

A fairer future for social care

Submission to the consultation,
‘Caring for our future’

Learning Disability Coalition
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A Fairer Future for Social Care

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Introduction

A Fairer Future for Social Care is the response of the Learning Disability Coalition to the Caring For Our Future engagement exercise. The Learning Disability Coalition has taken an overarching approach to the themes of the Caring For Our Future and directed its attention towards issues of funding and what our key asks are for the forthcoming social care white paper. A Fairer Future for Social Care is being developed in a staged process by the members of the LDC and subsequent versions will be published on the LDC website www.learningdisabilitycoalition.org.uk

The Learning Disability Coalition has 15 member organisations and over 160 supporter organisations and since its formation in 2007, has argued the case for better and more sustainable funding for social care support for adults with learning disabilities.¹ There is no doubt that the ongoing crisis in social care support for people with a learning disability, described by the Learning Disability Coalition in recent years, has been further exacerbated by the current deficit reduction strategy. As the Dilnot Commission states, in spite of the increased funding of social care by the Government, the current system has failed to cope with an increase in demand for services which has led to many people having their support cut, often with serious and long-lasting consequences. As of 2009/10, there were 1.7 million people using social care services, including 128,585 working age people with learning disabilities and 13,175 older people with learning disabilities.² The number of people with learning disabilities is predicted to rise by 30% over the next twenty years, and the number of older people is also expected to rise rapidly.³ This will sharply increase the pressure on already over-stretched social care services. The social care system is in crisis and is in desperate need of reform and of more and better funding. As the recommendations of the both the Law Commission and the Dilnot Commission are now being drawn together into a white paper, and the Health and Social Care Bill and the Welfare Reform Bill are progressing through Parliament, there is a great opportunity to leave a legacy of change that will enable people with a learning disability to live the lives that they want to lead.

¹ Association for Real Change (ARC); BILD (British Institute of Learning Disabilities); The Down's Syndrome Association; Foundation for People with Learning Disabilities; the Hesley Group; Mencap; National Autistic Society; People First; Real Life Options; Sense; The National Forum for People with Learning Difficulties; National Family Carer Network; Turning Point; United Response and Voyage.

² NHS Information Centre

³ The Commission on Funding of Care and Support, *Volume II Evidence and Analysis* (2011)

Key asks:

The Learning Disability Coalition broadly agrees with the direction of policy for comprehensive changes to adult social care, incorporating

- personalised support,
 - independence
 - development of local communities
 - accessible advice and information about rights and entitlements
 - Independent advocacy support
-
- Comprehensive reform of the funding and delivery of social care support.
 - The identification of need and unmet need, supported by a duty on local authorities for robust data collection, to take account of increased demographic demand.
 - A national entitlement to care and support with an effective assessment process and national portability.
 - Consideration of the way in which health, social care and benefits funding can be amalgamated into a single funding stream. Specific funding should be made available at transition, to provide an holistic approach to the care and support of the individual. Funding should be transparent and accountable.
 - Strategies to develop a range of different models of support provision, including improving access to mainstream community services to enable people with learning disabilities to make a full contribution to society.

1. The current situation

1a. Demographics

In England there are around 1.2 million people with learning disabilities, including 900,000 adults of working age.⁴ Of the 1.7million people in England who use social care services, 128,585 are working age people with learning disabilities and 13,175 are older people with learning disabilities.⁵ The Dilnot Commission estimates that the number of people with learning disabilities will increase by 30% over the next twenty years.⁶ Whilst specific information about the break down of needs of people with learning disabilities is sparse, a study in Sheffield has shown that there will be large increase in the number of high cost packages of care in the near future as the number of people with severe or complex needs has increased by 70% over a ten year period.⁷

The demographic increase means that there would need to be a significant increase in funding for social care to even maintain a standstill level of provision. The King's Fund has estimated that in order to meet demographic demand, social care budgets need a real terms increase of 3.5% per year.⁸ They predict that under the current system, social care will need an extra £6 billion to meet demand by 2015/16.⁹

1b. Spending on social care support

The most recent figures from the Department of Communities and Local Government show that spending on social care has dropped by 1.1% in the last year – the total was £14.4 billion in 2010/11, compared to £14.6 billion in 2009/10.¹⁰ Given the King's Fund analysis that a 3.5% increase is needed to meet increasing demand, this clearly shows that not only are local authorities unable to meet new demand, but that they will have had to reduce support to people who are currently receiving social care support. Analysis of DCLG statistics by the Learning Disability Coalition shows that 40% of local authorities have decreased their spend on learning disability services and a further 4% have had no change in their spend – effectively a real terms cut.

⁴ Learning Disabilities Observatory, *People with Learning Disabilities in England in 2010* (2011)

⁵ NHS Information Centre

http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/carestats0910asrfinal/Annex_A_National_Tables.xls

⁶ The Commission on Funding of Care and Support, *Volume II Evidence and Analysis* (2011)

