



The Learning Disability Coalition

The Learning Disability Coalition represents 15 learning disability organisations who have come together to form one group with one voice¹. The Coalition believes that people with a learning disability have the right to live independent lives with the support they need. The members of the coalition campaign to make sure that there is sufficient funding to enable people with a learning disability have the same choices and chances as everyone else.

Respondent Details

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This submission has been made by Anthea Cox on behalf of the Learning Disability Coalition	

1. Introduction

The Learning Disability Coalition has welcomed the fact that the government is giving greater priority to social care. The Coalition also recognises that some people on low incomes who live in their own homes who might otherwise have had to move into residential care will now get the chance to stay at home.

The Coalition has continually put forward in the debate about social care that policy and practice must respect the human rights of people with learning disabilities, funding should reflect increased demand, individual budgets must be truly person centred and not an excuse for cost cutting and that the specific needs of certain

¹ **LDC members** are: Association for Real Change, British Institute of Learning Disabilities, Down's Syndrome Association, Foundation for People with Learning Disabilities, Mencap, National Autistic Society, The National Forum for People with Learning Difficulties, People First, Real Life Options, Sense, National Valuing Families Forum, National Family Carer Network, Turning Point, United Response and Voyage.

segments of the populations, e.g. young people in transition, should be met.² The very specific nature of the Personal Care at Home Bill could have the unintended impact of working against these principles and causing an increase in the pressures of social care budgets.

The Learning Disability Coalition are aware that the majority of beneficiaries of the Personal Care at Home Bill are not people with a learning disability and that gives cause for concern when seen in the context of overall social care needs.

2. Overview

The concerns of the Coalition are based upon our knowledge of the nearly one million people in England with a learning disability and their families.

The Coalition would want to see the following considerations taken into account in the development of an approach to personal care at home provision:

- A commitment to a human rights based approach to entitlement to services for people with learning disabilities which enables them to fulfil their potential as equal citizens.
- Recognition of the complex changing demographics of people with a learning disability and the consequent impact on demand for services.
- The specific needs of people with profound and multiple disabilities and those with sensory impairments need to be taken into account.
- Explanation of how overall social care funding needs will be met.

3. Funding

The Coalition is aware that a significant pressure on social care budgets comes from meeting the needs of people with a learning disability. The Coalition therefore urges caution, recommending that at a time of severe resource constraints, money should be targeted at the most needy.

The requirement for local authorities to find £250 million a year, from 2011, in efficiency savings to fund the proposals could mean cuts for other people with care needs, who do not have the means to fund their own care and support. The Coalition claims that it makes no sense to direct extra funding towards people who have their own significant resources. Increasing the numbers of people who will become eligible for personal care funding at the highest level of need will reduce the funding available for those with substantial levels of need. There are already widespread concerns about cuts, that care is being rationed for people with moderate needs, and this will put further pressure on social care budgets, leading to further rationing.

The Coalition also points out that there are resource implications brought by reassessment for intensive support (re-enablement) to prevent/reduce personal care costs which will impact on already reduced social work teams. People with learning

² http://www.learningdisabilitycoalition.org.uk/download/Case_for_Real_Change.pdf
And http://www.learningdisabilitycoalition.org.uk/download/Learning_Disability_Coalition_SFCT_response.pdf

disabilities who have social care needs are already waiting for long periods for assessment of their needs.

We know that a large number of people already do not get the service they need, either because they are excluded by the tightening of eligibility criteria, or by inadequacy in the current level of funding getting through.

The Coalition is concerned that the actual number of beneficiaries and related costs of the Personal Care at Home Bill will not match Government estimates, with potentially greater numbers of individuals eligible for free personal care at home. If this is the case the result could be further cuts to meet the shortfall, resulting in people not receiving the care and support they need.

We are also concerned that there is a significant underestimate in the cost providing the scheme per person as well as in numbers likely to be eligible. Our understanding of the figures is that the cost of providing free care to 280,000 people has been calculated at 670 million. 670 million divided by 280,000 and then by 365 days, comes to £6.50 per person per day. The people whom the Bill proposes to help have profound and complex needs. £6.50 would pay for approximately one hour of care every day. For people who fulfil 4 of the ADLs this will clearly be insufficient.

