Social care – the continuing crisis: from the perspective of local authorities in England

The Learning Disability Coalition Local Authority Survey 2011



The Learning Disability Coalition (LDC) was formed in 2007 to prevent further cuts to funding for people with learning disabilities. We represent 14 leading learning disability organisations. The aim of the LDC is to make sure there is enough public funding for people with a learning disability to have the same life chances and choices as everyone else.¹

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 Family Carer Network, Turning Point, United Response and Voyage.



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Summary

We surveyed 152 local authorities about their funding situation and 61 responded (40%):

- 90% of councils stated that they have less funding than last year.
- 20% of local councils are making cuts, compared to 10% in the previous year.
- 64% describe the situation as difficult and are attempting to maintain services through efficiency savings.
- 57% have increased charges for services or raised eligibility criteria or have held a consultation on these options.

342 people with learning disabilities, their families and carers completed our online survey:

- 20% had been told that their hours of care would be reduced.
- 19% had been told that they would see a reduction in funding.
- 33% had been contacted by their council about an increase to eligibility criteria.
- 27% had been contacted by their local authority about an increase to service charges.



Introduction

"Efficiency savings are being driven hard but are insufficient to fully meet the gap given the reductions in resources to local authorities." Local authority

In early 2010, the Learning Disability Coalition conducted a survey of local authorities to find out the state of social care funding for people with learning disabilities. In the face of rising demand for services and fewer resources, many local authorities told us that they were very concerned for the future funding of social care for people with learning disabilities. The results showed that 10% of local authorities were already making cuts, and a further 74% were making efficiency savings in order to maintain funding for services.

Over the last year, there have been significant political and economic changes which have brought additional pressures on the financial resources available to local authorities. The Comprehensive Spending Review has resulted in local authorities facing cuts of 28% from their central Government grant over the next four years. Whilst the Government has promised to give an extra £2 billion per year to local councils to lessen the impact of the cuts on social care, this money is not ring fenced and it is not enough to mitigate the problems caused by the gaps left in local authority finances.

In light of the changing financial circumstances which local authorities are grappling with, the repeat of our 2010 survey demonstrates the impact of spending cuts on people with learning disabilities. We also surveyed people with learning disabilities, their families and carers in order to find out how their care and funding has changed over the last year.

The Government has insisted that it has provided enough funding for social care so that services do not have to be cut, and eligibility criteria do not have to be increased. However, the responses to our surveys indicate that the reality for local authorities and people with learning disabilities is starkly different.

"The forthcoming budget reductions mean that cuts are being made." Local authority



"Please do not stop my funding as I cannot cope with living my life without it." Person with a learning disability

"If my life is going to have any quality, and I'm going to be socially accepted, then social care is vital for me and my carer." Person with a learning disability

"Please do not reduce our level of support; this is our lifeline and our access to a stimulating, fulfilled life. Please do not remove this life that I have now to one where I will remain at home in isolation." Person with a learning disability

"Any further cuts to my service will put me in danger." Person with a learning disability

"How can we be all in it together if people with learning disabilities lose the support they need to be full citizens?" Parent of a person with learning disability

"I want to be like everyone else in society and do what they do, but I need some help. Without this help I will be left indoors by myself while everyone is enjoying their lives." Person with a learning disability



Methodology

The survey was sent to 152 county and unitary councils and metropolitan and London boroughs in England. Respondents were given the opportunity to make additional comments offering qualitative as well as quantative returns.

61 Local Authorities responded to the survey giving a response rate of 40%, a strong return reflecting the level of concern by the respondents.

We also asked for the views of people with learning disabilities, and their parents and carers, through a survey which was made available online and in hard copy. This asked a series of questions about if and how their care had changed over the last year and how their local authority had communicated these changes. It also gave respondents a chance to make additional comments about their situation. 342 people responded to the survey.

Both questionnaires can be found in the appendix.

The project was discussed with the Policy Network Chairs of the Research Group of the Association of Directors of Adult Social Services (ADASS).



How does the current financial situation compare with last year?

"Over the next 4 years the funding pressure will increase and we anticipate that most people will experience a reduction in funding." Local authority

We asked local authorities to describe their current funding situation for adults with a learning disability.