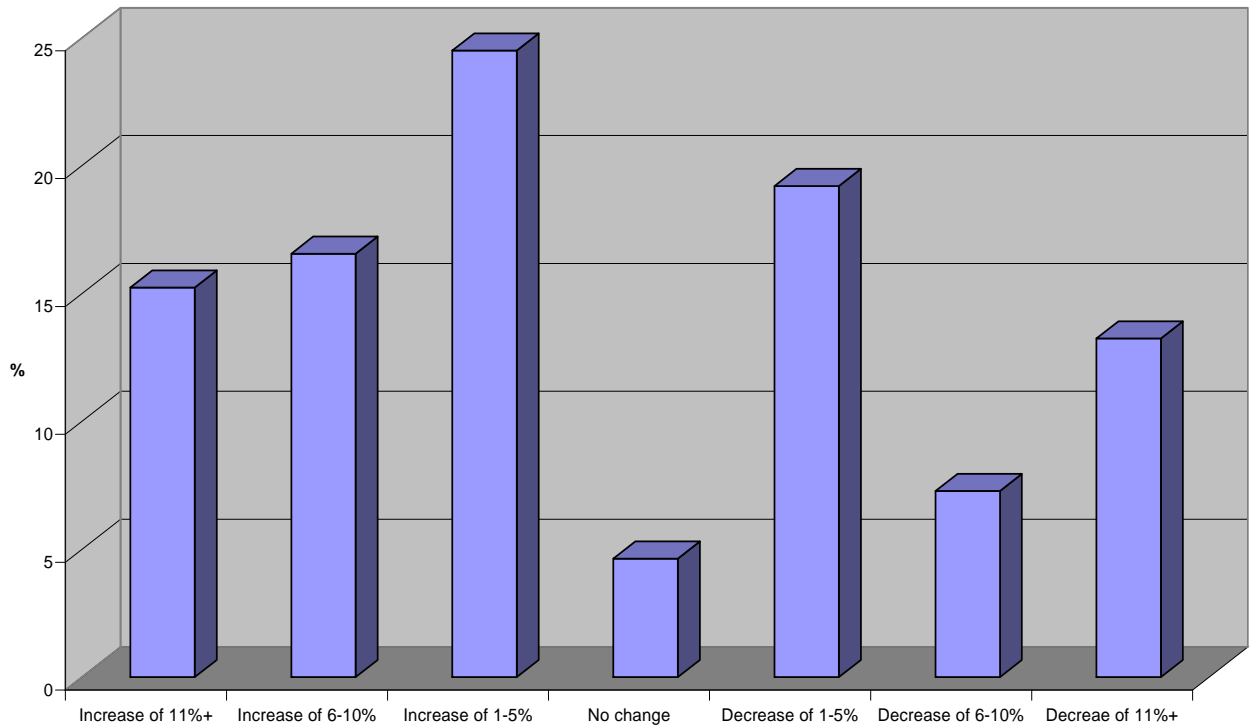
⁷ Parrott, R, *People with complex needs and profound and multiple learning disabilities in Sheffield* (2008)

⁸ Demos, *Destination Unknown* (2010)

⁹ The King's Fund, *Securing good care for more people* (2010)

¹⁰ DCLG, *Local authority revenue expenditure and financing England 2010-11* (2011)

Change in local authorities' spend on social care support for people with learning disabilities



In 2011-12, the overall grant from central Government to local Government decreased by 12.1%, this will clearly have an impact on social care budgets as they are the largest controllable area of spend for local authorities.¹¹ The Government has pledged an extra £7.2 billion funding for social care services over the course of the spending review, but as this is not ring fenced, it is unlikely that this money will reach the frontline of social care, given that over the course of the spending review, councils are facing a total budget reduction of £4.7 billion.¹² The cuts to local authority budgets will be deepest in the first two years of the Comprehensive Spending Review, with the bulk of the extra funding for social care not being delivered until the end of the spending review period.¹³ The announcement in the Autumn Statement that local authority funding will be reduced by more than previously expected will make the funding situation even tighter.

1c. Cuts to services

PricewaterhouseCoopers survey of local authorities found that 56% of social care services had contributed to the savings that local authorities have achieved to date, and 65% of local authorities thought that adult social care would contribute to savings over the next two years.¹⁴ More than three quarter of local authorities, 77%, are anticipating that increasing demand for services will be a challenge when delivering savings targets over the next few years - higher than any other challenge

¹¹ House of Commons Library Paper, *The local government finance settlement 2011-13* (2011)

¹² Audit Commission, *Tough Times: Council's Response to a Challenging Financial Climate* (2011)

¹³ Audit Commission, *Tough Times: Council's Response to a Challenging Financial Climate* (2011)

¹⁴ PricewaterhouseCoopers, *The (local) state we're in PwC survey on local government's financial challenge* (2011)

facing local authorities.¹⁵ Adult social care budgets have seen a decrease of 1.1% in the current year. Set against the demonstrable increasing demand, this is deeply concerning. Demos note that the danger of hasty cuts in services is that saving money initially will lead to a piling up of problems for the future as demand gets delayed rather than reduced.¹⁶

The Learning Disability Coalition's survey of local authorities from February 2011 showed that in response to the Emergency Budget and Comprehensive Spending Review, 20% of local authorities were already making cuts and 57% had increased charges for services or raised eligibility criteria or were considering these as options.¹⁷ For people with a learning disability, this meant that 20% had been told that their hours of care were being cut, 19% were seeing a reduction in the amount of funding that they received, whilst 33% had been contacted about a possible change to eligibility criteria and a further 27% had been contacted by their local authority about increases to service charges.¹⁸ The current situation of reduced spending and higher demand in social care is not sustainable if the Government is to maintain its promise not to cut frontline services and to ensure that disabled people are treated with dignity and respect.¹⁹

1d. The economic reality for people with a learning disability

The current economic crisis has left many people struggling. For people with a learning disability, the effects have been particularly pronounced and many are at a high risk of falling further into poverty. Many people with learning disabilities are struggling after a decrease in benefits, fewer employment opportunities, cuts to social care and the extra costs of disability, which can range from £7.24 to £1,513 per week.²⁰

In the spring of 2011, the Learning Disability Coalition carried out a survey of people with learning disabilities, their families and carers, which included questions about standards of living. We asked whether people had been unable to afford nine different items or activities over the last year and were able to compare the results to the Department of Health's 2003/04 survey of people with learning disabilities. The results were shocking, as in every category, the number of people who were unable to afford an item or activity had increased and in most cases, had nearly doubled.²¹

¹⁵ PricewaterhouseCoopers, *The (local) state we're in PwC survey on local government's financial challenge* (2011)

