

# THE NEED FOR COMMUNITY

A study of housing for adults with learning disabilities

June 2016



THE CENTRE FOR  
SOCIAL  
JUSTICE

The Need for Community: A study of housing for adults with learning disabilities  
© The Centre for Social Justice, 2016

Published by the Centre for Social Justice,  
4th Floor, Victoria Charity Centre, 11 Belgrave Road, SW1V 1RB  
[www.centreforsocialjustice.org.uk](http://www.centreforsocialjustice.org.uk)  
@CSJthinktank

Designed by Soapbox, [www.soapbox.co.uk](http://www.soapbox.co.uk)

# Contents

	About the Centre for Social Justice	2
	Special thanks	3
	Director's preface	4
	Introduction	5
<b>1</b>	<b>Accommodation</b>	<b>9</b>
	Residential care and supported living	9
	The advantages of residential care	10
	Commissioning trends	12
<b>2</b>	<b>Funding</b>	<b>15</b>
	Demand and future pressures	18
	Between a rock and a hard place	19
	Care Quality Commission	21
	Funding bias	23
<b>3</b>	<b>Conflicts of interest</b>	<b>25</b>
	Assessments	25
	Advocacy	27
<b>4</b>	<b>The solution</b>	<b>31</b>
	Structural recommendations	31
	Conclusion	35

# About the Centre for Social Justice

Established in 2004, the Centre for Social Justice (CSJ) is an independent think-tank that studies the root causes of Britain's social problems and addresses them through recommending practical, workable policy interventions. The CSJ's vision is to give people in the UK who are experiencing the worst multiple disadvantage and injustice every possible opportunity to reach their full potential.

Since its inception, the CSJ has changed the landscape of our political discourse by putting social justice at the heart of British politics. This has led to a transformation in government thinking and policy. The majority of the CSJ's work is organised around five 'pathways to poverty', first identified in our groundbreaking 2007 report, *Breakthrough Britain*. These are: family breakdown; educational failure; economic dependency and worklessness; addiction to drugs and alcohol; and severe personal debt.

In March 2013, the CSJ report *It Happens Here* shone a light on the horrific reality of human trafficking and modern slavery in the UK. As a direct result of this report, the government passed the Modern Slavery Act 2015, one of the first pieces of legislation in the world to address slavery and trafficking in the 21st century.

The CSJ delivers empirical, practical, fully-funded policy solutions to address the scale of the social justice problems facing the UK. Our research is informed by expert working groups comprising prominent academics, practitioners, and policy-makers. Further, the CSJ Alliance is a unique group of charities, social enterprises, and other grass-roots organisations that have a proven track-record of reversing social breakdown across the UK.

The 11 years since the CSJ was founded has brought with it much success. But the social justice challenges facing Britain remain serious. Our response, therefore, must be equally serious. In 2016 and beyond, we will continue to advance the cause of social justice in this nation.

# Special thanks

The Centre for Social Justice would like to thank a number of individuals that have kindly contributed their time and knowledge during the writing of this paper. Our thanks particularly go to our lead author Edward Stroud and to our researchers Camilla Monckton and Daniel Bell.

The Centre for Social Justice would also like to thank Mr Ian Moore who provided invaluable consultation and assistance during the writing and editing of this paper.

We are also extremely grateful to L'Arche UK, Newton Dee Camphill Community, and Choice Support for hosting us on visits during the course of our research as well as the numerous other providers and individuals with whom we met.

# Director's preface

The common thread running through our work at the Centre for Social Justice is a belief in a society in which citizens are empowered to achieve their potential. Our aim is to see vulnerable people empowered with dignity, responsibility and aspiration. This report is no different. It seeks to put the autonomy, independence and potential of those with learning disabilities at the heart of the care system.

The aim of this work is to examine the environment in which adults with learning disabilities can thrive, allowing them to learn, grow as individuals, and develop independence. Independence and autonomy are desirable but there are points or circumstances in which all people need more support. Moments at which, to leave individuals, and indeed their families without, is to fail as a compassionate society.

Developing policy in areas such as this is a balancing act between enabling autonomy, while providing the security of support when it is needed.

This report analyses how the current system of 'residential care' and 'supported living' balances these two duties. This is a complex issue and this report cannot solve the problems facing adult Social Care by itself. However, we hope that in our analysis and the recommendations which spring from it, some of the systemic challenges might be removed. In doing so, we take a step closer to the positive project of creating a Social Care system which empowers and enables those with learning disabilities.

**Baroness Stroud of Fulham**

Chief Executive

# Introduction

Over 120,000 people in England have learning disabilities so severe that they need daily help simply to perform the tasks so many of us take for granted – going to the shops, getting dressed, getting ready for bed. Without the right sort of support, people with learning disabilities can be left deeply isolated, and deprived of opportunities to socialise and be part of a community.

The CSJ knows how damaging to happiness and mental health isolation can be.<sup>1</sup> The provision of care needs, wherever possible, to help people grow and learn to take on degrees of responsibility and work. For those with the most severe needs who are unlikely ever to be able to work, it is essential that there is a community and a support network around them not only to ensure their physical health and development but to support them in this growth. Companionship and community are a human good which no person should be denied.

This report focuses on the problems of accommodation facing people with severe learning disabilities within the wider context of concerns facing this part of the care system. Only by examining their housing situation in this way can we properly understand the problem and its corresponding solutions.

We have heard that the care system is currently under a number of pressures which are presenting challenges to those who commission, those who provide, and, most importantly, those who receive care. Between 2011 and 2012 (the most recent year for which figures are available):

- 17 per cent of people with learning disabilities saw a reduction in the number of hours of support they received;
- 13 per cent were given less money to spend on their support;
- 18 per cent of people were being charged more for the services they received.<sup>2</sup>

Very often it is families who have to make up the difference. Nearly one in five people with learning disabilities have said that they would be unable to afford basic necessities such as food

<sup>1</sup> Centre for Social Justice, *Strengthening Relationships to Prevent Isolation and Loneliness in Old Age*, London: Centre for Social Justice [accessed via: <http://www.centreforsocialjustice.org.uk/UserStorage/pdf/Pdf%20reports/CSJ-full-think-piece.pdf> (14.01.16)]

<sup>2</sup> Learning Disability Coalition, *Social Care in Crisis – the Need for Reform The Learning Disability Coalition Annual Survey 2012*, London: Learning Disability Coalition, 2012 [accessed via: [www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf](http://www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf) (14.01.16)]

or clothes without additional funding provided by their families.<sup>3</sup> The toll on these families can be huge with almost eight out of ten of those caring for someone with profound and multiple learning disabilities saying that they have reached or come close to 'breaking point' because of a lack of short break or respite services.<sup>4</sup>

A major issue that faces all individuals in such a situation is the sort of care available to them. There have been many reports of care homes closing in recent years and of a shift away from *residential care* to *supported living*.

## Definitions

**Residential care** provides accommodation and personal care, defined under the Care Standards Act 2000 as 'assistance with bodily functions such as feeding, bathing, toileting when required.'

**Supported living** has no legal definition but has a commonly accepted set of principles that are defined in the Reach Standards in Supported Living. These are that people with learning disabilities own or rent their home and have control over the support they get, who they live with (if anyone) and how they live their lives.<sup>5</sup>

The CSJ's view is that both supported living and residential care have an extremely important place in the spectrum of provision. We do not take a position that one model is inherently preferable over the other. People with learning disabilities have a wide variety of needs as well as different wants and preferences. For example:

- For those who want it, supported living provides a much higher degree of autonomy and independence. However, others would find this experience lonely and isolating;
- Some find great fulfilment through living in the communal setting of residential care, however, others would find this stifling;
- It can be easier to meet the needs of those with more severe learning disabilities in the context of residential care. But it is worth noting that for many of those with learning disabilities this does not preclude supported living. Those who value a high level of independence may decide that the lower level of support in supported living is an acceptable trade-off. Crucially, however, this should be a decision those in receipt of care make, not a decision forced upon them.

What is crucial is that those with severe learning disabilities are able to lead the most fulfilling lives possible. For those with learning disabilities, this includes having as much choice as possible, others within society respecting those decisions, and Government ensuring that the provision of support is of a high quality, whatever form that takes.

3 Learning Disability Coalition, *Social Care in Crisis – the Need for Reform The Learning Disability Coalition Annual Survey 2012*, London: Learning Disability Coalition, 2012 [accessed via: [www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf](http://www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf) (14.01.16)]

4 Mencap, *Families at Breaking Point*, 22 November 2013 [accessed via: [www.mencap.org.uk/news/article/families-breaking-point](http://www.mencap.org.uk/news/article/families-breaking-point) (14.01.16)]

5 NDTi, 'Supported Living – Making the Move: Developing Supported Living options for people with learning disabilities', MMy 2010 [accessed via: [http://www.ndti.org.uk/uploads/files/Supported\\_Living\\_-\\_Making\\_the\\_Move\\_May\\_2010.pdf](http://www.ndti.org.uk/uploads/files/Supported_Living_-_Making_the_Move_May_2010.pdf) 14.01.16]

However, during the course of our research, the CSJ found that there has been an ongoing shift from residential care to supported living which does not reflect a demand for it. This trend is very concerning, especially at a time when there appears to be a high user demand for residential care.