- 84% of authorities rated the funding situation for learning disability services as difficult.
- 20% were being forced to cut services.
- **64%** described the situation as difficult and are attempting to maintain services through efficiency savings.
- Only 7% of authorities felt that learning disability services were wellfunded.

One council assessed their situation as difficult, with cuts being made for both 2010 and 2011. Last year, the council noted that:

"Our 4 year medium term financial strategy is scored on 20-25% savings given projected shortfalls in government funding. This cannot be achieved by efficiency savings."

This year they commented that:

"Efficiency savings are being driven hard but are insufficient to fully meet the gap, given the reductions in resources to local authorities."

20% of local authorities are already making cuts to services – double the number of councils making cuts last year. A further 64% are making efficiency savings and, whilst this has decreased from 2010 by 10%, this is likely to demonstrate a trend from managing through efficiency savings to budget management through cuts.

There was a small increase in the number of local authorities who described their financial situation for services for people with a learning disability as "well-funded". 7% of local authorities described their situation in that way; up from 3% last year. A number of councils in this category made significant savings or cuts last year, which may have helped to ameliorate this year's situation. This increase must also be balanced against only 8% of local authorities describing their financial situation as adequately funded, down from 13% last year.



One council which rated its service as adequately funded one year ago now said that its funding situation was difficult ,stating:

"Issue of ordinary residence [and] increases in the number of people coming through transition with complex needs is adding additional pressures to the current situation."

Changing demographics

"The learning disability budget is currently over-spent due to the increased number of people requiring support...savings will have to be made as budget will be reduced." Local authority

A significant number of councils raised concerns over demographics and rising cost pressures. Many indicated that, whilst they are striving to cope this year, demographic pressures mean that cuts in services are inevitable. If local authorities are expected to adequately meet rising demand for services, more funding is clearly needed.

"No likelihood of budget growth to meet increased demands, whereas in previous years, budget growth has occurred." Local authority

A council which responded that it had to make cuts over both years stated in 2010 that:

"The complex needs of users are increasing, as is the cost of specialist placements. Alternatives to specialist placements in line with personalisation are very expensive due to the support required."

By 2011, the situation had clearly worsened as they responded:

"Traditional services are to close...it is not known if additional funding for individual budgets is to be available from service closures...traditional services not being available will put additional pressure upon carers' families. Without sufficient funding being available it is very likely that some families will not be able to continue to support individuals."



When asked how their financial situation compared to last year 90% of local authorities said that their funding had been reduced, and that they were either managing through efficiency savings or were having to make cuts. Only 10% of local authorities who responded noted that they were either better funded or that they had experienced no change in funding since last year.

"The county council is making significant savings across nearly all of its services (25% on average). Adult social care is making savings in line with this overall percentage." Local authority

Loss of local authority care is very worrying for people with learning disabilities, their families and carers. Of the people we surveyed, 63% were reliant on their local authority for the funding of their care and support, and a further 21% received a combination of welfare support, Disability Living Allowance and money from the Independent Living Fund in order to pay for their care. Closure of the Independent Living Fund, changes to the Disability Living Allowance and overhauling of the benefits system, combined with reduced local authority funding, has left many people very afraid for the future of their support.

"Please don't take away my carers because I don't want to go back to living like I used to have to. This would be unbearable." Person with a learning disability

"Awaiting an annual review – everyone is expecting a further cut in hours of support. This is extremely worrying." Parent of a person with a learning disability



Impact of the Emergency Budget and Comprehensive Spending Review

"My sister, who has severe learning disabilities, has had ALL her care removed, with funding cuts being cited as the reason. It is not possible for the family to replace this care, as well as the support the family were already providing. We are also not trained to give the specialist services needed. My sister is now suffering from serious neglect certainly due to funding cuts." Family member of a person with a learning disability

The new Government has introduced a significant number of policy changes and proposals. Changes to welfare and benefits announced in June's Emergency Budget and October's Comprehensive Spending Review will bring additional pressures on the financial resources available to people with learning disabilities. These changes include the proposed removal of the mobility component of Disability Living Allowance from people living in residential care from March 2013, a programme of reassessment for Disability Living Allowance claimants from 2013-14 and changes to the rules for some recipients of Employment Support Allowance. The recent Welfare Reform Bill outlined the Coalition Government's plans in more detail, including the plans to replace Disability Living Allowance with a Personal Independence Payment which would realise a 20% reduction in expenditure on working age claimants.² In addition to this, the Independent Living Fund is no longer accepting new applicants, and will close in 2015. It is unclear how people who currently receive money from the Independent Living Fund will continue to be funded.