¹⁶ Voluntary Organisations Disability Group, *Gain without Pain: how the voluntary sector can help deliver the social care agenda for people with disabilities* (2010)

¹⁷ Learning Disability Coalition, *Social care in crisis* (2011)

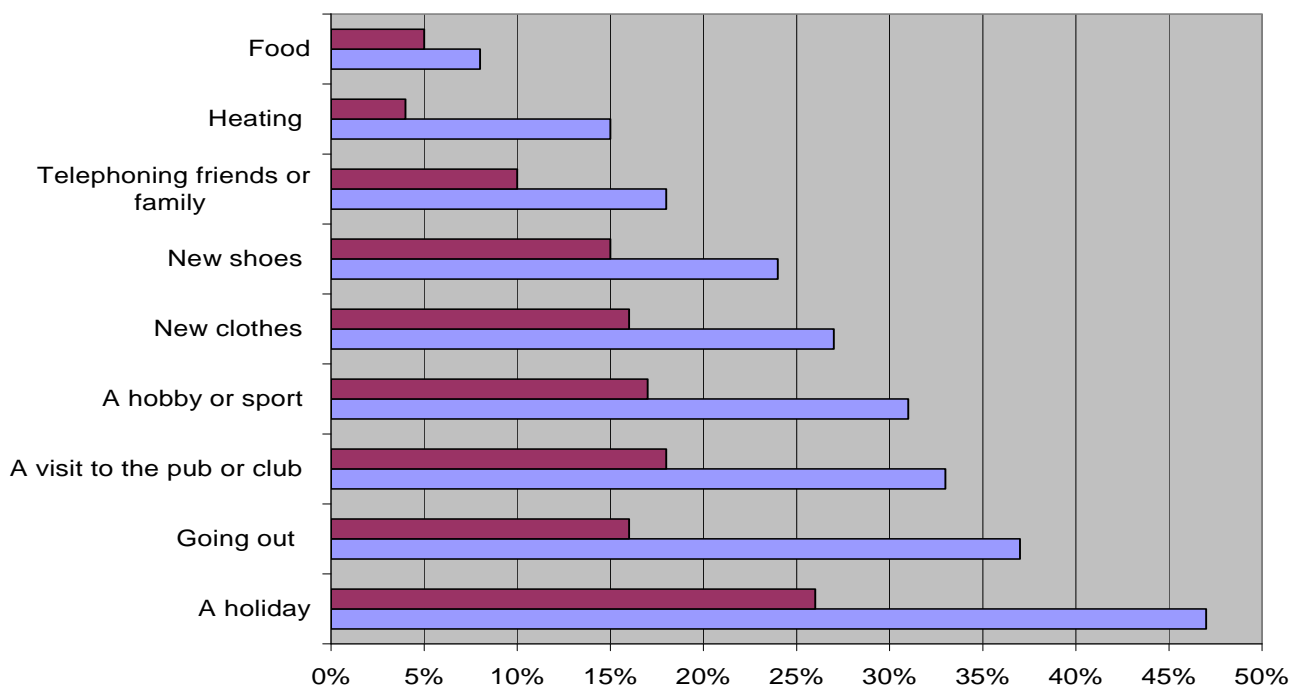
¹⁸ Learning Disability Coalition, *Social care in crisis* (2011)

¹⁹ HM Government, *The Coalition: our programme for Government* (2010)

²⁰ Demos, *Counting the cost* (2010)

²¹ Learning Disability Coalition, *Response to the ODI draft report on the UN Convention on the Rights of People with Disabilities* (2011)

It is particularly alarming that the number of people struggling to pay for basic necessities such as food has increased by 3%, and the number of people unable to pay their heating bills has increased by 11%. This number is likely to rise over the coming winter as many providers put their prices up and is of particular concern as many people with learning disabilities have health problems which are exacerbated by cold weather and lack of heating may place them further at risk.



High inflation means that the price of goods and services are rising twice as rapidly as average wages, indicating that many people's standards of living are already dropping. For many people who are dependent on benefits income, this could have serious consequences. The Government has linked benefits to the less generous Consumer Prices Index (CPI) rather than the Retail Price Index (RPI) – RPI includes mortgage costs and council tax, whereas CPI does not. However, the Chancellor's Autumn Statement has taken the positive step of increase next year's benefits by September's CPI inflation rate of 5.2% which will help people with learning disabilities to cope with the dramatic increase in living costs.

1e. Rationing care to existence levels

One of the significant ways in which the impact of the pressures on budgets has affected people is in the tightening of eligibility criteria. In 2008/09 of 148 councils assessed by the CQC, 3 (2%) had set their eligibility for services at critical, 103

(70%) at substantial, 39 (26%) moderate and 3 (2%) low.²² In 2011/12, a recent ADASS survey showed that 6 councils (4%) have set their eligibility criteria at critical, 116 (78%) at substantial, 22 (15%) at moderate and 4 (3%) at low.²³ It is inevitable that as access to services becomes increasingly restricted there will a subsequent increase in unmet need. Such a tightening of eligibility criteria suggests a new baseline for social care is evolving, where only those with the most critical needs are being supported, and that those with lower support needs are falling out of the system. This is concerning at a time when there are few jobs and benefits support is being restricted, thus limiting other sources of support. It raises questions about how unmet need can be met and what support there may be in the community for people with lower needs.