We have identified four core factors which put this kind of balanced care portfolio at risk:

1. A commissioning culture which favours supported living over residential care;
2. A systemic funding bias which favours supported living over residential care;
3. Widespread budgetary pressures;
4. Ideological considerations.

It is important that care commissioning decisions are based on evidence-led research and assessment of need not on ideological considerations. The answer to care for those with learning disabilities lies neither solely in supported living nor in residential care. We need a care system which offers the option of care delivered in either an independent or communal setting. When making commissioning decisions we should place the individual's needs and preferences at the heart of process; not the form of care in which these needs are met.

Much of the underlying debate between residential care and supported living lies in the drive to place individuals *within* the community, housing them at the heart of society in supported living. The CSJ thoroughly supports the driving motive behind this – to create a society in which those with learning disabilities play a fundamentally participative role. However, our findings suggest that not only is this equally possible in supported living and residential care, but it also shows that the communal setting of care can have an important role in enabling and supporting the individual to participate in this society.

In **Chapter 1** we outline the huge benefit that the provision of care in a residential, communal setting can have and yet how there has been a shift in commissioning towards supported living over residential care which threatens the sustainability of many residential care providers.

**Chapter 2** looks at how these commissioning decisions are being driven by funding pressures and the funding structures on which it relies.

**Chapter 3** considers how these same funding issues may be distorting both the assessment of need and the reliable advocacy necessary to help people with learning disabilities and their families choose appropriate provision.

Finally, **Chapter 4** outlines our recommendations for solving these issues.



# chapter one

## Accommodation

The type of care and accommodation that people with learning disabilities receive is fundamental to their quality of life. It is vital that as much as possible is done to personalise this accommodation to the specific needs, wants and preferences of the individual and their families. For some people supported living offers the right balance between independence and assistance, for others a residential care setting will fit better with the way they want their care delivered.

During the course of our research, the CSJ has heard reports that some people are being moved from communal settings to settings less appropriate for their needs. This chapter looks at the benefits that communal settings can provide and looks at the evidence that they are less often available to those who need them.

### Residential care and supported living

To quote directly from a Government White Paper, a learning disability includes the presence of:

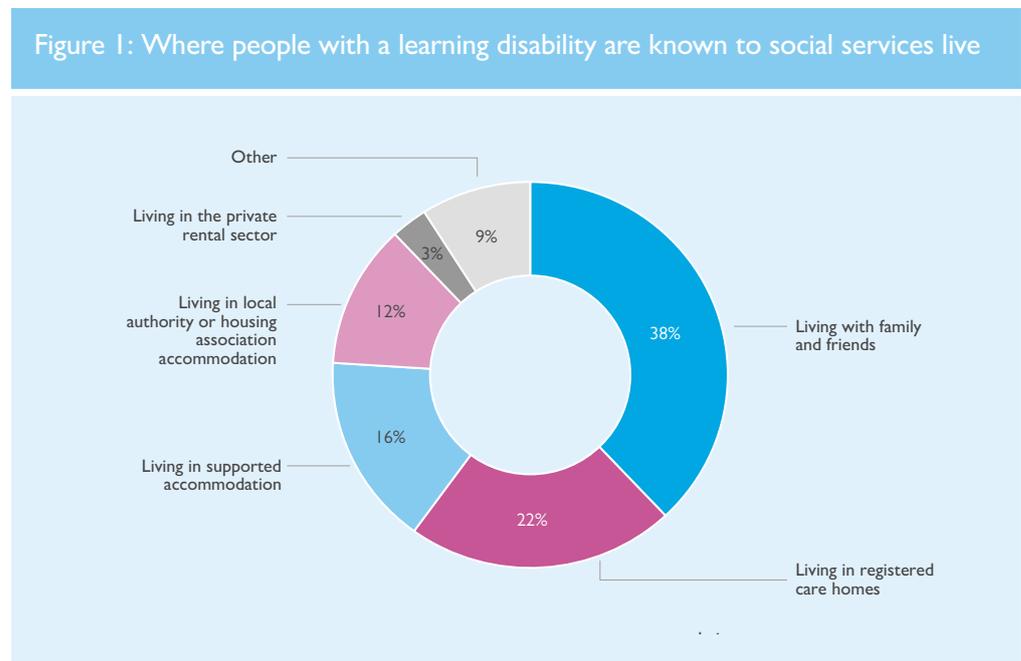
- *'A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *A reduced ability to cope independently (impaired social functioning);*
- *Which started before adulthood, with a lasting effect on development.'*<sup>6</sup>

In 2011, 120,000 people with a learning disability in England received Social Care. Of these, about 45,600 people lived with family or friends (38 per cent), 26,400 in residential care (22 per cent) and about 19,200 in supported living (16 per cent).<sup>7</sup>

6 Valuing People, 'A new strategy for learning disabilities for the 21st century, a white paper', 2001 [Accessed via: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/250877/5086.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf)] [Accessed 14.01.16]

7 Mencap, *Housing for People with a Learning Disability*, London: Mencap, 2012, p5 [accessed via: [www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report\\_V7.pdf](http://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf)] (14.01.16)]

The following pie chart shows the breakdown of where adults with a learning disability, known to social services, are living.



## The advantages of residential care

Residential care holds the potential to offer care in an environment in which community is an inherent part of daily life, and indeed is part of the care itself. When residential care is done well and funded properly, people with learning disabilities can take part in excursions and day activities together, spend leisure time together and develop friendships. Residential care also provides an environment in which care staff are present 24/7 – this is particularly relevant to those who have the most profound needs. There is the potential to offer a surprising degree of independence while safeguarding security.

One worry that some families, advocacy groups and others raise about the care which takes place in this explicitly communal setting is that it inhibits independence and growth by contributing to the 'ghettoising' of adults with learning disabilities. However, as the CSJ has seen, good communal care offers some people an unparalleled opportunity for community engagement and involvement both with other members of the care community but also those outside it.

**Newton Dee: where community and participation abound**

Located in the leafy suburbs of Aberdeen, Newton Dee's 18 houses of seven to 14 people form a community where those with learning disabilities live alongside those without. The mixed needs and abilities in each house create an atmosphere in which labels begin to breakdown. Those with learning disabilities help those with more profound needs and also help in the day-to-day running of the community. Newton Dee moves away from a power dynamic of carer and cared for, in a way which is empowering and yet still safe.

All members of the community work during the day, and there are workshops and farms which are part of the community. Talking to those who work in the joinery the conversation moved to what work is. They described it as 'doing what you can to the best of your ability' and as 'stressful' – both presented positively as indicators of hard work and responsibility. It is a key part of Newton Dee's philosophy to start with what a member of the community can do, rather than with what they can't. All members of the community are supported in doing the job to the best of their ability and in the growing pains of stressful work. This growth is a key component of Newton Dee: everyone there, with and without learning disabilities is encouraged to grow and develop.

The day-to-day work gives members of the community a strong sense of identity and purpose. This is not surprising considering that all work feeds back into daily life. Those in the joinery were fixing beds which would be used in the houses, and those in the garden or the farm take their produce back to be eaten.

It is Newton Dee's strong community which allows it to be so outward-looking. It is because of the safety and purpose that those living there feel that they are comfortable in turning towards others. The mutual support that those with and without learning disabilities offer each other allows all to grow. The relationships which the community members model to each other become a skill, and in turn a gift quickly offered to those who step into Newton Dee from beyond its borders.

The community's 'village green', cafe and local shop – the biggest supplier of dietary specific food in Aberdeen – all run by community members, have led to Newton Dee becoming a hub for the community. This further adds to community members' pride and self-worth.

Newton Dee offers many lessons for care provided in a communal setting. It demonstrates that:

- Strong community does not necessitate an inward-looking community;
- Strong community makes an outward-looking community possible.

This is made possible by empowering each individual by:

- Breaking down the standard relationship of carer and cared for;
- Showing that each person has something to give to the community, and giving each person responsibility;
- Supporting each person in their ability to contribute, involving a responsible level of risk;
- Locating community services alongside care services;
- Locating residential care within a wider community.

This approach shows that there is the potential to provide a surprisingly high level of personalisation in the context of residential care. The benefit of the community and the individual can be mutually reinforcing. Therefore, residential care as a model is by no means rigid and unchanging – indeed as Newton Dee has shown, residential care can be flexible and unique dependent upon user preference and care needs.

