assessing and funding and ensuring that resources follow the individual.

This report makes three recommendations for urgent action by the Department of Health, namely that they should:

- **Establish and enforce the principle that a person should receive appropriate social care and support from the authority where they are currently living, or wish to live, regardless of circumstances;**
- **Update the guidance to Social Services and PCTs to ensure they implement this principle in a person-centred way and to remove barriers to choice and independence;**
- **Put in place a framework for the transfer of funds between authorities so that the issue of ordinary residence can no longer be used as a basis for refusing to provide care and support.**

These are the minimum requirements necessary to sort out the current bureaucratic muddle which adversely affects the lives of many disabled people. This muddle results in discrimination against disabled people who are prevented from making simple decisions as to where they wish to live. It infringes their human rights and runs contrary to stated Government policy.

## Background

Many disabled people with physical or learning disabilities, with severe epilepsy or brain injuries, or with mental health problems require support to live their lives.

They may, for example, need help with everyday activities such as getting up, washing, dressing, preparing and eating food. Other people require support to take part in community life, securing or holding down a job or making friends and sustaining relationships. People also have health needs which may be met by their GP or hospital, or may require long term nursing care. Such health care and personal support is paid for by their local authority or PCT.

Disputes arise when local authorities or PCTs fail to agree their responsibilities for funding a person's care. For most people, the rules are simple. Social care is paid for by the local authority in which they are an 'ordinary resident' and health care is paid for by the PCT where they are registered with a GP, or where they are 'usually resident'. The rules are different when people are placed in long term residential care by one authority in the area of another. In those situations, the *placing* authority retains responsibility for paying for the person's care (see section on Legal and policy background on page 11).

Disputes typically occur when people wish to move home in a range of circumstances, for example:

- **A person paid for by one authority to live in a registered care home in another authority (an out of area placement) who then wishes to move out into their own accommodation with support in the new authority;**
- **Someone funded as an out of area placement in a care home which ceases to be registered as a care home;**
- **Someone leaving a residential college who wishes to stay in the area;**
- **Someone receiving support to live in the community who wishes to move to another authority area, where the two authorities fail to agree on what support they are eligible for and who should pay for it;**
- **Someone who is funded by a local authority and chooses to move to another area, but who is under a deferred payment scheme;**
- **Someone who is assessed by a local authority but moves to a home in another area as a 'self funder' but within a few weeks/months approaches the local authority for help with funding.**

Disputes can also occur where a person has been placed out of area into a care home, is registered with a local GP, and who then requires nursing care. Local authorities and PCTs can dispute whether the person is eligible for nursing care and who should pay for it. They may even refuse to carry out an assessment of the person, arguing over who has the responsibility for making the assessment.

Where such disputes occur, people are sometimes denied their rights as citizens to live where they choose and receive the care they need. There are situations where people are threatened with homelessness or with having their care withdrawn. This is nothing short of discrimination against people on the grounds of their disability and their need for support by health or Social Services.

Ordinary residence disputes can have substantial consequences for the ability of disabled people to exercise their basic human rights. David's story illustrates this:



## David's story



David has had a troubled life. At four years of age he was diagnosed as having Severe Emotional Difficulties with Autistic tendencies. His family were unable to care for him and he has spent most of his 25 years in residential care. Now he has the chance to move into a home of his own, with the support he needs. But David is caught up in a nightmare dispute between two local authorities and a Primary Care Trust and is in danger of finding himself both homeless and unsupported. All the authorities are refusing to pay for his care on the grounds that none will accept him as a resident.



A more detailed account of David's story is given on page 28

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David is one of a significant and growing number of younger disabled people in England who at any time are prevented from exercising their rights as citizens to move house and receive the support to which they are entitled. Authorities engage in bureaucratic and discriminatory disputes over which is responsible for paying for care services. This is because the rules are out of date and methods of transferring funding are unclear.

We estimate that over 500 people are caught up in such disputes at any one time and that nearly 20,000 people could be adversely affected in the longer term. Sometimes these disputes go on for months or years, with the people concerned unable to take important steps in their lives, and organisations providing services caught up in lengthy and costly negotiations. There is a high emotional cost to the people and their families, who are unable to understand the bureaucratic wrangling and may experience anger and frustration at being prevented from moving on with their lives.

Independent living is the centre piece of the Government's 20-year vision for disabled people with particular emphasis on people moving from residential to community care. Not only are the issues surrounding ordinary residence preventing the Government from achieving this laudable aim, but it is costing them millions of pounds in the process. Ironically this dispute is not about the person's right to receive support from the state, rather it is about which part of the state should pay.



## Legal and policy context

Ordinary residence is a means by which local authorities determine their responsibility for providing community care services for people who live in their area. In particular it is relevant to services provided under the National Assistance Act 1948, the Chronically Sick and Disabled Persons Act 1970, the Mental Health Act 1983, the Children Act 1989 and the Care Standards Act 2000. Most people are considered an ordinary resident of the authority in which they live, and that authority is responsible for providing and paying for any community care services to which they are eligible.