The reality of social care contrasts with the emphasis on prevention that has been a core component of the social care debate and sits uneasily with the welfare reform agenda that also proposes rationing spending to those with the highest needs. The Dilnot Commission supports an emphasis on prevention activities and early intervention recognising that this can stop an escalation of need. Whilst the Dilnot Commission found both the Government and local authorities have demonstrated strong support for prevention, this is not being worked out in practice. The Dilnot Commission hopes that public health funding could be used to support people as well as to encourage local bodies to work collaboratively in developing joint strategies and commissioning arrangements but looks unlikely to happen in the current context.²⁴

²² Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (February 2010)

²³ ADASS, *Budget Survey 2011* (2011)

²⁴ The Commission on Funding of Care and Support, *Fairer Care Funding* (2011)

2. The need for more funding and for long term reform of social care

2a. Long term funding reform

The incoming coalition Government recognised the need for reform and consequently established the Commission on the Funding of Care and Support in July 2010 to gather evidence and model different ways to fund social care. A year later, the Commission reported back with ten key recommendations, including capping the lifetime costs of care at £35,000, providing free care for those born with a care and support need and recognising that universal disability benefits should continue, but that they should be better integrated with the health and social care system.²⁵

The Learning Disability Coalition is supportive of the reforms proposed by the Dilnot Commission, particularly its emphasis on the need for better funding for social care. As the Commission states, there is clear evidence that the money allocated to social care services is not reaching frontline support services. The Commission makes the case strongly that social care is underfunded. The LDC do urge caution that the whole of the Dilnot Commission's report should be addressed as without the wider funding required for social care, any new system will be destined to fail – just as the current system is failing thousands of people.

2b. Integration of social care, health and welfare budgets

As already discussed, there is significant evidence to show that social care support is being rationed or cut across a number of local authorities. This suggests that as well as finding ways of bringing more money into the system, there needs to be a reconsideration of how social care, health and welfare budgets interact. Many people with a learning disability are reliant on support from at least one, if not all of these budgets. As eligibility criteria are tightened and as the Government begins to target welfare support at those with the highest needs, it is important that there is a holistic approach to supporting people with learning disabilities, regardless of people's level of support and care needs.

In 2009 the Care Quality Commission insisted that there was a need to “speed up joining health and social care as this represents better value for money than hospital or residential care”²⁶. The Learning Disability Coalition believes that there is scope for bringing together budgets, especially if this will enable a more holistic approach to care and support and an acknowledgement that this goes beyond just social care support. Care would need to be taken to ensure that in bringing budgets together, the focus is still on the social model of support and not the

²⁵ The Commission on Funding of Care and Support, *Fairer Care Funding* (2011)

²⁶ Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (2010)

medical model. In order for such an approach to be successful for people with a learning disability there would need to be a focus on well being within the community - GP health checks for people with a learning disability are one such example of a successful combined health and social care approach. It may be that an approach which focuses on health and prevention will reveal more unmet need, but if this prevents people from reaching costly crisis situations later in life, this seems to be a positive rather than negative consequence.

For many people with learning disabilities, benefits are an essential component for survival, but since 1997, disability benefits have risen with prices and not incomes. The Government has set out a clear commitment to reducing the welfare budget, including cutting Disability Living Allowance spending by 20% which the Government estimates that the changes will save £1.4 billion by 2015. Maria Miller, Minister for Disabled People states that these changes are necessary because, "the rising caseload and expenditure is unsustainable."²⁷ In addition to changed to universal disability benefits, the Government has announced a series of changes to Housing Benefit, the introduction of Universal Credit and is continuing with the previous Government's changes to Employment Support Allowance. The Comprehensive Spending Review set out £7 billion of cuts to the welfare budget, adding to the previous projected £11 billion savings announced in the Emergency Budget.²⁸

A total of 426,500 people with learning disabilities were in receipt of Disability Living Allowance as of February 2011 and 141,760 people with learning disabilities are dependent on social care support. There is a vital interaction between welfare and social care. Any reform needs to carefully understand this so that people with learning disabilities are not left without support.

2c. Knowing local needs and imaginative ways of funding

The lack of information that is available about local situations is a significant issue. A recent report by Demos which looked at how local authorities are coping with the cuts found that many do not collect the information that they need to accurately predict how cuts will affect disabled people in their area.²⁹ Demos found that many local authorities were relying on the 2001 census to give a picture of how many disabled people were living in their area, whilst others relied solely on the number of service users in their area, thereby excluding large numbers of people. Similarly, the Care Quality Commission reports that, "only 34% of councils systematically collect data on things such as the numbers of parents with a disabled child, the services which they use, and their needs – therefore services are not being commissioned on the basis of sound knowledge of their needs."³⁰

²⁷ DWP, *Disability Living Allowance Reform* (2010)

²⁸ HM Treasury, *Comprehensive Spending Review 2010* (2010)

²⁹ Demos, *Coping with the cuts* (2011)

³⁰ Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (2010)

For there to be a reform of the care and support system and an end to the care crisis, there needs to be a transformation in the way that funding streams are managed. In order for local authorities to be held to account for their expenditure, it is vital that funding allocated to social care through the local government is traceable and easily identifiable. This is not currently the case. If councils are to strategically plan their future social care delivery, they need sufficient data on the local care market and on the number of people who have care and support needs within their area. Without this information, councils are unlikely to be able to meet the costs of their statutory responsibilities.

There may be scope for considering an alternative mechanism of core central funding for supporting people with complex needs. The nature of the care that people with profound and multiple learning disabilities need may be costly and often requires provision from outside the local authority area. If a local authority has a high number of people with complex needs in their area, supporting them may take up a significant amount of their social care budget. Research needs to be taken urgently into higher cost packages in order to ensure quality and a fair and effective funding stream.

3. Key adult social care changes and reforms

3a. Eligibility criteria

The tightening of eligibility criteria by many local authorities means that people with a mild or moderate learning disability are unlikely to receive any social care support. There is great concern that further tightening may limit support to only assistance with personal care for those with very profound needs. The recent cases of Birmingham City Council and the Isle of Wight Council, which both attempted to severely restrict access to social care, clearly demonstrate that councils are making drastic and often ill-thought through decisions. The Learning Disability Coalition believes that the support required by people with learning disabilities over the course of their lifetime must be much more comprehensive than just basic care. The white paper needs to set out a vision that will ensure people are able to live fully in their communities throughout their lives and therefore any solutions needs to be long-term and sustainable.