## Commissioning trends

During the course of our research, the CSJ heard concerns from individuals, families and providers that current commissioning priorities and organisational practices are favouring supported living over residential care. Indeed the Department of Health (DH) includes the number of people permanently admitted to residential care in its metrics for measuring success. According to this, a low number of admissions would mean a high success rate.

'The number of permanent admissions to residential and nursing care is a good measure of the effectiveness of care and support in delaying dependency on care and support services. The inclusion of this measure in the framework supports local health and Social Care Services to work together to reduce avoidable admissions where appropriate.'

Department of Health, *The Adult Social Care Outcomes Framework 2015/16*

Despite this, a 2015 DH Green Paper states that adults with a learning disability should be free to choose residential care or supported living, explaining that there is:

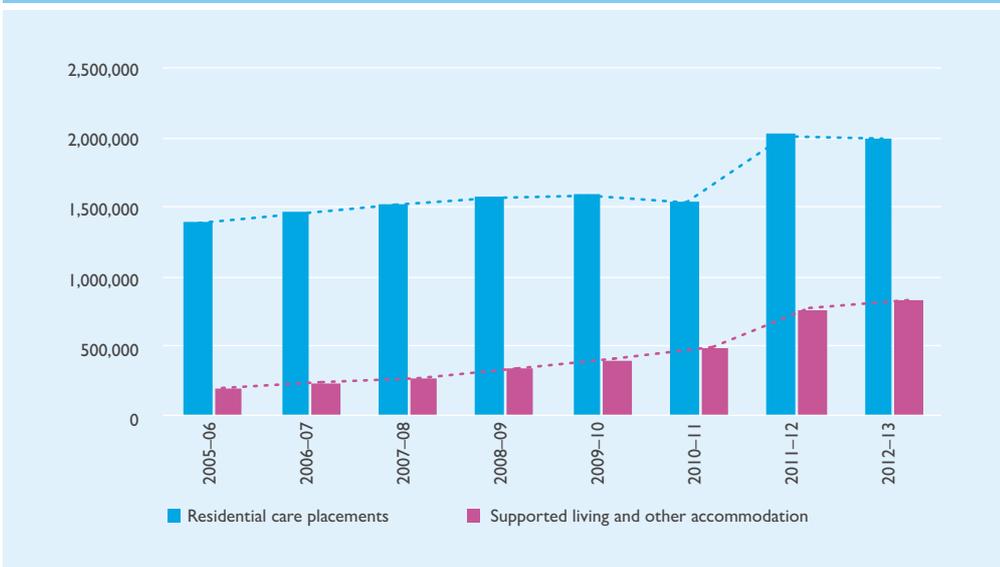
*'... no policy to prevent or deny people choosing these arrangements [residential care], including for people with a learning disability and for those with mental health needs.'*<sup>8</sup>

At a local level, a substantial change appears to be taking place. 80 per cent of Local Authorities studied by the CSJ reported a strategic policy shift away from residential care towards supported living between 2005 and 2014.

Below, figure 2 shows a growing expenditure on supported living and other accommodation in comparison to residential care.

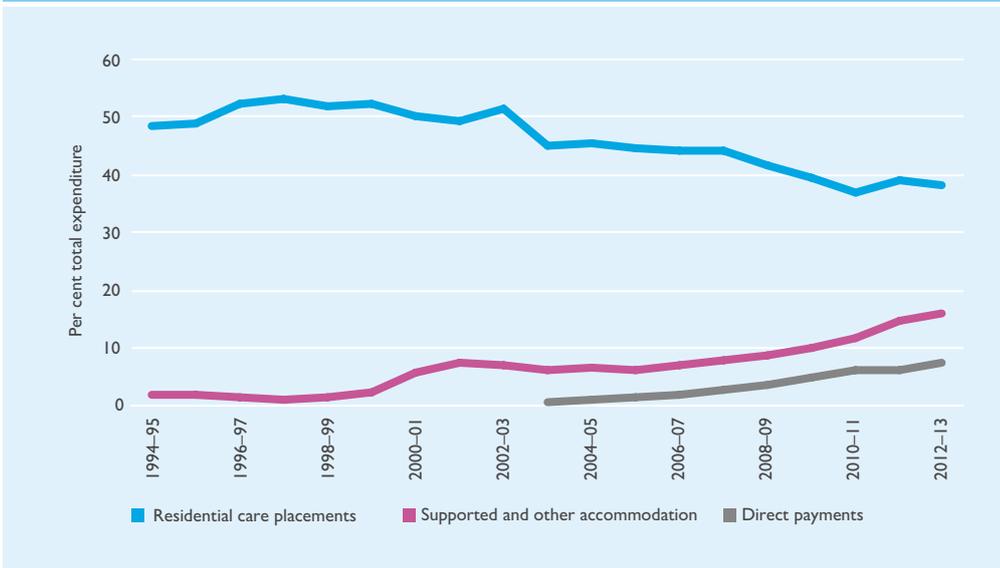
8 Department for Health, *No Voice Unheard, No Right Ignored*, London: Department for Health, 2015 [accessed via: [12](https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0ahUKewjZ5-y7ukKnKAhXE3SYKHbOADOQFggIMAE&url=http%3A%2F%2Fwww.gov.uk%2Fgovernment%2Fuploads%2Fsystem%2Fuploads%2Fattachment_data%2Ffile%2F409816%2FDocument.pdf&usq=AFQjCNEsBbDxN2MFR7xEDPyefQ-2PLRocw&sig2=cZBueb-Fh7g9RZZ2bHBr9rA (14.01.16)]</a></p></div><div data-bbox=)

Figure 2: Gross expenditure on residential care placements and supported living on adults with learning disabilities under the age of 65 from 2005–2014<sup>9</sup>



This growing trend towards higher proportional expenditure on supported living is emphasised when we look at the shift in expenditure as a percentage of total Adult Social Care spending on adults with learning disabilities, as figure 3 demonstrates.

Figure 3: Total adult Social Care expenditure on housing for adults with learning disabilities, by type of housing (exc. SP = excluding 'supporting people' funding)<sup>10</sup>



9 Health and Social Care Information Centre, *Personal Social Services: Expenditure and Unit Costs, England 2012–13*, Provisional Release, London: Health and Social Care Information Centre, 2013 [accessed via: <http://www.hscic.gov.uk/catalogue/PUB11644/pssexp-eng-12-13-prov-rpt.pdf> (14.01.16)]; The rise between 2010–2011 and 2011–12 is because of NHS funding which was transferred to Adult Social Services Budget. In actual fact it masks a cut to care for adults with learning disability which we draw out in the next chapter.

10 *Personal Social Services: Expenditure and Unit Costs, England, 2013–14*, National gross and net current expenditure, 1994–5 to 2013–14. [Accessed via: <http://www.hscic.gov.uk/catalogue/PUB14909> (23.05.16)]

Figure 3 shows two things clearly; first, the decline of residential care as a percentage of total Social Care expenditure on adults with learning disabilities; second, the corresponding rise of the percentage spent on supported living. This trend has been happening since 2002. This picture is complicated by the fact that some communal living settings – such as Newton Dee – are actually classified as supported living because of the way in which they have been constituted.

Beyond this, the CSJ has heard that funding is being taken out of residential care at such a rate in some areas that it is putting real pressure on providers of residential care and severely discouraging some from continuing to provide services.

The 2012 Learning Disability Coalition (LDC) survey found that 40 per cent of providers of residential care were 'affected by funding difficulties'.<sup>11</sup> These funding difficulties were compounded by cuts to day services, with 60 per cent of care providers reporting that Local Authority day activities have been cut.<sup>12</sup> This has meant that residential care providers whose service users used these services were now also having to cater for their needs during the day, putting further strain on budgets.

Providers of residential care increasingly feel that the services they provide are not wanted by Local Authorities. Despite the excellent work that many providers carry out, empowering and caring for many of society's most at risk, they feel misunderstood and unsupported.

'Residential care has grown to be unacceptable to Commissioners and yet (as our CQC inspector said) we are much more than residential care. All our residents have person-centred plans and live life to the full.'

Provider (LDC survey)

Funding pressures being put on England's residential care providers could severely narrow England's care portfolio such that there is far less care provided in communal settings such as Newton Dee and thereby reduce the choice available to those wishing to receive their care in this manner.

In attempting to follow the principles of personalisation through investing in supported living and the choice which it allows, changes in commissioning are actually acting to the detriment of the personalisation agenda, and hence to the detriment of enabling and respecting the choice of those with learning disabilities.