Similarly most people's eligibility for services provided by the NHS is determined by the area in which their GP is based, and the PCT serving that area is responsible for providing and paying for their health care.

Exceptions to these general rules occur when people are placed into long term care by one authority but in the area of another. If a person is supported to live in residential care and a placement is made out of area under the National Assistance Act 1948, the person is deemed to remain an ordinary resident in the *placing* authority and the placing authority remains responsible for paying for the person's care. However, if the person moves out of residential care, or if the care home de-registers, the 1948 Act no longer applies and the person's place of ordinary residence can come into dispute.

Where a PCT arranges a continuing care placement (either on its own or jointly with another body, such as a local authority) in a care home or independent hospital in the area of another PCT, the placing PCT remains responsible for the NHS contribution to the care. Disputes can arise in situations where people move out of long term care, or where their health needs are re-assessed.

There is no legal definition of ordinary residence, but guidance to local authorities is set out in the Government circular *Ordinary Residence* LAC93(7), which says that ordinary residence should be given its ordinary and natural meaning, subject to any interpretation by the courts.

For people receiving services from the NHS, *Establishing the Responsible Commissioner* (DH, 2006A) defines the responsibilities of PCTs in commissioning care within the NHS. In general, PCTs are responsible for commissioning health services for people registered with GPs associated with the PCT or, where GP registration cannot be used, for people 'usually resident' within their area. The guidance states that:

*Primarily, the arbiter of the patient's residence is the patient.*

## Legal and policy context (continued)

Two general principles arise from both sets of guidance.

Firstly, a person should be considered an ordinary resident of the area in which they live, even if they have moved there recently (apart from those people placed in long term care by another authority).

Secondly, the provision of treatment or services should not be refused or delayed if ordinary residence is disputed.

This was recently clarified by the Department of Health in a letter responding to an enquiry by a leading disability charity.

*Where a local authority provides a person with accommodation under Part 3 of the National Assistance Act 1948, then the provision will apply and the person will be deemed to be ordinarily resident in the area in which he or she was ordinarily resident immediately before the accommodation was provided.*

*Where a person ceases to be in Part 3 accommodation then the question of where they are ordinarily resident is decided by looking at each particular case. However, if a person is living in their own home the starting assumption would be that they are ordinarily resident in the local authority in which their home is located. The cost of any non-residential care they require will, therefore, usually be the responsibility of the local authority in the area they have chosen to settle.*

*Where a person is transferring from Part 3 accommodation to other forms of social care and the responsibility for funding that care moves from one local authority to another, the Department expects the local authorities involved to make any necessary changes to the funding arrangements in a way which ensures continuity of care and appropriate care for the service user.*

(DH, 2007A)

The Housing Options Factsheet *Ordinary Residence* identified a number of issues, including:

- Perverse incentives for a Social Services department to seek accommodation in another authority's area;
- Ordinary residence status when a care home de-registers;
- Uncertainties about whether an individual's care package will be transferred to a new area because of differences in eligibility criteria, priorities or views about the suitability of a service.

A wide range of issues, mainly relating to NHS-funded care, were identified by Featherstone and McGavin, 'Bridging the Divides', including ambiguity in Government guidance in a number of situations.

Current guidance is unclear in a number of instances, as was recognised by the Department of Health in 2003, when it issued health and local authority circulars (DH, 2003).

These contained the commitment:

*Local authority circular LAC93(7), Ordinary Residence, contains guidance on ordinary residence issues. The Department of Health will be updating this circular in 2004. This will clarify a number of issues, but will not change the underlying position with regard to the requirement that a local authority must take responsibility for providing care to a person while a dispute about ordinary residence is ongoing. (Para 68).*

This updated guidance, promised for 2004, has not yet been issued, nor has existing guidance been reinforced effectively.

The direction of Government policy in recent years has broadened traditional thinking about how the needs of disabled people should be met (ADSS 2005). Direct payments, *Valuing People*, *Supporting People* and *In Control* initiatives, for example, are driven by the recognition of the civil rights of disabled people and the need to enable more control over the support they receive. A key objective of *Valuing People* is to give people with learning disabilities a greater choice over where and how they live, as well as increasing the range of housing options available for people to live independently.

Other recent policy documents, such as *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit 2005), the adult social care Green Paper *Independence, Wellbeing and Choice* (DH 2005), and the White Paper *Our Health, our Care, our Say* (DH 2006B) each set out a vision of independent living, supported by individualised budgets aimed at promoting choice, rights and citizenship.



## Legal and policy context (continued)

This policy direction is summarised in the recent briefing paper on self-directed support produced by the Government's Care Services Improvement Partnership (CSIP, 2006).