The Coalition would want to see the Government have a contingency plan if the number of those eligible is higher than the estimate as well as if the costs of providing the required personal care support are higher than the estimate. We are particularly anxious that people with a learning disability, who currently receive care and support, should not face cuts to their services in order to pay for the scheme.

The Coalition would want funding decisions to be compatible with the Human Rights Act and the Disability Equality Duty, and local councils should be advised that cutting services and excluding people from social care because of lack of funding could constitute a breach of their human rights, and any such decisions could be susceptible to judicial review.

4. The specific Needs of People with a Learning Disability

People with a learning disability may have very specific needs that are not encompassed in the criterion for free personal care at home.

- A learning disability is life-long and support is likely to be for life.
- Learning disability takes many different forms and a “one size fits all” approach will not reflect the wide variety of support needs of people with learning disabilities.
- Packages of care and support need to provide whole-person support, including further education, employment support, suitable housing, day, evening and weekend activities, advocacy, housing and good health care.
- The provision of good quality support at the right time will be better for the individual and their family carers and save money.
- There should be a universal set of entitlements for people with learning disabilities that include the right to the social care and support they require to have independence, choice and control that is relevant to their needs, free at the point of support and based on personal outcomes

- People with learning disabilities must have the right to an individual budget which reflects the whole of their life needs, and not just social care and support, available in a system which reduces the number of assessments and different funding streams.
- The right to sufficient financial support to make the Government's objectives of independence, choice and control a reality irrespective of where they live and with no artificial capping of the funding available.
- People with a learning disability may require highly trained staff in order to provide the specialised personal care that they require; an example would be if they have challenging behaviour or specific communication needs.
- People with sensory impairments and mobility needs may often qualify as having the care and support needs determined to be critical under the FACS guidance. The Personal Care at Home Bill will discriminate against this group as these specific needs are not described in the criteria as personal care.

5. Pressures in current funding

The Coalition believes that current funding is inadequate. Despite services for people with learning disabilities having increased from a 17% to 23% proportion of spend of local authorities' adults social care budgets³, 34 per cent of respondents to our survey Tell it like it is said that their daytime activities had been cut.⁴ John Bolton reported that the Department of Health does not know what percentage of money being spent comes from central government and what comes from within local authority resources. He also acknowledges that there is wide variation and this has an impact on services⁵. In spite of additional funding, three quarters of councils' social care budgets are under pressure. Learning disability budgets in three quarters of councils were under pressure in 2005-6⁶ and in 2006-7 were overspent by 2.7 percent⁷.

A large number of people are excluded from social care services, or "lost to the system"⁸ because of tightening eligibility criteria. Inadequate official data makes it difficult to identify how many people who are in need of support get none at all. Funding shortages mean that 73 per cent of councils now only support those with critical and substantial needs⁹.

The Coalition believes that the proposal to fund much of the Personal Care at Home Bill from efficiency savings is misguided and likely to cause severe pressure on budgets that are already overstretched. The Local Government Association¹⁰ has stated that local authorities already face a demanding 3% efficiency requirement this year, rising to 4% next year prior to the levels estimated in the Personal Care at Home Bill, "It is difficult to see how local Government could meet the cost of this proposal from existing plans for efficiency savings, without the lifting of other existing burdens".¹¹

³ DH (2009) *Use of Resources in Adult Social Care* page 42

⁴ http://www.learningdisabilitycoalition.org.uk/download/Tell_it_like_it_is.pdf

⁵ Transcript health Select Committee, 29th October.