In conclusion, ongoing trends in government expenditure and provider surveys have shown a commissioning bias towards supported living over residential care. This is a worrying trend which is acting to impair personal choice. This all exists within a pressured funding environment that has seen multiple years of underinvestment. Chapter 2 looks at the issue of funding in more detail.

11 Learning Disability Coalition, *Social Care in Crisis – the Need for Reform The Learning Disability Coalition Annual Survey 2012*, London: Learning Disability Coalition, 2012 [accessed via: <http://www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf> (14.01.16)]

12 Ibid

# chapter two

## Funding

As discussed in the previous chapter, there has been an overall reduction in the amount of funding provided to residential care. This comes at a time of general funding cuts for the care of adults with learning disabilities and Adult Social Care more broadly.

Adults with learning disabilities who require care receive funding from Adult Social Services. This is funded by Local Authorities which in the 2010 spending review had their funding from central government cut by 26 per cent over the spending review period, from £29.7 billion to £22.1 billion. The spending review forecast that overall Local Authority income (there is some income which is not funded by central government) would therefore fall by 14 per cent.<sup>13</sup>

Despite cuts of 8.26 per cent between 2010 and 2013 across adult Social Care funding, the National Audit Office (NAO) reported that Local Authorities had largely protected adult Social Care funding for people with learning disabilities.<sup>14</sup> The NAO reported that between 2010 and 2013:

*'Older adults aged 65 and over have experienced the greatest reduction, 12 per cent in real terms. Younger adults with learning disabilities have experienced the smallest reduction of 0.2 per cent in real terms.'*<sup>15</sup>

This claim appears to be supported by Personal Social Services Expenditure (PSSEX) data which shows that there has actually been a slight investment in care for adults with learning disabilities.

<sup>13</sup> National Audit Office, *Financial sustainability of local authorities*, London: National Audit Office, 2013, p14 [accessed via: [www.nao.org.uk/wp-content/uploads/2013/03/Local-Authority-Full-Report.pdf](http://www.nao.org.uk/wp-content/uploads/2013/03/Local-Authority-Full-Report.pdf) (14.01.16)]

<sup>14</sup> National Audit Office, *Adult social care in England: overview*, London: National Audit Office, 2015, p32 [accessed via: [www.nao.org.uk/wp-content/uploads/2015/03/Adult-social-care-in-England-overview.pdf](http://www.nao.org.uk/wp-content/uploads/2015/03/Adult-social-care-in-England-overview.pdf) (14.01.16)]

<sup>15</sup> Ibid

Figure 4: Social Care funding spent on adults with Learning Disabilities, £ billion<sup>16</sup>

	2008–09	2009–10	2010–11	2011–12	2012–13	2013–14
Social Care funding spent on adults with Learning Disabilities	3.57 bn	3.76 bn	3.93 bn	4.92 bn	4.98 bn	5.08 bn
						

However, figure 4 shows how the huge increase between 2010–11 and 2011–12 actually hides a slight cut to care for adults with learning disability. As figure 5 shows, this is due to the 'Valuing People Now' (VPN) component of the NHS budget only partially being transferred to the Adult Social Services budget. It is also because before this NHS transfer, the VPN budget was not included in the figures for total Social Services expenditure. However, after the VPN budget was transferred to Local Authorities in 2011/12, it is included in total Social Services expenditure. Combined, this means a real-terms cut in total net expenditure on adults with learning disabilities between 2010–11 and 2011–12.

Figure 5: Net current expenditure on Adult Social Care Services: by source of funding, £ billion<sup>17</sup>

	2007–8	2008–9	2009–10	2010–11	2011–12	2012–13	2013–14	2014–15
Social Services	13.3	13.85	14.46	14.61	14.75	14.63	14.65	14.41
Valuing People Now	1.21	1.24	1.28	1.31	–	–	–	–
NHS transfer to Local Authorities	–	–	–	–	0.65	0.62	0.86	1.10
Winter Pressures Transfer	–	–	–	0.16	0.15	0.10	–	–
Total net expenditure	14.34	15.09	15.74	16.08	15.55	15.35	15.51	15.51

As can be seen from figure 5, the reason for the apparent increase in Social Care spending on adults with learning disabilities from 2010–11 to 2011–12 is more nuanced than figure 2 suggests. The reason is that the Valuing People Now component of the NHS budget, which was targeted at the care outcomes of adults with a learning disability, switched from the NHS to the

<sup>16</sup> Health and Social Care Information Centre, *Personal Social Services: Expenditure and Unit Costs*, England 2012–13, Final release, London: Health and Social Care Information Centre [accessed via: [www.hscic.gov.uk/catalogue/PUB13085/pss-exp-eng-12-13-fin-rpt.pdf](http://www.hscic.gov.uk/catalogue/PUB13085/pss-exp-eng-12-13-fin-rpt.pdf) (14.01.16)]

<sup>17</sup> Ibid

Adult Social Services budget. However, this apparent increase in expenditure actually hides a reduction in total net expenditure. While £0.65 billion was transferred from the NHS budget to the Social Services Budget in 2011–12, this was in place of a Valuing People Now budget of £1.31 billion the previous year, resulting in a real cut of £0.66 billion, equal to an 11% cut in the learning disabilities budget of 2010–11.

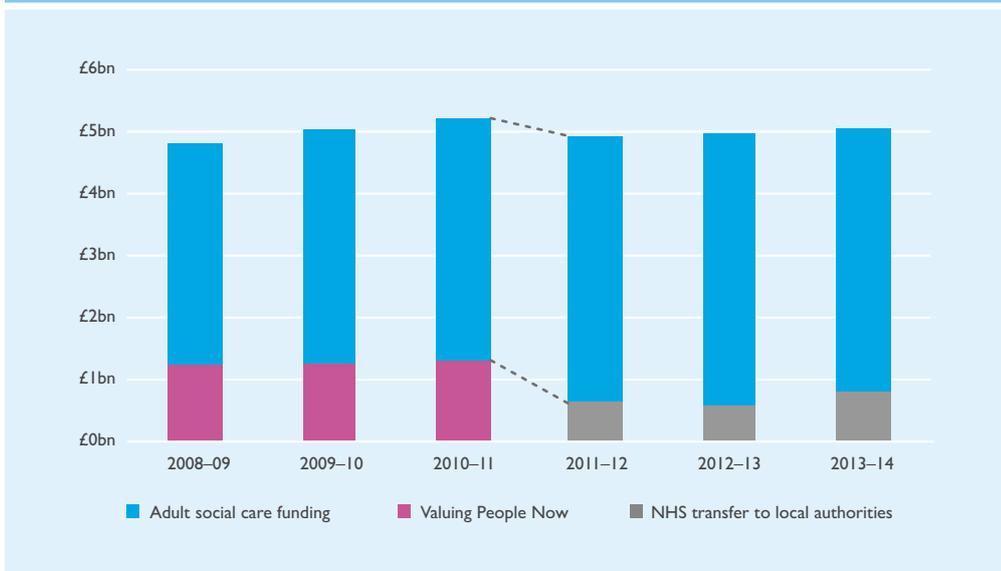
The table below shows net current expenditure on adults with learning disabilities, per source of funding.

Figure 6: Net Total expenditure on adults with learning disabilities (£ billion), 2008–2014

	2008–09	2009–10	2010–11	2011–12	2012–13	2013–14
Valuing people now	1.24	1.28	1.31	–	–	–
NHS transfer to Local Authorities	–	–	–	0.65	0.62	0.86
Adult Social Care funding	3.57	3.76	3.93	4.27	4.36	4.22
Total	4.81	5.04	5.24	4.92	4.98	5.08

Below, figure 7 shows a graphical representation of figure 6, showing total net expenditure on adults with learning disabilities, per source of income.

Figure 7: Total net expenditure on adults with learning disabilities, 2008–2014



As can be seen from figures 6 and 7, once the VPN budget and NHS Transfer have been taken into account, the overall expenditure for adults with learning disabilities was marginally cut between 2010/11 and 2011/12 and there has been significant underinvestment since. We believe this pattern demonstrates almost a decade of underfunding at a time of increased demand. This lack of investment must be addressed before increased pressures push care providers to the brink of survival and leave care provision in doubt and jobs under threat.

In the 2015 Autumn Statement, the Chancellor, George Osborne, announced that he would allow councils to levy a new Social Care precept of up to 2 per cent on council tax.<sup>18</sup> Nationally he calculated that this would bring in almost £2 billion in revenue. The CSJ welcomes this increase, however, we ask that the Government monitors whether less well-funded Local Authorities, facing increasing demand and pressure with older populations are able to raise enough revenue from the precept to meet their needs. The major demand that councils will face on this new resource will come from the provision of services for the elderly. In particular the recent introduction of the National Living Wage (NLW) is likely to consume a large portion of it and may leave relatively little for additional investment.<sup>19</sup>

It has been raised by many residential care providers that the introduction of the NLW is likely to increase funding pressures and add additional strain on the residential care sector. To alleviate this, the Government must seek to allocate sufficient funding in order to close the gap between what the Local Authorities are able to pay and the growing cost of providing care.