*The underlying principle for the development of self-directed support is the desire to move to a system where adults have the ability to take greater control of their lives and the social care that they receive, enabling them to make the decisions and manage their own risks. This would put people at the centre of assessing their own needs, deciding how best those needs can be met, and tailoring care to meet these individual needs. Self-directed support is founded on the ethos that people accessing social care are real citizens and should enjoy the same rights as everyone else. Self-directed support is a system aiming to offer people the optimum control and personalisation of their support, whatever their willingness to take on the responsibility for its delivery. It is a method of ensuring people are central to the design of their service, which they can then choose to manage in a variety of ways to suit their willingness and capacity.*

The recently published Government consultation document *Commissioning Framework for Health and Wellbeing* (DH, 2007B) includes the key outcome:

*Commissioning for the health and well-being of individuals means helping local citizens to:*

- *Look after themselves, and stay healthy and independent;*
- *Participate fully as active members of their communities;*
- *Choose and easily access the type of help they need, when they need it.*

Article 8 of the European Convention on Human Rights asserts the right to respect for private and family life, including the person's home. The Disabled Persons (Independent Living) Bill, a private member's bill introduced to the House of Lords in November 2006, emphasises the rights of disabled people to independent living and proposes the imposition of duties upon authorities to respect these rights.

The guidance set out in LAC93(7) relates to legislation passed some 60 years ago and does not reflect these 21st-century policy developments.



## Chris's story



Chris has a learning disability and is part of a network which supports him to live in his own flat. He receives funding under the Supporting People initiative to enable him to live as independently as possible. Chris wanted to move home to live with his partner Jackie, who receives support from another network. Jackie has her own flat, just two miles away and the plan was for Chris to move in with her and for the two to live as a couple. After a year of living as a couple Chris could apply to be a joint tenant.

However, Jackie's flat is in a neighbouring authority. That authority initially refused to pay for Chris' support on the grounds that they wanted a local resident to fill the vacancy in Jackie's flat. They also criticised the support network for enabling their members to become couples, pointing out that the original agreement stated that each member would have their own one bedroom flat and therefore in their view should live separately.

The situation was eventually resolved after four months of negotiations, involving long phone conversations between the support agency and the Supporting People officer in the new authority. An argument had to be made for the couple to build their relationship and move forward with their lives together. Supporting People finally changed their decision and agreed to fund Chris's support. However they stated that this was a one-off move and they wouldn't support another similar case.

At no stage did the Supporting People team contact Chris, or ask his views. All negotiations were through his support agency. During that four months, Chris and Jackie's lives were put on hold. They were held back from making an important decision in their lives. The support agency, too had to use its valuable resources in protracted negotiations.

In spite of the delays and frustration, Chris says that he is happy now in the new support network and is glad that he is living with Jackie.



## Determinations by the Secretary of State

The National Assistance Act 1948 includes provision for the resolution of disputes about ordinary residence by the Secretary of State. A number of such disputes have been the subject of such determination. In 2005, details of these determinations were made available under the Freedom of Information Act 2000 and can be viewed on the Government website.

Twelve determinations were published on the DH website in October 2006, ten of which relate to disabled people. Many of the determinations relate to complex situations where individuals and families have moved between authorities. Two concern disabled people placed by a local authority into residential care, who have moved into their own accommodation in another local authority area. In both cases the Secretary of State held that the person is an ordinary resident in their new area. Both contain the following statement. In the judgment from Lord Scarman:

*“Unless, therefore, it can be shown that the statutory framework or the legal context in which the words are used requires a different meaning, I unhesitatingly subscribe to the view that ‘ordinary residence’ refers to a man’s abode in a particular place or country which he has adopted voluntarily and for settled purposes as part of the regular order of his life for the time being, whether of short or long duration.”*

In discussing mental capacity, the determinations also refer to a legal precedent, Regina v Waltham Forest London Borough Council, ex Parte Vale, *The Times* 25.2.85 (Vale):

*Vale makes clear that in cases where a person’s mental health is such that they are not capable of forming an intention to live in a particular place, the fact that that person may not therefore reside voluntarily in that place does not prevent it from being their place of ordinary residence. Such cases must be decided by reference to different considerations.*

The general implication of these determinations is that where someone moves into their own home or tenancy in a local authority area, they will normally be considered an ordinary resident in that area. If a person is deemed not to have mental capacity, they will be treated as residing at their parents’ home, or, more commonly, the case will be considered as if the person does have mental capacity.

This view is supported in a detailed analysis of these and other legal precedents undertaken by Collard (2000), who obtained information relating to thirteen legal judgments and nineteen determinations by the Secretary of State.

Determinations by the Secretary of State are time consuming, protracted and costly for authorities. Assembling information, obtaining legal advice, submitting a case and obtaining a decision takes many months. The Secretary of State will only make a determination if one authority has agreed to take responsibility on a temporary basis. This exacerbates the problem and can result in delays and substantial periods of uncertainty for all involved. Some lawyers spoken to as part of this research were of the opinion that more should be done by the Department of Health to publicise determinations already made, since these offer a great deal of guidance about the resolution of ordinary residence disputes. Others told us that greater efforts should be made to speed up the determination process.

Determinations by the Secretary of State do not apply in cases such as that of David quoted on page 28, where an authority has threatened to unilaterally terminate funding responsibility for an individual. There are likely to be many such people whose ordinary residence is under dispute, but where no authority will accept responsibility and so no determination can be sought.