The Dilnot Commission recommended that there should be national eligibility criteria for social care services, which should be set at no higher than the 'substantial' level of the current system. The Commission believe that this will increase consistency and fairness. The recommendation also stated that assessments should be portable to make it easier to move between local authorities. The Commission also recommended that the Government should develop a new and more objective eligibility and assessment framework. The Learning Disability Coalition supports a national eligibility framework, portability and any move towards a more objective eligibility and assessment framework. Whilst we are supportive of the recommendations to move to a national eligibility criteria, entitlement must be at a level that enables people to live their lives. The Dilnot recommendations must not be used to ration support to provide basic care to those with the highest needs, a situation that is already developing as many local councils tighten their eligibility criteria.

There is a significant discrepancy between the lives of people with a learning disability and the general population as a recent survey by the Learning Disability Coalition shows. During the summer of 2010 we asked people with learning disabilities how they spend their spare time³¹. The most common activities were watching television, being on the computer, listening to music or spending time with their families – all predominately within their home environment. Only 14% went to the pub and 15% spent their time in the cinema; this compares to 48% of the overall population who spend their time going to pubs/bars/clubs and 48% who go to the cinema.³² In 2011, the Learning Disability Coalition carried out a further survey of people with learning disabilities which showed many people with a learning disability are facing financial difficulties in accessing leisure activities. 31% have been unable to afford a hobby or sport in the last year, a third have been unable to

³¹ Learning Disability Coalition, *Stories from the frontline* (2010)

³² Office for National Statistics, *Social Trends 41*, http://www.statistics.gov.uk/articles/social_trends/ST41-Lifestyles.pdf (accessed 16th June)

afford a visit to a pub or club and 37% have been unable to afford to go out.³³ A further 47% were unable to afford a holiday.³⁴ If people are to be expected to continue to live year on year without the resources to access basic community and leisure opportunities this is storing up long term problems of isolation and will damage well being.

3b. Personalisation

Changing eligibility and reductions in spending by Local Authorities is preventing people accessing personalised services. We are worried that the crisis in social care is severely restricting access to personal budgets. 'Recent work by Demos has found a growing minority of local authorities are placing a 'deflator' on their personal budgets - giving a personal budget value of up to 25 per cent lower than the monetary equivalent of the care a person needs, based on their assessment'³⁵. The four key elements of person-centred health and social care reinforced by the Care Quality Commission show the breadth of approach needed to ensure that people receive a personalised service:

1. Giving people choice and control over their treatment
2. Allowing for fair and equal access to care
3. Promoting equality and respecting human rights
4. Involving people in shaping services in their local community³⁶

Despite the difficulties of amalgamating or co-ordinating different funding streams, it is vital that personal budgets are comprehensive, covering all aspects of an individual's needs i.e. housing, training and education, support to find and sustain work, positive day time activities, leisure activities as well as social care. They should include appropriate elements of health funding, including NHS continuing care funding. Initiatives such as 'Working Together for Change', which draws together people who use services and their families in commissioning and service development, could make a significant impact on realising this ambition.

Support should be provided on the basis of need, not on the basis of arbitrary cash limited entitlements. If personal budgets are set too low they will not only fail to provide the care and support necessary, but also push wage rates down and reduce the availability of specialised staff. There should be thorough and independent research (including the views of people with learning disabilities and their families) into whether and how assessments and payments for benefits, such as the Disability Living Allowance as well as direct payments for social care, might be co-ordinated. This research needs to address services from other funding streams such as further education and employment support.

³³ Learning Disability Coalition, *Response to the ODI draft report on the UN Convention on the Rights of People with Disabilities* (2011)

³⁴ Learning Disability Coalition, *Response to the ODI draft report on the UN Convention on the Rights of People with Disabilities* (2011)

³⁵ http://www.demos.co.uk/files/Tailor_made_-_web.pdf?1318945824

³⁶ Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (2010)

Direct payments should be a clear choice for people with a learning disability. However the take up has been patchy and the percentage of adult social care budgets spend on direct payments is still very low, only 4% in 2008/9³⁷. According to CQC many people with learning disabilities would like to use direct payments but only a few receive them. Those that do are most likely to receive payments of more than £2,000.³⁸ However, not everyone will want to choose this as option and care will need to be taken to avoid generalised assumptions about how care should be delivered. Decision making about options will need to be supported with good information and advocacy in order for people to make an informed choice.

In order to personalise services we need to ensure that we are looking at outcomes and how people can meet these outcomes. The Putting People First group emphasise the need for personal budgets to be 'authentic' and for there to be a process to ensure that they do actually increase choice and control.³⁹ The suggestion is to develop an outcome based performance measure within social care in order to be able to demonstrate the benefit of the support given, and if it is value for money. They point out that, "most councils have yet to build into routine practice systems that will enable them to check the results from personal budgets."⁴⁰ If the Dilnot proposal to set national eligibility levels at no higher than substantial is implemented, people with low/moderate needs may lose support and be placed potentially at risk.

The Resource Allocation System, which often strictly uses FACs criteria, rarely looks at outcomes which must be changed if people are to receive holistic support. We are observing that the 'indicative budgets' that are created following an assessment through using Resource Allocation Systems are failing to provide adequate money to meet individuals needs. This leads to situations where individuals have to fight for funding in order to access the services they have been assessed as needing.