More so than other sectors, adult Social Care relies heavily on its workforce, spending a greater share of turnover on wages than any other sector.<sup>20</sup> Despite this, the care sector has been vocal about its support for the National Living Wage in principle, however, we agree with the Chief Executive of Care England, Professor Martin Green, when he says:

*'It is not sustainable for us to meet the increased cost of care when Local Authorities are already paying well below the true cost of delivery.'*<sup>21</sup>

## Demand and future pressures

This increase in funding is welcome but demand for services is rising. There is due to be a substantial increase in the number of adults with Learning Disabilities requiring care from Adult Social Services. Mencap estimated that between 2011 and 2026, Local Authorities would have to provide an additional 1,324 registered care home places and 941 supported living placements per year.<sup>22</sup> The number of service users with Profound and Multiple Learning Difficulties is also

---

18 Her Majesty's Treasury, *Autumn Statement 2015*, London. [Accessed via: [www.gov.uk/government/speeches/chancellor-george-osbornes-spending-review-and-autumn-statement-2015-speech](http://www.gov.uk/government/speeches/chancellor-george-osbornes-spending-review-and-autumn-statement-2015-speech) (14.01.16)]

19 Local Government Association, Press Release, 'National Living Wage to cost councils £1 billion a year by 2020/21', 2015 [Accessed via: [www.local.gov.uk/web/guest/media-releases/-/journal\\_content/56/10180/7386419/NEWS](http://www.local.gov.uk/web/guest/media-releases/-/journal_content/56/10180/7386419/NEWS) 14.03.16]

20 Resolution Foundation, *More than a minimum: The Resolution Foundation Review of the Future of the National Minimum Wage*, March 2014

21 Nursing Times, 'Care Home chiefs warn of sector 'collapse' from living wage plan', 2015 [Accessed via: [www.nursingtimes.net/roles/nurse-managers/care-home-chiefs-warn-of-sector-collapse-from-living-wage-plan/5089776.fullarticle](http://www.nursingtimes.net/roles/nurse-managers/care-home-chiefs-warn-of-sector-collapse-from-living-wage-plan/5089776.fullarticle) 17.02.16]

22 Mencap, *Housing for people with a learning disability*, London: Mencap, 2012, p19 [accessed via: [www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report\\_V7.pdf](http://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf) (13.04.16)]

set to rise by 38 per cent between 2010 and 2026.<sup>23</sup> This is itself driven in part by an increase in life expectancy which funders will need to adapt to in the future.<sup>24</sup>

In addition, a lack of preventative services is, in some cases, failing to halt the decline in people's conditions who then become more complex and costly to support.<sup>25</sup> The merits of prevention have been shown by initiatives such as *The Camden Reablement* scheme led by the Red Cross. Regarding this scheme, the British Red Cross said to an inquiry by the All Party Parliamentary Group for Disability:

*'The Camden Reablement scheme which The British Red Cross were involved in provided £77,000 of total expected savings over a twelve month period, including savings to Social Care. This represents £246 per user. In addition to the financial benefits, 74 per cent of users rated the service as "excellent" and 11 per cent rated it as "good."'*<sup>26</sup>

Furthermore, research by Deloitte showed that prevention achieved savings of £1.50 for every £1 invested by avoiding acute costs.<sup>27</sup>

If local services identified and supported just four per cent of adults with high-functioning autism or Asperger Syndrome, the outlay would become cost neutral over time, and that if they identified eight per cent of adults in their local population then the Government could save £67 million a year.<sup>28</sup>

National Audit Office

## Between a rock and a hard place

90 per cent of service providers described the funding situation for support for people with learning disabilities as difficult, with 72 per cent saying that funding for their services from Local Authorities had been cut over the last year.

LDC Survey 2012

Before the Care Act 2014 was introduced, in order to cope with this increased demand and fewer resources, Local Authorities would have had to increase the eligibility criteria. This would have meant there would only have been adequate funding for those with the

23 Ibid, p18.

24 Ibid

25 Local Government Knowledge Navigator, *Need to Know: Review Number One*, London: Local Government Knowledge Navigator, 2013 [accessed via: [www.solace.org.uk/knowledge/reports\\_guides/LGKN\\_NTK\\_LEARNING\\_DISABILITIES.pdf](http://www.solace.org.uk/knowledge/reports_guides/LGKN_NTK_LEARNING_DISABILITIES.pdf) (14.01.16)]

26 All Party Parliamentary Disability Group, *Promoting Independence, Preventing Crisis*, London: 2013, p38 [accessed via: [www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Promoting-Independence,-Preventing-Crisis-APPG-report.pdf?ext=.pdf](http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Promoting-Independence,-Preventing-Crisis-APPG-report.pdf?ext=.pdf) (14/01/16)]

27 Ibid

28 National Audit Office, *Supporting people with autism through adulthood*, London: National Audit Office, 2009 [accessed via: [https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwicg2lu6nKAhVFNSYKHczqAAQFgggMAA&url=https%3A%2F%2Fwww.nao.org.uk%2Fwp-content%2Fuploads%2F2009%2F06%2FAutism\\_Tech\\_Paper.pdf&usg=AFQjCNE3JMbfn2CYkmaloQsjvbP7AAI3Vw&sig2=IVmTmcQYqIs\\_ANOgeN32Ew](https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwicg2lu6nKAhVFNSYKHczqAAQFgggMAA&url=https%3A%2F%2Fwww.nao.org.uk%2Fwp-content%2Fuploads%2F2009%2F06%2FAutism_Tech_Paper.pdf&usg=AFQjCNE3JMbfn2CYkmaloQsjvbP7AAI3Vw&sig2=IVmTmcQYqIs_ANOgeN32Ew) (14.01.16)]

most acute needs.<sup>29</sup> This had grave problems in and of itself, and the CSJ welcomes the Care Act's introduction of a national eligibility criteria. However, reduced resources, a substantially increased number of users, and a national eligibility criteria which increases the number of needs which require funding, paints a stark picture for the future of care for learning disabled people.

### The National Eligibility Criteria

The National Eligibility Criteria in the Care Act 2014 sets out in one place, Local Authorities' duties in relation to assessing people's needs and their eligibility for publicly funded care and support. The National Eligibility criteria outlines what Local Authorities need to consider when making an eligibility determination.

Local Authorities are now obliged to provide funding packages for those who meet the national eligibility criteria but cannot afford to do so adequately with the resources available.

Reductions in funding have led to two thirds of providers being expected to provide more support, such as transport or day services, to people, without any extra funding.<sup>30</sup> Service providers and Local Authorities have then passed a proportion of this cost down to service users: 38 per cent of service providers and nearly half of Local Authorities have increased the amount they charge service users between 2012 and 2013.<sup>31</sup>

This is further reflected in the increased prevalence of top-up payments. When service users are deemed eligible for means-tested Social Care they are only supposed to be asked to contribute their or their family's own funds when they express a preference for a form of care that is more expensive than one which would fulfil their needs – and only if their family is able to pay.

However, some Local Authorities make these payments standard practice for residential care. These authorities provide a basic rate of care to service users lower than the cost charged by any care provider in the local area, meaning families and learning disabled people have no choice but to use top-up payments.<sup>32</sup> Laing and Buisson (2013) supported these findings reporting that although Local Authorities on average contributed £500 a week to residential care costs, the average cost of residential care was between £531 and £600, forcing service users to resort to top-up payments.<sup>33</sup> These trends are very worrying – alongside evidence of severe funding

29 National Audit Office, *Adult social care in England: overview*, London: National Audit Office, 2015 [accessed via: <http://www.nao.org.uk/wp-content/uploads/2015/03/Adult-social-care-in-England-overview.pdf>] (14.01.16)]

30 Learning Disability Coalition, *Social Care in Crisis – the Need for Reform The Learning Disability Coalition Annual Survey 2012*, London: Learning Disability Coalition [accessed via: [www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf](http://www.learningdisabilitycoalition.org.uk/download/SocialCareinCrisis2012%20-%20final.pdf)] (14.01.16)]

31 Ibid

32 Demos, *The Commission on Residential Care*, London: Demos, 2014, p93 [accessed via: [www.demos.co.uk/files/Demos\\_CORC\\_report.pdf?1409673172](http://www.demos.co.uk/files/Demos_CORC_report.pdf?1409673172)] (14.01.16)]

33 LaingBuisson, *Care homes costs no longer outpacing council fees but no sign of operations recoupling the 5 per cent real terms fee cut since 2010–11*, Press Release, 19 Dec 2013 [accessed via: [www.laingbuisson.co.uk/MediaCentre/PressReleases/FairPriceforCareifthedition.aspx](http://www.laingbuisson.co.uk/MediaCentre/PressReleases/FairPriceforCareifthedition.aspx)] (14.01.16)]

pressures and demands on services seen in the previous chapter, there is no indication this situation will improve in the near future.