## John's story



John is in receipt of an individual budget through the *In Control* programme. He lived with his parents, but wanted to move into his own house in an adjacent authority. He arranged a mortgage for the purchase of the house, funded through housing benefit. The new authority originally refused to consider him eligible for support, and only agreed to consider him an ordinary resident when it became clear that his family would be moving also.





## Robert's story



Robert is 63 and has epilepsy. He lives in specialist residential care for people with epilepsy, but is being encouraged to become more independent. This will involve him moving for assessment into a supported housing scheme before moving on to a local tenancy with specialist support. Robert is currently funded out of area, but would become an ordinary resident in his new area. That authority has taken legal advice which suggests that Robert should remain the responsibility of his placing authority and is refusing to fund an assessment, so that Robert's move to independence is blocked.

The cost of Robert's current residential care is £890 per week. His support costs would be £500 per week during assessment, reducing to £300 per week in the new supported housing scheme. There would therefore be a net saving of £590 per week if this dispute could be resolved.

Robert is now trapped in an inappropriate and unnecessarily expensive placement that is no longer relevant to his needs because no authority will accept responsibility for him.



## The human cost of ordinary residence disputes

In each case where ordinary residence is in dispute there are significant human costs to disabled people and their families, whose lives are disrupted by delays and uncertainties. The decision to move into more independent living is a significant life event for many people, and is often the result of long and careful consideration and planning. To learn then that the move is being blocked because of disputes not of their making over which authority should meet the costs of support is often devastating, frustrating and inexplicable to the people concerned.

As one family member told us:

*“My son has the right to choose where he wants to live. Now he’s in danger of losing the flat he has chosen because two authorities can’t get their acts together.”*

In some cases, authorities refuse to carry out an assessment of the person’s needs for support on the grounds that they have no responsibility to do so. This effectively blocks the move, because the person cannot obtain support without such an assessment.

People are also deterred from making a move because of the likely difficulty in reversing the situation, should it not work out. Many of the people whose stories are included in this report had to fight hard for the right to live in their own home. If things don’t work out, the prospect of having to move back to where they came from or to fight again in order to live somewhere else is beyond contemplation.

The obstruction and delays experienced are against the spirit of Government guidance. For example LAC(93)7 clearly states that:

*...the provision of services for individuals requiring Social Services should not be delayed because of uncertainty about which authority is responsible... (DH, 1993).*

For Primary Care Trusts, *Establishing the Responsible Commissioner* (DH, 2006A) states:

*The underlying principle is that there should be no gaps in responsibility – No treatment should be refused or delayed due to uncertainty or ambiguity as to which PCT is responsible for funding an individual’s healthcare provision.*



### Stephen’s story



Stephen has a learning difficulty and Downs Syndrome. He has been supported by his local authority to stay at a residential college in another authority area. The placement is due to come to an end and Stephen wishes to remain in the area of the college as he has established relationships and a social life there. However the new authority is refusing to accept a transfer of responsibility as they are concerned that many other residents from the college will want to do the same thing. The new authority is also challenging the capacity of Stephen to take on his own tenancy, so he is denied the right to choose his ordinary residence.





## Stuart's story



Stuart is 30 years of age and has a learning disability. He is funded 'out of area' and shares a flat with three other people. He works at a garden centre and bakery and has a Saturday job in a café. He has also completed a two year course and has qualified as a trainer in the Trainers for Change initiative. As part of the Trainers for Change team, Stuart travels to various parts of the country and helps to train staff and people with learning disabilities about community living and person centred planning. Stuart has a good social life, he knows his way around his local community, and has made major strides in developing his confidence and independence.

Stuart now wants to move into a place of his own. He has found a flat, close to where he is currently living. This is ideal, since it will enable him to maintain his existing friendships and networks and he knows his way around the local area. Stuart will claim housing benefit but will need additional funding from the local authority for his personal support.

However, Stuart has now learned that his move may not be possible. His placing authority has told him that he will now become an ordinary resident in the authority where he wishes to live, and no longer eligible for funding by them. The authority he wishes to live in say that they will not fund his care until he has been resident in his own flat, claiming housing benefit, for six months. The authorities are disputing which section of the 1948 National Assistance Act applies in Stuart's case. So Stuart is caught up in a Catch-22 situation; he can't move into his flat and claim housing benefit until his support package has been agreed, and he can't have a support package until he has been living in his flat for six months. Whilst the two authorities are in dispute, neither is prepared to carry out an assessment of the support he will require in his new life.

Because of this, Stuart doesn't know how much support he will receive if the new arrangements are agreed. He needs this information now if he is to make informed choices. The fear is that he will be assessed as needing less support than he needs and have his service levels cut just when he is feeling most vulnerable.

Also there is no way back. It will be very hard for Stuart to reverse the move if for some reason it doesn't work out. Even if his previous home is still in operation, the placement is likely to have been filled. The funding arrangements are not flexible enough to allow him to change his mind. This increases the worry for Stuart and his family at a time of major change.