3c. Advice and info

The Dilnot Commission recommended that "there should be a new information and advice strategy to help when a care need arises. This will mean that the public have easy-to-understand information about services and funding sources. This should be available to everyone, regardless of whether they or the state pays for their care"⁴¹. The Learning Disability Coalition is fully supportive of this recommendation. The current system is confusing and makes it difficult for people to know if they are receiving the support which they are entitled to. The difficulty of navigating around the current system is well documented; in 2010 the Care Quality

³⁷ Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (2010)

³⁸ Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (2010)

³⁹ Putting People First, *Personal Budgets: Checking the Results* (2010)

⁴⁰ Putting People First, *Personal Budgets: Checking the Results* (2010)

⁴¹ The Commission on Funding of Care and Support, *Fairer Care Funding* (2011)



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Commission stated that, “people need high quality information, to be fully informed about what’s going on and to ensure that their human rights are respected.”⁴²

People with learning disabilities may need a range of support to ensure that information is accessible. Support with communication may be necessary and policies, consultations and official forms should be available in easy read. This support should be available as standard for people with learning disabilities rather than being considered exceptional.

⁴² Care Quality Commission, *The State of Health Care and Adult Social Care in England, Key Themes and Quality of Health Services in 2009* (2010)

4. Community support

In order for people with learning disabilities to receive personalised, whole life support, it will be vital to equip local communities to assist in providing that support. The Joint Committee on Human Rights was very definite in asserting the importance of a wider community approach and the change that needs to occur; “real change for adults with learning disabilities will only happen if practical steps are taken to promote a more positive approach to the (human) rights of adults with learning disabilities on the ground, in mainstream public services.”⁴³ The Learning Disability Coalition is fully supportive of this view.

Community facilities should be designed and equipped to meet the health and social care needs of people with learning disabilities including those with profound and multiple learning disabilities (PMLD). Services specifically needed by people with PMLD due to the associated medical conditions they may have, for example hydrotherapy pools, should be designed in such a way that they can be shared with other members of the community, such as those with severe arthritis, where appropriate. Another example would be constructing more Changing Places toilets in public places.

4a. Attitudes

If people with learning disabilities are to live the lives that they want to live, local councils need to develop access to community based support, including leisure and community services. Support for community development must be increased, in order for community services to be safe and inclusive for people with care needs. This is particularly important at a time when there has been a sharp increase in negative portrayals of people with disabilities both by the Government and in the media and rising concerns at hate crime.

According to a recent survey of 1,000 people by Turning Point there remains a high level of misconception surrounding learning disability. Nearly 1/3rd of people surveyed felt that people with learning disabilities could not live independently or be employed and 23% believed that all people with learning disabilities live in care homes.⁴⁴ A further 23% believe that learning disability is a mental illness.⁴⁵ In order for people with learning disabilities to flourish in their communities, these attitudes must be changed.

A study by the University of Glasgow looked at how people with disabilities have been portrayed by the media across five newspapers in October to January 2004/05, October to January 2010/11 and March to April 2011. The results of their study showed a marked increase the politicisation of news coverage of disability

⁴³ JCHR, *A Life Like Any Other? Human Rights of Adults with Learning Disabilities* (2008)

⁴⁴ Turning Point, *Benefits Realisation: Assessing the evidence for the cost effectiveness of integrated health and social care* (2010)

⁴⁵ Turning Point, *Benefits Realisation: Assessing the evidence for the cost effectiveness of integrated health and social care* (2010)

and a significant drop in the proportion of articles which described disabled people in sympathetic terms.⁴⁶ Many stories tend to focus on the idea of disabled people as ‘benefits cheats’ – these types of stories have doubled over the period studied, and has led to misconceptions such as members of the public believing that fraud levels are up to 70%, when in reality they are very low.⁴⁷ The Department of Work and Pension’s own figures show that fraud levels for Disability Living Allowance stand at 0.5%.⁴⁸

This type of news coverage must have an impact on public opinion and can leave many people with a learning disability feeling very afraid that they will lose their benefits and support, as well as vulnerable to harassment in their communities. In order for people to be able to live their lives making a full contribution to society and for communities to be inclusive, supportive, environments for people with a learning disability there needs to be an immediate shift in the way that people with disabilities are portrayed by the media and the Government.

4b. Investing in well being; prevention

The debate about care and support has rightly emphasised the need for prevention to be built into any reformed system and this is a key aim for social care, as set out by the Government in its Vision for Adult Social Care.⁴⁹ There is a tendency however for the focus to be around what prevention means for older people and keeping people out of hospitals. With the differences in needs for prevention being so starkly different for people with learning disabilities and older people, the Learning Disability Coalition believes that the debate needs to be reframed to be about investing in people’s well being.

For people with learning disabilities, prevention can mean a range of differing approaches not only about maintaining health but also reducing isolation, increasing opportunities to work and in leisure and keeping people from entering the criminal justice system. Encouraging people with learning disabilities to be as independent as possible is also not only likely to be positive for individuals but also cost effective. Learning Disability Coalition member, Turning Point have suggested that, “services that are designed to ensure that people retain their independence and quality of life can deliver cost savings through the prevention of hospital admissions and residential places.”⁵⁰ A key part of such a preventative approach is to identify the right support for people as they become adults but as the VODG points out, “all too often people with learning disabilities fall through the system after they leave children’s services, never making it through the transition into adult services. They often reappear on the radar later on in life as adults with

⁴⁶ University of Glasgow, *Bad news for disabled people* (2011)

⁴⁷ University of Glasgow, *Bad news for disabled people* (2011)

⁴⁸ DWP, *Fraud and error in the benefits system: 2010/11 estimates* (2011)

⁴⁹ Department of Health, *A Vision for Adult Social Care* (2010)

⁵⁰ Turning Point, *Benefits Realisation: Assessing the evidence for the cost effectiveness of integrated health and social care* (2010)

more developed needs and problems.”⁵¹ Assistive technology can play a big role in promoting independence, preventing people’s needs from spiralling and can help local authorities to make savings. Learning Disability Coalition member, United Response reports that assistive technology has made a significant difference to the lives of people with severe learning disabilities at one of their services in Kent.⁵² They move away from the traditional model of using waking night support, which can disrupt people’s sleep, to a system of assistive technology which monitored people as they slept. This has helped to increase people’s independence and to reduce overall costs.