### Case study: Kate has learning disabilities, the following is from correspondence with Kate's sister\*

My sister, Kate, has profound and multiple learning disabilities, she is 52 and lives in a residential care home near Woking. Previously she had lived in a care home in Esher for 16 years and only moved because the home was closed. Prior to her moving the management of the care home looked after her finances. I now do this for her and I am her Appointee. I am currently in dispute with the Local Authority over the level of Accommodation Charges they wish to levy against her. They are following the Charging for Residential Accommodation Guide (CRAG) and will allow my sister to keep only £22.60 of her benefits a week. They state that Kate has no other expenses, despite her having to pay for all of her toiletries, clothes, haircuts and chiropody. She also has to supplement the pitiful allowance of four incontinence pads a day.

My correspondence with the Local Authority has been going on now for over two years, and as I am asking them to negotiate with me and find a figure that my sister can afford, I have yet to pay any of their invoices. They insist that my sister has no expenses and that they 'have no alternative other than to apply charges at the maximum amount', they have now passed my details to their legal department for collection.

\* Names and places have been changed throughout

## Care Quality Commission

During our research, we heard from providers an additional concern that the burden and nature of regulation by the Care Quality Commission (CQC) brought a further pressure for providers already concerned about the viability of the care places they offered. When combined with a reduction in funding and increasing cost pressures, some providers felt that, even though they fully understood the need for external scrutiny of their performance, the seemingly ever increasing time spent by staff on demonstrating and evidencing compliance with regulations was a further factor in their decision to consider closing provision.

For these providers, this remained the case despite the changes to the CQC's approach to regulation announced in October 2014, about which the then Care Minister, Norman Lamb, commented: 'Gone is the tick-box exercise for inspecting care homes and home care.' We are aware that this issue may not solely be a concern for providers of Residential Care for adults with Learning Disabilities and see merit in further research outside the scope of this study to look further at how widespread these concerns are.

These concerns from providers reflect the findings of the December 2015 Public Accounts Committee report on the CQC, which noted that 'the Care Quality Commission has made

substantial progress since the Committee last reported in 2012.<sup>34</sup> But it is behind where it should be, six years after it was established, in that it is not yet an effective regulator of health and Social Care.' The Committee also noted that 'there is no way for parliament or the public to know whether the Commission is performing its statutory duties to protect the health, safety and welfare of people who use health and Social Care Services.' Based on what we heard during our research, it appears that 'providers' could be added to 'parliament or the public' in that latter observation.

In addition, the CQC's recent response to views submitted by providers during the consultation on the CQC's proposals for a new scheme of regulatory fees on providers noted that all sectors, including adult Social Care providers, expressed: 'serious concern at the scale of the increases, irrespective of the options for their implementation, and corresponding concern about their impact on quality of care and sustainability of services.'<sup>35</sup>

The CQC noted in the same report that:

*'The adult Social Care sector's main reason for opposing fee increases was providers' inability to recover the full costs of their services in fees from Local Authorities or CCGs. They also cited increased costs associated with the introduction of the National Living Wage, employer pension contributions, and recruitment and retention of staff.'*

*'Many respondents commented that increasing fees would have a detrimental impact on quality and/or sustainability and that CQC's proposals did not recognise the operating environment and operating margins that providers were working within. A number commented on providers' inability to pass on increased costs to the users of their services, and that the cost recovery requirement placed on CQC by government was not matched by a similar requirement of state funding of care services.'*

*'Despite the critical nature of many of the responses to the consultation, a number of positive comments were received about CQC's value, particularly from representative organisations and community Social Care providers. Improvements to regulation were noted, and positive experiences were commented on. However, it was also clear that respondents thought CQC had not yet sufficiently demonstrated value for money, and that there were a number of areas where our efficiency and effectiveness were critically questioned, such as the timescale for reporting, consistency of judgements and aspects of our registration processes.'*

Again, these observations by the regulator itself suggest that even though the scope of such research is wider than this study, there is a clear need for close scrutiny of the impact of regulation on all adult Social Care providers, including those of residential care and supported living.

---

34 House of Commons Committee of Public Accounts, 'Care Quality Commission', Twelfth Report of Session, 2015–16 [Accessed via: <http://www.publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/501/501.pdf> 17.05.15]

35 Care Quality Commission, 'Response to Consultation: regulatory fees from April 2016 under the Health and Social Care Act 2008 (as amended)', April 2016 [Accessed via: [http://www.cqc.org.uk/sites/default/files/20160406\\_response\\_cqc\\_consultation\\_fees\\_2016-17.pdf](http://www.cqc.org.uk/sites/default/files/20160406_response_cqc_consultation_fees_2016-17.pdf) 02.03.16]

## Funding bias

The CSJ heard that reduced funding has contributed to a lower standard of care provided to adults with learning disabilities, but this has also compromised the personalisation agenda by reducing the choices available to people with learning disabilities as to how they receive their care.

This appears to be the result of an apparent commissioning bias in favour of supported living because the funding system means that placements in these settings create less pressure on Local Authority budgets.

At the moment, those in supported living can pay for their housing costs using housing benefit and receive Disability Living Allowance (DLA) or Personal Independence Payments (PIP) along with means-tested Social Care. However, those in residential care cannot receive housing benefit nor the care component of DLA or PIP (though they do receive the mobility component). Supported living is thus attractive to Local Authority commissioners because it moves people with learning disabilities from a Local Authority social services budget onto the Department of Work and Pensions' (DWP) welfare budget.

Transferring service users onto the DWP budget is not only attractive because it eases pressure on the Local Authority finances but because the DWP budget is an Annually Managed Expenditure (AME) budget which means that it is demand led, while Local Authorities have a Department Expenditure Led (DEL) budget, meaning it is a capped sum. In essence the move from DEL to AME is easier because AME budgets are inherently less constrained than DEL.

Not only does this compromise the personalisation agenda, and therefore care outcomes, it also creates artificially high care costs. This is because, while supported living is given more funding because of budgetary considerations, no thought is given as to whether this is the most cost-effective decision from a holistic perspective.



# chapter three

## Conflicts of interest

Having identified how funding pressures and system bias are affecting the commissioning of care, we turn to look at how the same funding issues are distorting both the assessment of need and the reliable advocacy necessary to help people with learning disabilities choose appropriate provision.

### Assessments

Local Authorities' assessments of need are absolutely pivotal to a proper care system for adults with learning disabilities. Without recognising the full extent of an individual's care needs, and ensuring these are properly provided for, we will see the most vulnerable put further at risk.

However, over the course of this research the CSJ has heard much anecdotal evidence that the assessment process is not working as it should. Time and time again we have heard that those with considerable care needs feel unheard by assessors, and feel their care packages have been cut without good reason.

The National Adult Social Care Intelligence Service reported the number of new adults with learning disabilities who became new service users following an assessment dropped significantly after the 2010 spending review. Although it has risen again since, this rise has not made up for the initial fall nor the increase in demand since 2010.<sup>36</sup> This is surprising since the number of people with learning disabilities is widely accepted to be on the rise.<sup>37</sup>

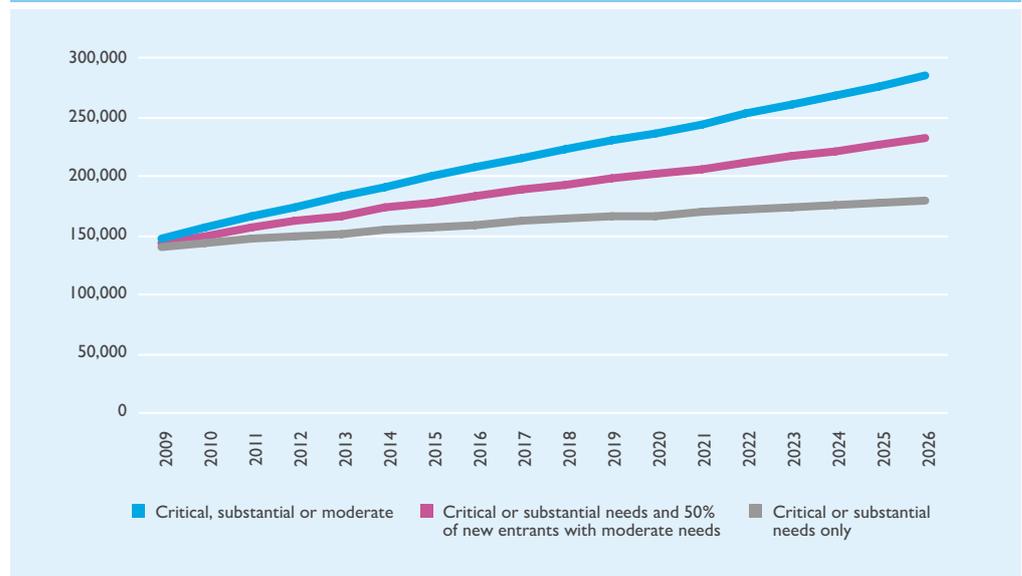
As data from a 2008 Centre for Disability Research report demonstrates, the projection for future need for Social Care Services for adults with learning disabilities shows a gradual increase over the next decade. This trend is similar across all need assessments (critical, substantial, and moderate).