⁶ Local Government Association (2006) *Social Services Finance 2005/06*, p.3

⁷ Local Government Association (2008) *Report on Adults Social Services Expenditure 2007-8*

⁸ CSCI (2008) *The State of Social Care in England 2006-7*

⁹ CSCI (2008) *The State of Social Care in England 2006-7*

¹⁰ Local Government Association, *Personal Care at Home Briefing*, 14 December 2009

¹¹ P3 Ibid

6. Demographic Trends

It will be important to factor into the Personal Care at Home Bill the increasing needs for services to older people with a learning disability due to demographic trends. Professor Eric Emerson estimated that there will be a growth in the number of adult social care users in a range between 2 and 5 per cent, or 19 to 38 per cent over a 6-8 year period from local studies in Manchester¹² and Stockport¹³. The Coalition supports the view that both of these studies suggest that previous figures, based on prevalence, may underestimate future growth in need. The number of older service users will increase in a range between 36 and 38 per cent, and younger service users aged 18-29 between 70 and 129 per cent. These figures reflect other research undertaken in Sheffield¹⁴. Over the last decade the number of those with severe or complex needs in Sheffield has increased by 70 per cent suggesting a large increase in the number of high cost packages of care in the near future.

7. The Needs of Carers and Older Carers

The Coalition would emphasise that the state has a responsibility to provide funding and services to meet the human rights and needs of people with a learning disability and therefore their support.

Carers make a huge contribution in time and money to help the Government to discharge this responsibility. It should not be assumed that family carers can or will provide all of a person's care and support. The Coalition would require greater recognition of the role of carers and how this role interrelates to the proposals for Personal Care at Home.

Consideration needs to be made for situations where a long term family carer becomes unable provide care any longer, or who requires care themselves. The Personal Care at Home Bill may in such a situation enable families to remain together longer, but will require an assessment process that addresses the needs of those requiring care, carers and family members. It is at these times of crisis that people with a learning disability may become reliant on services provided by the state – often for the first time in their lives. There are often no plans in place for this eventuality; so support is provided quickly and often not in a cost effective manner or in a way that provides the best outcomes for the individual.

Government estimates suggest that 29,000 people with a learning disability live in their family home supported by a parent who is aged 70 or over. In the Manchester study the numbers of people with a learning disability aged 60+ would increase by 36% between 2008 and 2014,¹⁵ whilst the number of people with a learning disability aged 50+ in Stockport would increase by 38% between 2008 and 2017.¹⁶ One council, Hertfordshire, said that in the last financial year ten unexpected cases emerged at a total cost of £1 million to their budget. In the 20 years from 2001 to 2021 there is expected to be a 19.6% increase in the number of people with learning disabilities. However, there is predicted to be an increase of 48.2% in the number of people over 60 with learning disabilities known to social services.¹⁷ Half of all

¹²Emerson, E (2007) *Estimating Future Need for Services for Adults with Learning Disabilities in Manchester* pii

¹³ Emerson, E (2008) *Estimating Future Need for Services for Adults with Learning Disabilities in Stockport* pii.

¹⁴ Parrott, R (2008) *People with complex needs and profound and multiple learning disabilities in Sheffield* p5

¹⁵ Emerson, E (2007) *Estimating Future Need for Services for Adults with Learning Disabilities in Manchester* pii

¹⁶ Emerson, E (2008) *Estimating Future Need for Services for Adults with Learning Disabilities in Stockport* pii.

¹⁷ Butcher referencing Emerson.

councils do not know how many people with a learning disability are living with older parents. Only 1 out of 4 of these councils have made housing and care plans for people living with older parents aged 70 and over.

8. Personalisation

The proposals in the Bill are likely to create perverse incentives, and go against the principle of personalisation. For example some people might prefer to choose residential care to reduce loneliness and isolation.

9. Regulations and Guidance

The Learning Disability Coalition welcomes the opportunity to provide input to the regulations and guidance which will support the implementation of the Personal Care at Home Bill.

Our overriding concern is to make sure that local authorities do not find themselves in a situation where they have to cut the care and support services of others or tighten eligibility criteria or reduce the level of care and support of an eligible individual in order to fund the scheme. The Coalition strongly believes that the regulations and guidance must protect current levels of support and would welcome a statement in the regulations and guidance from the Department of Health to support this position.

10. Conclusion

The Coalition is extremely concerned that the financial commitments of the Personal Care at Home Bill on local authority budgets could threaten existing support for people with a learning disability.

The Coalition has considerable knowledge and expertise amongst its members and supporters and looks forward to working in partnership with the Government as the proposals in the Personal Care at Home Bill are developed.

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