The Supporting People programme is another example of the success of prevention and early intervention for people with learning disabilities. A report by the Joseph Rowntree Foundation found that although there was still some work to be done, the introduction of Supporting People funding for housing support for people with learning disabilities enabled the development of a number of supported living facilities which allowed people to have more choice and control over their lives.⁵³ DCLG reported that for people with learning disabilities, the cost of Supporting People is £369.4 million, but this is vastly outweighed by the net financial benefit of £711.3 million.⁵⁴ Over the period of the current Spending Review, the Government has allocated £6.5 billion for Supporting People, but as this is no longer ring fenced, there is no guarantee that this will be spent as intended. A number of councils have already announced significant cuts to Supporting People funds, and the Learning Disability Coalition is concerned that this will add to the funding pressures already faced by support services for people with learning disabilities.

4c. Plurality of support: employment and housing

We have already described the need for people with learning disabilities to be able to access a broad base of support. The UK is a signatory of the UN Convention on the rights of people with disabilities, which gives the Learning Disability Coalition a strong basis to continue to call for a rights based approach for access to health, education, housing, transport, leisure, employment and a reasonable standard of living for people with learning disabilities as well as social care and support so that people the opportunity to live a life like any other.

Research shows that 65% of people with learning disabilities would like a job, although many would need time and support in order to find and keep a job.⁵⁵ In 2005, 17% of people with learning disabilities were thought to have a job and with the sharp increase in the number of people out of work due to the recession it is to

⁵¹ Voluntary Organisations Disability Group, *Gain without Pain: how the voluntary sector can help deliver the social care agenda for people with disabilities* (2010)

⁵² Community Care, ‘Assistive technology helps people with severe learning difficulties at night’ (24th June 2011)

⁵³ Joseph Rowntree Foundation, *The impact of the Supporting People programme on adults with learning disabilities* (2007)

⁵⁴ Communities and Local Government, *Research into the financial benefits of the Supporting People Programme* (2009)

⁵⁵ Department of Health, *Adults with learning difficulties in England 2003/04* (2005)

be assumed that this percentage will currently be significantly lower.⁵⁶ In 2009/10, only 0.67% of people with a learning disability known to social services were in paid employment of more than 30 hours per week, whilst 3.8% of people with a learning disability known to social services were in paid employment of less than 30 hours per week.⁵⁷

People with learning disabilities may require significant support in order to secure employment. In a Learning Disability Coalition survey carried out in 2011, to support our work around the UN Convention, we asked if people had any support in order to find a job – just under a third said yes.⁵⁸ For many people it was felt that work was not appropriate, either due to health issues or their levels of understanding or because there was a lack of appropriate employment in their area. Other people responded that they felt they were able to work, but only with support which in some cases was no longer available due to a lack of funding. Half of people who responded said that they wanted to have a job or a way of contributing to their community, but without proper support and training to find and keep a job, this will remain nothing more than an aspiration

It is increasingly difficult for people with learning disabilities to find work, especially as 38% of local authorities have reported that they are cutting or closing their employment support services for people with learning disabilities.⁵⁹ In addition to this, many people with learning disabilities are very afraid about the changes to welfare support, particularly Employment and Support Allowance and the time limiting of the Contributory Work Related Support Group. For people with a learning disability who may take considerably longer than non-disabled people to find suitable employment, this is highly inappropriate. The Harrington review of the WCA, published in November 2010, found that the assessment process was not “working as well as it should”.⁶⁰ The review identified that more work was needed in addressing the “particular difficulties in assessing mental, intellectual and cognitive impairments” and makes recommendations to ensure that people with these impairments are “assessed more accurately”.⁶¹

It is important to remember that people with learning disabilities may have their own caring responsibilities. It is estimated that there are 53,000 parents with learning disabilities in England.⁶² Many are reluctant to seek support or make themselves known to social services for fear of having their children removed – around 40% of parents in English National Survey of Adults with Learning Disabilities were not living with their children⁶³. As already stated many people with a learning disability are living with older parents and may be providing care. Families where there is

⁵⁶ Department of Health, *Adults with learning difficulties in England 2003/04* (2005)

⁵⁷ House of Commons. Parliamentary Question response, c532W (1 November 2011)

⁵⁸ Learning Disability Coalition, Response to the ODI draft report on the UN Convention on the Rights of People with Disabilities (2011)

⁵⁹ Learning Disability Coalition, *Social care in crisis* (2011)

⁶⁰ Harrington Review, *An independent review of the work capability assessment* (2010)

⁶¹ Harrington Review, *An independent review of the work capability assessment* (2010)

⁶² Working together with parents network, *Facts and figures about parents with learning disabilities in England* (2008)

⁶³ Working together with parents network, *Facts and figures about parents with learning disabilities in England* (2008)

two-way support being given may be in very precarious situations and it is vital that a multi agency approach and support is made available at an early stage.