---

<sup>36</sup> Health and Social Care Information Centre, Mental Health and Learning Disabilities Statistics, 2015 [Accessed via: <https://nascis.hscic.gov.uk/Tools/Olap/Rap/RapA11B.aspx> 14.01.16]

<sup>37</sup> Mencap, Housing for People with Learning Disability, London: 2012 [Accessed via: [https://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report\\_V7.pdf](https://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf) 18.02.16]

Figure 8: Predicted need (middle estimate) by level of rationing<sup>38</sup>



As the above graph demonstrates, the estimated number of eligible adult users of Social Care Services is set to gradually increase between 2009 and 2026. Projections of all scenarios suggest sustained growth in the need for Social Care Services for adults with learning disabilities over the period 2009 to 2026. These estimates would involve providing support to between an additional 47,000 (34%) adults (lower estimate) to 113,000 (82%) adults with learning disabilities over the next ten years.<sup>39</sup>

Not only are those who need an assessment often not receiving one, but when they are assessed by Local Authorities the true extent of their needs may not be always recognised. Local Authorities have a clear conflict of interest between providing proper assessments and staying within their budgets.

The potential for a conflict of interest is also seen when the findings of these assessments are taken before funding panels, on which members of Local Authorities and therefore the Local Authority's budget sits. It is here that the amount of funding assigned to fulfil each need is decided; however, the CSJ heard that those needs which are recognised are often underfunded.

38 Centre for Disability Research, Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England, Lancaster: Centre for Disability Research, 2008, p11 [accessed via: [http://eprints.lancs.ac.uk/21049/1/CeDR2008\\_Estimating\\_Future\\_Needs\\_for\\_Adult\\_Social\\_Care\\_Services\\_for\\_People\\_with\\_Learning\\_Disabilities\\_in\\_England.pdf](http://eprints.lancs.ac.uk/21049/1/CeDR2008_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf) (14.01.16)]

39 Ibid

## Case study: Personal testimony (author withheld) – unrecognised and underfunded needs

One of our clients is a perfect example of how the cuts have affected someone. She has a degenerative disability and we have known her for 30 years. She was one of our first clients when we set up 25 years ago. At that time she was able to walk and talk well. About 8 years ago she was finding walking more difficult and was using a wheelchair occasionally when out. She fell and broke both her ankles very badly and social services moved her to a larger residential home for older people about three hours away. She was 40 at the time and had no contacts in the new area. We visited regularly but she was deeply lonely and unhappy. During the years there she lost many skills, including walking confidently, and her eyesight and hearing deteriorated. We eventually got agreement for her to come 'home' if we built an extension to accommodate her greater needs, which we did.

She returned five years ago and the care manager did an assessment for a personal budget. In our opinion it was very low and did not take account of all her support needs. We were told we could question this at the six week review – which never happened. We kept asking for another assessment but none was done. Obviously reviews are supposed to be annual, she and many of our clients had none at all – as was true of most of the Local Authority clients. Mencap eventually got involved and held a conference for parents, attended by many social service staff, where they said pressure needed to be put on the Local Authority. This led to the appointment of several staff, including those described above.

We were originally delighted but quickly realised things were not going in our client's favour. The client highlighted was assessed as needing less hours, even though she is now almost totally deaf, has far less mobility, can no longer shower herself and is often incontinent. Our manager was actually in a meeting with the two care managers when she had a phone call from the day service where the client was to say she had been doubly incontinent and they wanted us to collect her. The manager handed the situation to the care managers asking them how we should deal with this situation, knowing that we wouldn't be able to because the care managers had now cut support for 'general' hours that allowed us to support clients in such situations. The care manager took our daily work sheets that show each client and said that the client had support that evening for a shower so she could wait till then. This was mid morning and the care manager was happy for the client to stay in soiled clothing for about 8 hours. The client is also assessed as being able to be left alone in the house. She can't be. She can't manoeuvre her wheelchair out in case of fire or be able to phone in an emergency.

The author has asked not to be named to protect their service, their staff and those who rely on them.

## Advocacy

We heard similar stories from adults with learning disabilities, their families and care providers about the quality of advocacy contracted by Local Authorities. Independent advocacy plays an essential part in both safeguarding the most vulnerable and in creating a gateway to greater participation in society. Moreover, as residential care homes shut down and people move to different accommodation advocacy has a vital role in ensuring that people's preferences and needs are given a voice.

The Care Act 2014 enshrines advocacy in law, establishing that if an individual does not have a family member or friend to represent them, then an 'appropriate individual' must be assigned to support them by the Local Authority. This independent advocate is assigned if the individual has 'substantial difficulty' communicating and participating in one of the following processes:

- A needs assessment;
- A carer's assessment;
- The preparation of a care and support or support plan;
- A review of a care and support or support plan;
- A child's needs assessment;
- A child's carer's assessment;
- A young carer's assessment;
- A safeguarding enquiry;
- A safeguarding adult review;
- An appeal against a Local Authority decision under Part 1 of the Care Act (subject to further consultation).<sup>40</sup>

'Substantial difficulty' is judged by trouble:

- Understanding relevant information;
- Retaining information;
- Using or weighing information;
- Communicating views, wishes and feelings.<sup>41</sup>

Advocates are sometimes employed and recruited by independent agencies, which should safeguard their independence. However, they are usually funded by Local Authorities, and are sometimes employed directly by them.

Although we have no evidence that there is a systemic problem regarding the independence of advocates, we did hear some worrying anecdotal evidence that the way advocates are funded and sometimes employed by Local Authorities can create a conflict of interest. A large component of an advocate's job is to potentially oppose the decisions and interests of the Local Authority.

### Case study: The challenge with advocacy

Our advocacy service is now funded by a grant from the Local Authority and their office is in a day service building run by the Local Authority.

Last year our Local Authority had one of the biggest cuts to funding in the country, and we were already seriously underfunded. We are one of the poorer counties. We knew that cuts would be made. The Local Authority appointed a new head of services and two new care managers were appointed just to do reassessments. When it became obvious that all assessments were being done without any input from ourselves we asked advocacy to support those clients who had no family or friends. Original emails and contacts were very positive and there was agreement that they would visit all our clients to ensure someone was supporting them. After these visits happened we received an email from them saying that our clients were the ones who had shown most confidence in speaking to them and who had clearly had support to prepare for the advocates visits. They also said that it was clear that some of our clients had higher needs than previous assessments showed.

<sup>40</sup> Social Care Institute for Excellence, *Independent advocacy under the Care Act 2014*, October 2014 [accessed via: [www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/duties/independent-advocacy-care-act.asp](http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/duties/independent-advocacy-care-act.asp) (14.01.16)]

<sup>41</sup> Ibid

The clients then had initial draft re-assessments sent to them by the Local Authority which indicated a large reduction in funding for all our clients. None of our clients could read these or fully understand them when we read them to them because they were heavy on jargon, indeed staff had to read them several times. We queried them. We had emails saying that the care managers were going to come back and collect them all a few days later and they had to be signed by clients and we were not to help them. We contacted advocacy immediately as clients had not been given time to fully understand them and they wouldn't be able to without help from someone. The reply was that the advocates had already visited and didn't need to come again.

It was at this point we started having grave concerns. I rang the Advocate who heads the service and she was very rude, accusing me of only querying the draft assessments because I was afraid I would lose money if clients lost hours. I tried to say that in our professional opinion our clients were potentially being put in danger by the assessments and that they were being pressurised into signing documents they did not understand. She put the phone down on me.

We managed to get the head of services and two care managers to meet with us, mainly because Mencap and a specialist solicitor backed us. We asked the Advocate to attend and she was on the list to be there but never attended. Our clients were eventually made to sign their assessments by being told they wouldn't have any support if they didn't. Only one dad actually stood his ground and started a judicial review proceeding, the Local Authority immediately put his son's hours up again. The whole meeting we had with social services was very threatening and there was no attempt to listen to our concerns. We believe that advocacy was threatened with loss of funding if they fought the cuts.