Stuart and his family are very upset by this. Stuart was looking forward to this new step in his life. He has found an ideal place to live and just needs support to enable him to do so. As an experienced trainer in community living, he doesn't understand why he should be discriminated against in this way. As a citizen, he should be able to make his own choice of where to live, without getting caught up in a dispute between two local authorities.

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## The size of the ordinary residence problem

There are no published figures showing the size of the problem of ordinary residence, but VODG has been able to make estimates of the size of the problem.

A significant part of the problem relates to people living in registered care homes, who may wish to move out to a more independent life in the community. In addition the problem affects a range of people already living in the community who wish to move house to another area.

There are various estimates of the number of younger adults living in residential care in England, but according to the NHS Information Centre for Health and Social Care, there are a total of 65,000 people in some form of permanent residential service, in the 18-64 age group.

The Information Centre (2006) estimated that at 31st March 2006, a total of 19,825 younger adults were supported in residential or nursing care homes out of area.

Information collected from VODG members and the Association for Real Change during 2006 identified 5127 people in residential care who were funded on an out of area basis. Of these, 136 (2.65%) were currently caught up in ordinary residence disputes.

Applying this percentage (2.65%) to the estimated 19,825 adults aged 18-64 in England who are in residential care out of area gives a conservative estimate of 525 people *at any time* who may be affected by an ordinary residence dispute.

However, this estimate relates to people who are actively involved in an ordinary residence dispute at any time. It does not include:

- People who are considering making a move, but have not yet taken any steps towards it;
- People who are deterred from making a move because of ordinary residence complications and have effectively become resigned to their current situation even if it is inappropriate;
- People already living in the community (for example those in receipt of individual budgets, or in supported living schemes) who wish to move between authorities;
- Younger disabled people under 18;
- People aged 65 and over;
- People living in Wales, Scotland and Northern Ireland.

The true figure of people affected by the ordinary residence problem is therefore likely to be substantially higher than our estimate. Indeed the problem of ordinary residence is likely to become considerably more acute in the future, given that core Government policy emphasises the importance of ensuring that disabled people are supported to become full citizens exercising choice and being independent. As a consequence many homes are de-registering and more people are seeking supported living arrangements and individual budgets. Government initiatives such as *In Control* and the White Paper *Valuing People*, promoting moves towards independence, are likely to result in an increase in the numbers of people seeking to become ordinary residents.

Indeed, the ordinary residence issue, if not resolved, could affect a significant proportion of the 19,825 adults aged under 65 in England who are placed in residential care out of area. It is likely to prevent thousands of disabled people achieving the independence they have worked towards, and will derail several key Government policy initiatives.



## Yvonne's story



Yvonne was placed for continuing care in a residential nursing home in a neighbouring authority by her PCT. She is now no longer eligible for continuing care and the two authorities are in dispute about who is responsible for her care.



## Implications for service providers

The ordinary residence issue affects substantial numbers of voluntary sector service providers, particularly those who are attempting to follow current guidance and support people to move from residential care into more independent living within the community. Plans are often disrupted or delayed whilst authorities dispute who is responsible for paying for care. Long and costly legal disputes are often necessary. Delays of months, and sometimes years, are commonplace.

In some cases the authorities refuse to make an assessment, so that planned moves are blocked. Withdrawal of funding for an individual may be threatened, with the provider agency left to tell the person and their family that the service can no longer be provided. In some cases funding is actually withdrawn and the provider agency is left to provide support without payment.

One member of VODG told us:

*“We are very disappointed at the way the local authorities and Primary Care Trusts involved have conducted themselves, concerned only about saving money and without any regard for the individual service user caught up in the middle of their dispute.*

*Currently, there is so much rhetoric about choice, increasing independence and self advocacy for adults with learning disabilities but when it came to funding, none of these are taken into consideration, not even the letter written by the service user to the local authority, stating his needs and expressing his wishes.*

*Sadly, whilst the authorities are in dispute and refusing to accept responsibility, it has been a voluntary organisation that has had to provide the support to the user and his mother, who did not know where else to turn. This has imposed a cost on our organisation in obtaining legal advice and time and resource allocation. If the funding ceases in the next few weeks what will we be expected to do and what will happen to the service user then?”*

A service manager said:

*“The issue has been greatly complicated where registered services have de-registered to offer supported living. Some authorities have chosen to honour long standing commitments to people so affected: other authorities have ruthlessly walked away from people they have funded for 15 years or more, or persistently try to do so.”*



## Sylvia's story



Sylvia has a learning disability and had lived in a residential service for a number of years, sharing a flat with two other people.

Sylvia and a friend decided that they wished to move out into the community and were supported to take their own tenancy with a private landlord in the local area. As she had been placed out of county many years before, the host local authority argued that Sylvia was not an ordinary resident in their area and refused to pay for her support. The authority which originally placed Sylvia in the residential service also refused to pay for her, arguing that

she was no longer an ordinary resident with them.

A legal argument ensued with neither authority paying for Sylvia's care or support. The agency providing Sylvia's support had to pay out of their own funds. Eventually the placing authority lost the legal battle and had to continue to fund the service.

