

Voluntary
Organisations
Disability Group

V O D G

NOT IN MY BACKYARD

Ordinary residence,
Discrimination and
Disabled people

Three years on

Foreword

In 2007 the Voluntary Organisations Disability Group's report 'No Place like Home' called for urgent action by the Department of Health to sort out the bureaucratic muddle which adversely affected the lives of disabled people trying to move home.

The root cause of the problem was the definition of someone's place of ordinary residence – the means by which local authorities and Primary Care Trusts (PCTs) determine which authority has responsibility for financing care services for people living in their area.

Local authorities and PCTs were using disputes over a person's place of ordinary residence as a device to delay, or avoid paying, the costs of care.

The report highlighted that this was discriminatory against disabled people, as well as infringing their human rights and in contradiction to stated government policy.

Disputes between local authorities and PCT's over who should pay for a person's care were causing untold distress to the people concerned as well as wasting millions of pounds of public money.

The VODG called on the Department of Health to:

- establish and enforce the principle that a person should receive appropriate social care and support from the authority where they were currently living, or wished to live, regardless of circumstances
- update the guidance to social services and PCTs to ensure they implemented this principle in a person-centred way and removed barriers to choice and independence
- put in place a framework for the transfer of funds between authorities so that the issue of ordinary residence could no longer be used as a basis for refusing to provide care and support

Three years later only one of these recommendations has been acted on

In April 2010 new government guidance came into effect on the application of the ordinary residence rules. The guidance recognises the shift towards independent living and that social care is being delivered in new and innovative ways. However, it only clarifies the rules. It does not address the key issue of transfer of funding.

Citizenship and fairness

On October 1 2010 the new Equality Act was introduced – protecting individuals from unfair treatment and promoting a fair and more equal society.

And one of the key underpinning principles of the latest government White Paper, 'Equity and Excellence: Liberating the NHS,' is that of, 'choice'. *"Patients will have choice of any provider, choice of consultant-led team, choice of GP practice and choice of treatment."* This means, *"Money will follow the patient through transparent, comprehensive and stable payment systems across the NHS to promote high quality care, drive efficiency, and support patient choice."*

Despite this, the principles of personalisation and of funds following the individual do not currently apply to disabled people wishing to exercise choice and move from one local authority area to another, or from one care provision to another – denying them access to their basic human rights and citizenship as members of a fair and equal society.

The scale of the problem

There are no Government statistics available to establish the scale of the problem. The previous VODG report suggested that there were at least 500 people at any one time affected by ordinary residence disputes and that millions of pounds could be being wasted in bureaucratic wrangling.

The real size of this scandal is however masked, as disabled people and their families who are aware of the barriers involved often decide not to move home, even when their personal circumstance would be improved as a result. The true number of people affected is likely to run into thousands.

The heartache and frustration felt by so many disabled people is shared by the members of the VODG .

The evidence

Passing the buck

In the last three years the National Society for Epilepsy (NSE), in Buckinghamshire, has enabled 35 disabled people to move from residential care to more independent living.

Twenty five of those were originally placed in residential care by authorities other than Buckinghamshire – out of county placements – but the individuals chose to remain in Buckinghamshire, where they had made friends and where they could still easily access NSE's specialist medical facilities.

Living more independently meant that the cost of their care fell dramatically – in fact a total estimated saving of more than half a million pounds a year.

But for Buckinghamshire, where they had become 'ordinary residents' it represented an increase in costs of more than one million pounds. This is not an increase in costs to the public purse or treasury it is simply the financial impact on Buckinghamshire as a result of inflexible and unfair funding mechanisms.

25x £1,200 per week-
Cost of residential care

25x £785 per week-
Cost of living independently

Annual saving
to the public
purse £540,000

Savings to the public purse BUT additional cost to
Buckinghamshire £1,020,000

"Buckinghamshire is currently not able to fund the placements. After lengthy and distressing negotiations the original placing authorities are finding the funding –but this is in direct contravention to the Department of Health guidance."

Graham Faulkner, Chief Executive, National Society for Epilepsy

Limiting ‘choice’

The charity Self Unlimited strives to ensure that the several hundred people with learning disabilities it supports live as active citizens, taking as much control over their own lives as possible. But ordinary residence disputes between funding authorities severely limits the choices available to many of them. More than 55% of the people Self Unlimited works with are funded by councils, ‘out of area’ and therefore will be subject to inter-authority arguments.

“This is a clear infringement of people’s basic rights brought about by unresolved funding disputes, disabled people are in effect, ‘caught in the middle.’ Social care is thankfully moving towards a more person centred, or personalised approach, and where someone chooses to live is surely one of the most basic choices any of us will ever make? There must be action taken by the Department of Health to make funding portable between councils. It can’t be that difficult; if politicians were really serious about the rights of disabled people then they would find a way to resolve this long-standing issue –so that it doesn’t disadvantage any single council, but fully respects the individual’s choices. Unless a sensible solution is found, the most vulnerable in our society will continue to have their human rights denied and that is simply wrong in a modern society.”

Patrick Wallace, Chief Executive, Self Unlimited

Disabling not enabling – personal stories

Chrissy’s story

Chrissy is 26 and her family have sought advice from the National Autistic Society on her behalf. She has complex needs including severe learning disabilities, autism, epilepsy, challenging behavior and a rare chromosome disorder. For the last three years Chrissy’s family have been fighting for the expert help and support she needs. Residential homes have said they cannot manage her behaviours, expert support services have shunned responsibility and she has been pushed from one local authority to another throughout the south of England.