The author has asked not to be named to protect their service, their staff and those who rely on them.



# chapter four

## The solution

Care for adults with learning disabilities faces a real crisis caused by underfunding, hugely increased demand, an assessment and advocacy process which fails to protect those who need it most, and Health and Adult Social Care systems which do not understand or cater specifically to the needs of learning disabled people. In what follows we cannot solve all of these issues, but we do propose nine reforms and two best-practice recommendations, which would provide an inroad to solving some of the challenges which the sector faces.

### Structural recommendations

#### Terminology

As we noted above, the registration of care needs to be reformed.<sup>42</sup> At the moment care providers need to register the accommodation which they provide as either Residential Care or Supported Living. The determining difference between the two hinges on whether the tenancy agreement is separate from the care provided. If it is, then the care needs to be registered as supported living; however, if it is not, then it must be registered as residential care.

However, this contingency fails to capture any real qualitative or practical difference between supported living and residential care. It need not necessarily effect either the form of care provided, or the way in which this care is provided. As such we recommend that CQC reform its registration, abolishing the distinction between 'supported living' and 'residential care'. Instead it should introduce just one registration – *housing with care*.

*'Abolishing the regulatory distinction between residential care and supported living would create a simpler, more efficient care system which would make it easier for both Commissioners and care providers to focus on the needs and care outcomes of people with learning disabilities rather than focusing on a specific accommodation model.'*

Dr Alison Rose-Quirie, CEO of Swanton Care & Community, and the Learning Disability representative on the board of Care England

<sup>42</sup> This recommendation is in line with Demos, *The Commission on Residential Care*, London: Demos, 2014 [accessed via:[http://www.demos.co.uk/files/Demos\\_CORC\\_report.pdf?1409673172](http://www.demos.co.uk/files/Demos_CORC_report.pdf?1409673172) (14.01.16)]

**Recommendation 1: The regulatory terms ‘Supported Living’ and ‘Residential Care’ should be abolished in favour of a single regulatory term ‘housing with care’.**

## Simplifying funding streams

Under this new registration, we recommend that care providers differentiate between how much they charge for ‘housing’ and how much they charge for ‘care’ costs. This would help to create transparency for service users, who would know exactly how much they’re charged for a specific service, and it would also rectify the current discrepancy between the way that residential care and supported living is funded.

**Recommendation 2: Care providers should differentiate between how much they charge for ‘housing’ and how much they charge for ‘care’ costs in order to maximise transparency for service users and aid user choice between services.**

Alongside this we recommend that those in what would have been ‘residential care’ are able to claim housing benefit and the daily living component of Personal Independence Payments.

This would be a highly significant step, effectively abolishing the structural funding bias in the commissioning of care which we highlighted in Chapter 2. As a result, many more people with learning disabilities would find that they have a genuine choice about the kind of support they receive.

**Recommendation 3: Adults with learning disabilities in housing with care should receive housing benefit and both the care and mobility components of DLA/PIP regardless of whether their tenancy agreement is connected to the care they receive.**

It is important to create a funding structure which does not artificially incentivise one form of care. This should be a core tenant of personalisation. This requires an integrated funding structure which holds together funding from adult social services, NHS healthcare funding and DWP benefits. This will hugely help adults with learning disabilities who will not have to work across a number of different departments to get the funding they need. This will prevent them having to repeatedly tell multiple agencies the same information, and prevent delays in funding which causes stress, anxiety, and can contribute to deteriorating mental health.

## Independent assessments

Above we saw that while it is illegal for Local Authorities not to fund a recognised need, too often needs go unrecognised or simply underfunded to get around this legal requirement and budgetary considerations.

In light of the conflict of interest at the heart of assessments and funding panels, which can result in the needs being unrecognised and underfunded we propose the following:

**Recommendation 4: That an independent assessment provider and funding panel be set up, whose assessments and the funding decisions which stem from them are independent of Local Authorities.**

It is important that the voice of learning disabled people resonates throughout this new assessment process. Therefore we recommend that learning disabled people should play a key role in its practice.

*'A vital part of a just care system is that we have independent assessment panels. Furthermore I strongly recommend that adults with learning disabilities should be represented on these panels, not in a tokenistic way, but as fully valued and paid members.'*

Gary Bourlet, People First England

In our research for this report we came across Q360. Q360 runs a team of adults with learning disabilities who inspect and provide quality checks for residential care. Not only can members of the team provide a distinctive point of view to how the service might affect service users but in running the inspection they challenge the concern that carers are always in a position of responsibility above those with learning disabilities. It empowers adults with learning disabilities and puts their input at the heart of the service; as it should be. We recommend that adults with learning disabilities be at the heart of the assessment process in a similar way.

**Recommendation 5: While not compulsory, we strongly recommended that an adult with learning disabilities be involved in the assessment and funding allocation process. This involvement should be in an official and fully paid manner.**

## Local Authority budgets

In the current funding system this new assessment process will cause problems for Local Authorities because it will remove much of the control that they have over how they assign their funding, and ensure that they don't overspend their budget. This problem reveals a deep contradiction which runs through the heart of the care sector. Funding is assigned by 'need'; however, there is only so much funding which Local Authorities have. Only so many needs count. There is a national eligibility criteria; but, limited resources. If the government is serious about the national eligibility criteria established by the Care Act then it needs to change Local Authorities Social Care budget from a fixed DEL budget to a demand led AME budget.

This move to a AME budget must be done alongside the further reforms we outline in our conclusion to make sure that adults with learning disabilities receive the right kind of funding – effective care.

**Recommendation 6: The government should change Local Authorities' Social Care budgets from a fixed DEL budget to a demand led AME budget.**

## Independent advocacy

The impact caused by a flawed assessment system was exacerbated by the fact that ‘independent’ advocacy – a process which was meant to safeguard the interests of learning disabled people, is also subject to conflicts of interest, and pressure from Local Authorities.

To rectify this situation we propose that:

**Recommendation 7: That a truly independent advocacy process be established, whose funding and working is separate from Local Authorities.**

As above, it is vital that people with learning disabilities be at the heart of this reform, therefore we recommend:

**Recommendation 8: While not mandatory, we strongly recommended that adults with learning disabilities be involved in the advocacy process in an official and fully paid manner.**

Moreover, stronger measures need to be in place to protect people with learning disabilities if this system fails. At the moment the only legal avenues open to those who feel that assessments and advocacy have failed them are a complaint or a judicial review, both of which can only overturn a decision if there has been a flaw in procedure. What is difficult, but sorely needed, is the ability to look in detail at the decision and judge if it is inadequate or not – whether the person has sufficient funding for their need.

**Recommendation 9: The introduction of a Social Care tribunal, chaired by a legal professional, with medical professionals, carers, social workers, and service users present to investigate the detail of assessment and funding decisions which are suspected to be inadequate.**

# Conclusion

In this report we have identified that there is a commissioning preference which artificially favours supported living over residential care. We have explored the funding system and funding pressure which puts residential care under real threat. This in turn puts care settings, which offer a unique opportunity for community, at risk as well. This serves to limit the choices open to people with learning disabilities, and therefore limits the impact of the personalisation agenda at the heart of the care sector.

We also saw how this same funding pressure put those with learning disabilities further at risk by compromising the standards of the assessments to determine their care, and also compromised the quality and trustworthiness of the advocacy available to them.

We have offered key structural reforms which are vital if we are to have a just and efficient care system for adults with learning disabilities. They will correct a structural bias which prioritises investment in supported living above residential care, creating a streamlined funding system which makes it easier for users and Local Authorities to make informed and efficient financial decisions.

In addition to this we offered reforms to the assessment and advocacy system to ensure that the needs and preferences of learning disabled people are recognised, and the provision of a safety net is available when the system fails to provide one.

Throughout this research we found that services for adults with learning disabilities are under significant funding pressures. It is unfortunate that services have faced cuts in a time when demand has increased. The Government cannot ignore this problem. But the solution does not only lie in increased financial support.

Individuals do not simply need more care, and more hours of care, they need the right care. They need care which is going to continue to grow and develop them as valued individuals, which is going to support them to take responsibility and ultimately to give back to the community to the extent to which they are able. This means that the problems facing care for adults with learning disabilities will not simply be solved by increased budgets (though any additional funding would of course be welcomed).

Social justice is about giving people the opportunity to shape their own lives for the better and participate fully in society. Only by giving those with learning disabilities the options to choose effective support that is right for them will we achieve this in our society.

# THE CENTRE FOR SOCIAL JUSTICE



The Centre for Social Justice  
4th Floor, Victoria Charity Centre,  
11 Belgrave Road  
London  
SW1V 1RB

[www.centreforsocialjustice.org.uk](http://www.centreforsocialjustice.org.uk)  
@CSJthinktank