Sylvia has now lived in her own flat for three years. Her care is still paid by the placing authority, but they are now challenging the situation once again.

This puts Sylvia's future into doubt, whilst the two authorities argue yet again over who should pay for her care.



## Implications for local authorities and Primary Care Trusts

There are significant issues for some local authorities and PCTs, particularly those who host registered care homes in which substantial numbers of people have been placed by other authorities. If people move out of care but choose to remain in the same area, or if homes de-register and become supported living projects, their residents could become ordinarily resident in the host area and thus eligible for support by that authority. The same applies to residential colleges, where people may choose to remain in the area of the college once their course has finished. Thus some authorities can face substantial increases in the numbers of people they support, with a consequent impact on their resources.

Particular problems arise where specialist long term care facilities are provided in national or regional centres. The authorities in which these centres are based face substantial numbers of people who have been placed out of county wishing to leave residential care to move into the local community. These authorities are likely to be particularly reluctant to accept financial responsibility and the people concerned may well be the least able to fight for their rights in disputes between statutory authorities.

A number of such authorities have sought legal advice. In some cases this appears to contradict stated policy and Secretary of State determinations, and suggest that there is a legal duty

on placing authorities to fund in perpetuity the people they have placed, irrespective of whether they are in residential care or in the community. Without clear guidance on this issue, costly and time consuming legal disputes are likely to continue.

Conversely, authorities who have substantial numbers of people placed out of area face perverse incentives to encourage the people they support to move out of residential care (whether this is appropriate or not) or to encourage care homes to de-register, so that they are no longer responsible for funding their care.

### **Local agreements**

Not everyone in these situations is the subject of an ordinary residence dispute. A number of authorities have reached agreement on a local or regional basis on how they will approach ordinary residence issues when someone moves between those authorities.

Whilst such agreements may be helpful, the problems with them are threefold. Firstly they are not legally binding and may be challenged at any time if an authority decides that it does not wish to abide by them. Secondly, they may run contrary to the spirit of ordinary residence guidance. Thirdly, because authorities in various parts of the country draw up different agreements, there is no consistency between them. There is no substitute for clear national guidance.

## Resource implications of ordinary residence disputes

There is no published information on the resource implications of such disputes. However, it is clear that families, provider organisations, local authorities and PCTs are wasting significant amounts of time and money in seeking a resolution.

A significant amount of money is being spent on legal advice, some of it seemingly contradictory. One local authority solicitor told us:

*'I am a solicitor advising Social Services in relation to ordinary residence. Unfortunately, the current LAC 93(7) is so vague that it is extremely difficult to advise upon. In conflict with other authorities, I can usually see how they have been able to argue the same point in a different way.'*

It should be emphasised that ordinary residence disputes are generally resource neutral in the sense that they do not involve significant increases in care costs. Indeed, for some people substantial savings can be made. The argument between authorities is about which should meet an individual's care cost; neither is seeking additional resources from the Exchequer.

However, money which could be spent on care is being diverted to administrative and legal costs. There are no published figures for these costs, but it is possible to make an estimate. If 525 people are caught up in ordinary residence disputes at any time, we could assume that around 1000 people each year are involved. On the basis of a conservative assumption that around 60 hours of direct administrative and legal time are taken up in each of these 1000 disputes, and assuming that time is costed at £50 per hour, we can arrive at a figure of £3,000,000 wasted annually on ordinary residence disputes.

In addition to this figure there will be a much greater sum spent on more general costs around the ordinary residence issue. Service providers, commissioners, and Department of Health officials attend meetings, make telephone calls, prepare documents and spend a great deal of public money around the issue. The Secretary of State determinations are also an additional cost to the public purse.

The net result is that very substantial sums of public money are wasted on disputes which run contrary to Government policy and guidance and are clearly against the interest of the people concerned.



## David's story



David is a young man, aged 25. At four years of age, he was diagnosed as having Severe Emotional Difficulties with Autistic tendencies. His parents were unable to support him at home and from the age of eight years he was placed in various specialist residential boarding schools.

In 2002 David's local Social Services department agreed to pay for him to live in a new registered care home in an adjacent authority. Although he is challenging to support, he has an active and fulfilling life in the home.

In November 2004 the agency running the home was told that David's funding would now be from the placing authority's Primary Care Trust, although no reason was given for this decision. However the Social Services department continued to attend his reviews and all communications regarding David were through them.

In October 2006 the voluntary agency running David's care home gave formal notice that the home would close in March 2007 as the service would move to a newly adapted, more accessible house in a better location within the same authority. The new home would not be registered as each person would have their own care package, in line with independent models of living. In November the agency received a letter from the PCT announcing that David no longer met their criteria and that funding would cease in February 2007. The agency had not been involved in any assessment of David's needs. David's mother appealed this decision by the PCT. The placing authority Social Services department was contacted, requesting an assessment for David. They initially agreed to this, but subsequently wrote to say that they would not complete an assessment because they had no responsibility for his funding since he is now an ordinary resident in the authority in which the home is located. This is disputed by that authority which states that they are unable to support David's move to his new home, unless the placing authority agree to continue funding.