Three times in the last year alone her parents have taken out litigation to try to resolve the situation. Her PCT have said that what Chrissy needs is a fully staffed local supported living single person service—acknowledging that residential services cannot provide what she needs.

But who will pay for her to live in local supported accommodation? Chrissy’s funding has been a tussle between two local authorities – one arguing that her predominant need was social care provision, the other arguing that her predominant need was for health care and, in addition, they could not agree which area’s authority was responsible. In January this year, after litigation, one authority was forced to accept 100% responsibility for funding her health care.

“Chrissy became invisible in the midst of all the funding wrangles. We can only hope that she will emerge happier and more stable after getting the assessment and treatment she so desperately needs.”

Chrissy’s mum

The worst outcome

AB was a profoundly deaf sign language user who spent 18 months in psychiatric care after transferring from prison. He then spent eight years in a round the clock high support scheme as he was prepared for what promised to be a successful move back into the community. Sadly, after 18 months of independent living, he committed suicide.

At the coroner's enquiry the evidence pointed to the fact that his move to independence had involved a transfer of care to a different funding authority – who assessed his physical needs. They made no assessment of his mental health needs and ignored recommendations from the charity SignHealth that he needed outreach support. The charity made ongoing representations for his support to be reinstated – which were ignored.

“We can’t help but feel the issues around ordinary residence and funding disputes sadly contributed to this tragedy.”

Steve Powell, Chief Executive, SignHealth

Conclusions

There is still a need for urgent action. People should be able to exercise choice of where to live and have control over the support they receive.

The Department of Health guidance acknowledges the key issues of ordinary residence – yet local authorities are still choosing to call it into question. Proposed cuts to local authority spending will only make the matter worse – the desire to ‘pass the buck’ even greater. But as the case studies above demonstrate, sorting out the ordinary residency rules does not represent an increase in costs to the public purse and in many cases savings will be made. If the funds could follow the individual, disabled people could exercise choice over where, and how, they live and there would be a saving to the public purse. It could be a “win-win” situation.

The VODG calls on the government to:

- put its core principles of fairness and equality into practice by demonstrating effective leadership which resolves this issue once and for all
- establish and enforce the principle of choice so that disabled people can receive appropriate social care support from the authority where they are currently living, or wish to live, regardless of inter-authority funding mechanisms
- put in place a framework for the transfer of funds between authorities (similar to the NHS) so that the issue of ordinary residence is no longer used as a basis for refusing to provide care and support

VODG members

Advance UK
www.advanceuk.org

Leonard Cheshire Disability
www.lcdisability.org

RNIB
www.rnib.org.uk

Affinity Trust
www.affinitytrust.org

Livability
www.livability.org.uk

RNID
www.rnid.org.uk

Brandon Trust
www.brandontrust.org

MacIntyre
www.macintyrecharity.org

The Royal London Society for the Blind
www.rlsb.org.uk

The British Home
www.britishhome.org.uk

Martha Trust
www.marthatrust.org.uk

Scope
www.scope.org.uk

The Camphill Village Trust
www.cvt.org.uk

mcch
www.mcch.co.uk

SeeAbility
www.seeability.org

Canterbury Oast Trust
www.c-o-t.org.uk

Mencap
www.mencap.org.uk

Self Unlimited
www.selfunlimited.co.uk

Certitude Support
www.southsidepartnership.org.uk
www.supportforliving.org.uk

Multiple Sclerosis Society
www.mssociety.org.uk

Sense
www.sense.org.uk

Crossroads Care
www.crossroads.org.uk

National Autistic Society
www.autism.org.uk

SignHealth
www.signhealth.org.uk

Deafblind UK
www.deafblind.org.uk

The National Society for Epilepsy
www.epilepsysociety.org.uk

St. Elizabeth's Centre
www.stelizabeths.org.uk

Dimensions
www.dimensions-uk.org

NCYPE
www.ncype.org.uk

Sue Ryder Care
www.suerydercare.org

The Disabilities Trust
www.disabilities-trust.org.uk

Norwood
www.norwood.org.uk

Thomas Pocklington Trust
www.pocklington-trust.org.uk

Elizabeth FitzRoy Support
www.efitzroy.org.uk

Outlook Care
www.outlookcare.org.uk

United Response
www.unitedresponse.org.uk

The Guide Dogs for the Blind Association
www.gdba.org.uk

Papworth Trust
www.papworth.org.uk

Vitalise
www.vitalise.org.uk

hft
www.hft.org.uk

QEF
www.qef.org.uk

Walsingham
www.walsingham.com

KeyRing
www.keyring.org

RCHL
www.rchl.org.uk

Westminster Society for People with Learning Disabilities
www.wspld.org.uk

The Voluntary Organisations Disability Group (VODG)

The VODG is the leading umbrella group of voluntary sector providers of social care services for adults with disabilities. Our members' shared aim is to ensure that people with disabilities are supported in ways that they themselves define. We are committed to personalisation and the principle of "no decisions about me, without me".

Our ambition is to shape the development of social care policy, to influence its implementation and to provide sector leading information and research.

VODG members believe that meaningful engagement and fair negotiation between commissioners and providers, focused on the needs of people who rely on social care services, helps build strategic relationships, enhances service design and is more likely to ensure that beneficial outcomes and efficiencies are achieved.

If you're passionate about delivering services that people with disabilities want and are keen to have an influence and say in the wider sector then why not join us?

www.vodg.org.uk