In terms of housing, it is estimated that 38% people with a learning disability live with family or friends, 22% live in registered care homes and 16% live in supported accommodation.⁶⁴ As the numbers of people with learning disabilities increase, there is a need for more suitable housing to be built – 89% of local authorities agree that there has been an increase in the number of adults with learning disabilities needing housing support over the last three years.⁶⁵

It is essential that different forms of housing and accommodation are available for people with a learning disability in order to enable choice and control. Different forms of accommodation create different costs, PSSRU estimated that in 2009/10, group homes for people with a learning disability cost £1,394 per care package each week, full-staffed residential care homes cost £1,693 per care package, supported living schemes cost £1,577 per care package with semi-independent living centres averaging care packages at £777.⁶⁶

4d. Addressing all levels of need

According to Valuing People Now, there are around 800,000 people with learning disabilities with mild and moderate needs.⁶⁷ In 2010/11 145,525 people with a learning disability were receiving a service meaning that there are over a million people with a learning disability who are unknown to services.⁶⁸ As far back as 2006/07, the Commission for Social Care Inspection stated that there was an increasingly sharp divide between those who are and those who are not supported by the system.⁶⁹ This divide will only be increased with the tightening of eligibility criteria. The recent case of Gemma Hayter is a stark reminder of the potentially catastrophic consequences for individuals who fall out of the system.⁷⁰ The serious case review showed how her vulnerability had not been recognised due to the lack of specific 'diagnosis' or learning disability. Whilst the assumption of Warwickshire County Council is that better transition measures now in place through personalisation mean that this situation would be less likely in the future it remains to be seen the most recent developments in services for people would offer the multi agency support that would have ensured much better outcomes in this case.

There is a strong correlation between mild and moderate learning disability and poverty and social deprivation, which has significant implications for people's exposure to health and social risks.⁷¹ Although very few people with mild and moderate needs will be receiving any form of social care support, as previously

⁶⁴ Mencap, *Housing and learning disability – the facts* (2011)

⁶⁵ Mencap, *Housing and learning disability – the facts* (2011)

⁶⁶ PSSRU, *Unit costs of health and social care 2010* (2010)

⁶⁷ Department of Health, *Valuing People, a New Strategy for Learning Disability for the 21st Century* (2001)

⁶⁸ http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/caresstats1011ssa/Annex_A_National_Tables.xls

⁶⁹ CSCI, *State of Social Care in England 2006-07* (2008)

⁷⁰ Community Care, 'Serious case review of murder of woman with learning disabilities reveals support gaps' (14th November 2011)

⁷¹ Leonard Cheshire Disability, *Disability Poverty in the UK* (2008)

discussed, people with learning disabilities are often excluded from employment. The ending of Valuing People Now with its strategy for increasing employment is regrettable. Furthermore, research shows that low esteem from being unemployed and the isolation that arises from a lack of positive daytime activities can be associated with mental health issues which can lead people into crisis situations. As already discussed, it would be more cost effective for local authorities to provide low level support than allow people to reach crisis situations.

There is very little research undertaken into people with mild and moderate needs, they will often remain invisible in communities unless a crisis occurs. The Learning Disability Coalition has consistently called for further research to be undertaken, both on the grounds of human rights, to enable the UK to comply with its responsibilities under the UN Convention but also because it is likely that identifying support early, promoting well and meeting unmet being may prevent expensive crisis management being required later on.

There is also a need to invest in well being for people who require higher levels of support. Some people with PMLD will require as many as three supporters working with them 24 hours a day. They may be technology dependent, requiring oxygen, tube feeding or suctioning equipment to survive. Research is urgently needed to show how many people there are with PMLD, what their characteristics are, what good quality support would look like for them in a range of settings and what this will cost.

The Learning Disability Coalition is also calling for the recommendations of the 2007 report, *services for people with learning disabilities and challenging behaviour or mental health needs*, by Professor Jim Mansell.⁷² For people who have behaviour that challenges insufficient support may result in secure residential care becoming more likely.

4e. Advocacy

For the new system of social care support and funding to work, people with learning disabilities and their families need high quality information and advice about services as well as advocacy support. We support the Dilnot Commission's proposal for the Government to fund a new information and advice service to help when a care need arises.⁷³ This backs up the Law Commission's call for a statutory duty to be placed on local authorities to provide information, advice and assistance services in their areas.⁷⁴ This will be particularly important in light of the Government's goal of moving everyone who needs social care onto a personal budget by 2013. Without good advice and information, many people with learning disabilities will be unable to access personalised services in their area.

⁷² Department of Health, *Services for people with learning disabilities and challenging behaviour or mental health needs* (2007)

⁷³ The Commission on Funding of Care and Support, *Fairer Care Funding* (2011)

⁷⁴ The Law Commission, *Adult social care* (2011)

Conclusion

As the Government draws together the recommendations of the Law Commission and the Dilnot Commission into a white paper and progress report on the funding of social care, the Learning Disability Coalition urges them to remember the specific needs of people with learning disabilities. The Learning Disability Coalition's key ask is for a comprehensive reform of the funding and delivery of social care support, including looking at how people with lower needs can be supported and how to draw together different streams of funding such as welfare, health and social care. The increasing numbers of people with a learning disability and the existing crisis in social care mean that funding and reform need to be urgently addressed especially when set against the current financial climate.

A new social care system must be underpinned by the values of personalisation, and investment in well being for people who need social care support. We must move away from the idea of support that is based solely on value for money and look at quality of life and how support enables a person to contribute to their community. This means that local authorities need to take on a role as place shapers in their communities to ensure that a plurality of support is available, including suitable housing, employment support and accessible community facilities.

There must be an end to the current postcode lottery of care which sees people being eligible for different kinds of support in different areas of the country. The Learning Disability Coalition is supportive of the Dilnot Commission's call for portable assessments and for national eligibility criteria, providing this does not ration support to only those with the highest needs. This needs to be accompanied by a robust system of advice and information so that people are aware of what they are entitled to and what services are available in their local area.

In order for local authorities to meet the needs of people who require social care support, it is vital that there is better data available about the needs and numbers of people within a local area who may need support. Without more accurate data, local councils cannot accurately plan for future needs and demand. There must be transparency and accountability to ensure that funding allocated for care and support is being used to meet assessed needs and desired outcomes.

Finally, we call on the Government to ensure that reforms to the welfare system and social care are complementary and enable people to live the lives that they want to live, rather than seeing thousands of people falling through the safety net of both welfare and social care support.

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