David, his mother and the service were told that if the appeal failed, his funding would cease on the date of the decision. In that situation David would have nowhere to live. He still requires a high level of support and would be unable to move when his co-residents move into their new home.

The service took legal advice, which was that David is not currently an ordinary resident in the new authority because he is in registered care. He would become an ordinary resident there if he were to move to an unregistered property in the Borough. However the new authority refused to support such a move.

The matter remained unresolved for some time. Both Social Services departments and the PCT refused to take responsibility for David. His mother was distraught and bewildered. David had made it clear that he wished to move into the new home with his friends and wrote to Social Services to say so. Solicitors were engaged in appeals and there was talk of a judicial review. All this took time and cost a great deal of money.

The appeal against the PCT decision eventually took place and found that David did not meet eligibility criteria for continuing care funding. The placing Social Services department refused to accept responsibility for funding. In spite of this, David did move into the unregistered home with his other flatmates and the new authority eventually agreed to support him and to carry out a comprehensive assessment of need. However, they are considering a legal challenge to the placing Social Services department.

Whilst the situation for David was eventually resolved, both he and his mother suffered considerable stress and anxiety for nearly six months, and the service and the authorities involved expended significant resources in administrative and legal costs.



## Conclusions:

### Resolving ordinary residence issues

The VODG believes that it is essential that action is taken at a number of levels in order to resolve ordinary residence issues. Steps need to be taken to ensure that authorities are clear about their responsibilities and that equitable financial arrangements are made, so that disabled people and their families are free of the disadvantage and delay chronicled in this report.

We have identified the need for action to:

- **Establish and enforce the principles of ordinary residence in the light of current Government policy and promulgate these to all local authorities and PCTs;**
- **Update the definition of ordinary residence and the related guidance to reflect present day health and social care policies;**
- **Establish clear principles for funding arrangements between authorities and, where necessary, the transfer of resources.**

#### **Principles of ordinary residence**

The spirit of Government policy and human rights legislation is that disabled people should be supported to become full citizens in the communities in which they choose to live, with the support they require to do so. People should be able to exercise choice of where to live and have maximum control over the support they receive. The determinations by the Secretary of State tend to support this view and any other policy would discriminate against disabled people.

In the light of such policies and guidance, it is clear that people should generally be considered an ordinary resident of the authority in which they live. This has significant advantages in terms of the planning and monitoring of their support; services would be provided and monitored locally.

Whilst the National Assistance Act 1948 makes special arrangements for people placed in residential care, an increasing number of people will receive support which falls outside the remit of that Act.

In addition, current guidance makes it clear that people should not be disadvantaged because of ordinary residence disputes between authorities.

There is a clear principle that people not in residential care will be considered ordinary residents in the authority in which they live, and will be eligible for support by that authority from the day they move into the area on the same basis as any other citizen. This principle needs to be strengthened in any revised guidance and its application enforced. In addition it should be clearly stated that no one should have their care disrupted or be refused an assessment on the grounds of a dispute about their place of ordinary residence or which authority is responsible for paying for their care. Both of these principles must apply, in particular, to those moving from residential care to independent living.

## **Definition and guidance**

There is a clear need for the Department of Health circulars on *Ordinary Residence* and *Establishing the Responsible Commissioner* to be updated to reflect modern policies and practice around self-directed support, de-registration of care homes and long-stay hospitals, joint packages of health and social care support.

The complexities of some situations and the lack of relevance of current guidance to present day community care policy has been documented (Featherstone and McGavin, 'Bridging the Divides'). Clarification is needed in particular in complex situations, sometimes involving several statutory authorities.

Greater awareness of the outcome of determinations by the Secretary of State may give additional guidance and avoid the need for delay whilst a determination is sought. A list of determinations was published in 2006 as the result of an application under the Freedom of Information Act 2000, but it is not clear whether arrangements are in place to ensure that this list is kept up to date and publicised. A digest of the main issues arising from the determinations would be helpful.

There is a clear need for the Department of Health to issue new guidance on ordinary residence, promised for 2004, and we understand that it has now been agreed that work will start on this. On the basis of our

research, we do not think that this will be a major undertaking. The thrust of policy and of the determinations is that people should be considered an ordinary resident of the authority in which they live. The major issue to be resolved is that of funding arrangements.

## **Funding arrangements**

The principle that people are ordinarily resident in the authority in which they live would have serious financial implications for some authorities, particularly those who have placed significant numbers of people into residential care homes, and those who have large numbers of people placed by other authorities. There would be perverse financial incentives for placing authorities to discharge people from care homes into the local community or to encourage such homes to de-register, so that they would no longer retain financial responsibility for their support. Those authorities in which large numbers of people have been placed, would face the prospect of a significant increase in the numbers of disabled people needing support, with consequent budgetary implications.

It is therefore essential that arrangements are put into place to ensure that these funding inequalities are resolved.

## Conclusions:

### Resolving ordinary residence issues (continued)

The options are:

- To do nothing, allowing the new authority to meet the cost of care as soon as the person becomes ordinary resident, with the inequities and perverse incentives this entails;
- To make arrangements, similar to those involved in the closure of long-stay hospitals, for funds to be transferred between authorities so that people have full access to health and community services in the area in which they now live;
- To make arrangements for the funding for individuals to continue on a time-limited basis, perhaps tapering;
- To make arrangements for the revenue support grant for authorities to be adjusted according to the numbers of people they support in the community.

In the longer term, it may prove possible to link ordinary residence issues to those of individual budgets, finding ways in which a person's funding for their care and support is 'portable', i.e. capable of being transferred between authorities. Safeguards may be required to ensure that such funding is deemed 'reasonable' and there would need to be arrangements for it to be reviewed, but such an arrangement would give peace of mind to people with concerns that their current level of support may be reduced if they move between authorities.



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## Recommendations

The Voluntary Organisations Disability Group strongly recommends that the following action should be taken **urgently** by the Department of Health to resolve the funding disputes around ordinary residence, the resultant discrimination against disabled people and the attack on their human rights.

The VODG calls on the Government to:

- Establish and enforce the principle that a person should receive appropriate support from the authority where they are currently living or wish to live, regardless of circumstances
- Update the guidance to Social Services and PCTs to ensure they implement this principle in a person-centred way and to remove barriers to choice and independence
- Put in place a framework for the transfer of funds between authorities so that the issue of ordinary residence can no longer be used as a basis for refusing to provide care and support.

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## Appendix: Working methods

The research was carried out between December 2006 and March 2007.

The researchers identified key policy documents and carried out an analysis of their contents, referring to analytical work which had already been completed. They also examined ten determinations of ordinary residence by the Secretary of State.

Member organisations of VODG provided background information on the ways in which people they support have been caught up in ordinary residence disputes. During 2006, VODG members provided data on the numbers of such people known to them. This information was supplemented with data provided by the Association for Real Change. Using this information and national statistics, it was possible to provide estimates of the numbers of people affected by such disputes.

VODG members and others identified disabled people and their families who were affected by the issue and who were willing to relate their stories. A total of 12 people were approached during January and February 2007 and their stories recorded.

A number of people with concerns about ordinary residence were identified and approached by the researchers. These included service personnel, legal experts and officials within the Department of Health. Ordinary residence has been the subject of legal judgments made by the Secretary of State for Health and these were examined and analysed.

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## Acknowledgements

The research forming the basis of this report was carried out by Roger Blunden, PhD and Angie Ash, BA, MSc, MA , Dip Social. Admin., CQSW.

The researchers and the Voluntary Organisations Disability Group are grateful to the many people who contributed to this work. Members of VODG provided information about the impact of the ordinary residence problem on the people they support. We are particularly grateful to the people affected by the problem and their families who told their stories and allowed us to include them in the report. Thanks also to the many professionals and civil servants who spoke to us in connection with this work.

This research report has been made possible with the support of a grant from the Big Lottery Fund.

## Members of the VODG

### **Adepta**

[www.adepta.org.uk](http://www.adepta.org.uk)

### **Brandon Trust**

[www.brandontrust.org](http://www.brandontrust.org)

### **Care**

[www.care-ltd.co.uk](http://www.care-ltd.co.uk)

### **Crossroads**

[www.crossroads.org.uk](http://www.crossroads.org.uk)

### **Guide Dogs**

[www.gdba.org.uk](http://www.gdba.org.uk)

### **HFT**

[www.hft.org.uk](http://www.hft.org.uk)

### **Jewish Care**

[www.jewishcare.org](http://www.jewishcare.org)

### **John Grooms**

[www.johngrooms.org.uk](http://www.johngrooms.org.uk)

### **KeyRing**

[www.keyring.org](http://www.keyring.org)

### **Leonard Cheshire**

[www.leonard-cheshire.org](http://www.leonard-cheshire.org)

### **MacIntyre**

[www.macintyrecharity.org](http://www.macintyrecharity.org)

### **MCCH**

[www.mcch.co.uk](http://www.mcch.co.uk)

### **Mencap**

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### **Multiple Sclerosis Society**

[www.mssociety.org.uk](http://www.mssociety.org.uk)

### **Norwood**

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[www.qefd.org](http://www.qefd.org)

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### **TACT UK**

[www.tactltd.org](http://www.tactltd.org)

### **The Disabilities Trust**

[www.disabilities-trust.org.uk](http://www.disabilities-trust.org.uk)

### **The National Society for Epilepsy**

[www.epilepsynse.org.uk](http://www.epilepsynse.org.uk)

### **The Papworth Trust**

[www.papworth.org.uk](http://www.papworth.org.uk)

### **The Shaftesbury Society**

[www.shaftesburysoc.org.uk](http://www.shaftesburysoc.org.uk)

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### **United Response**

[www.unitedresponse.org.uk](http://www.unitedresponse.org.uk)

### **Vitalise**

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## Notes



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