The Government has promised to provide an extra £2 billion per year to lessen the overall impact of the cuts. Whilst this is welcome funding it will not adequately fill in the gaps left in local authority funding caused by the cut of over 28% in grant funding from central Government over the next four years. There is a very real possibility that as this money is not ring fenced, it could be lost to other budgets.

When asked how the changes implemented by the Emergency Budget and Comprehensive Spending Review are affecting services for people with learning disabilities, 20% of local authorities responded that services are already being cut.

"The forthcoming budget reductions mean that cuts are being made." Local authority

"I have had two reviews [in the last year] which is unprecedented. The last one cut [my] hours [of care]." Person with a learning disability

² June's Emergency Budget http://www.hm-treasury.gov.uk/d/junebudget_complete.pdf
Comprehensive Spending Review http://cdn.hm-treasury.gov.uk/sr2010 completereport.pdf
The Welfare Reform Bill http://www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/welfare-reform-bill-2011/



Of the other authorities who responded, 36% had either raised service charges or had held a consultation on this. A further 21% said that they had either raised their eligibility criteria or had held a consultation on this option, as a response to the changes in the Emergency Budget and CSR.

Many local authorities who responded to our survey saw the reprovision of services as a route to making further savings. 34% said that in response to the Emergency Budget and Comprehensive Spending Review, they were making further investment in modernising services.

"We are managing the situation with a mixture of approaches. One of these is to take an 'invest to save' approach to some services."

Whilst moving towards personalisation through the modernisation of services is welcome, the main driver behind personalisation and modernisation of services should be service improvement, and not cost reduction. It is also problematic that there is very little, if any, money available for 'pump priming' of new services which will lessen the progress towards modernisation which local authorities are keen to make. In some cases, local authorities are closing traditional services in order to find money for modernising of services. Whilst this may be beneficial in the long run, in the short term it will end up putting further pressure on families who are already over stretched.

We asked people with learning disabilities, their parents and carers if they had been contacted about any changes to their care or funding. A high proportion had already been contacted by their local authority about a number of proposed changes to their care. 27% had been contacted about an increase to the amount that their local authority charged for services, 33% had been contacted about a possible tightening of eligibility criteria.

A further 19% said that they had been told they would see a reduction to the amount of funding they receive and 20% had been told that they would have their number of hours of care reduced.

"They are proposing 50% cuts to the care budget, total removal of 1-to-1 support, and a threatened move, against our daughter's will, to a cheaper provider." Parent of a person with a learning disability

"50% cuts to budget and forced to move to different county and care home." Parent of a person with a learning disability



The effect on services and the need for further investment

There is a sharp discrepancy in what local authorities would like to be able to provide for people with learning disabilities and what they are able to offer within their budget constraints. Many local authorities would like to meet the aims and aspirations of the people that they support, but without extra funding, this will not be possible.

Mild to moderate needs

A high proportion of local authorities are concentrating their resources only on people with the highest level of need, which means that many people with mild to moderate needs are no longer able to access services. For people with less severe learning disabilities this can have devastating effects, leaving some people vulnerable to abuse and other crisis situations eventually resulting in the need for costly long term support.

When asked which services were most likely to be affected by cuts, 39% felt that services for people with mild to moderate needs were likely to be affected.

"No work [is] now done with people with mild / moderate needs." Local authority

"My local authority does not provide any respite care for me. My mother receives only her pension and nothing for the hours that she cares for me...who cares for the carers? Without my mum I would be in residential care." Person with a learning disability

Employment services

The reduction of local authority care also increases people's dependence on the welfare state at a time when it is being overhauled and employment services are being reduced. 38% of local authorities said that employment support services would receive less funding or are likely to close altogether.

This is concerning as only 6.1% of people with learning disabilities are in paid employment – most of which is part time.³ Whilst many people with learning disabilities want to work, most would be unable to without some level of support to find and sustain employment.

"Ceasing employment services altogether and signposting people to mainstream existing services - a few will receive some short term Community Access support." Local authority

³ Learning Disabilities Observatory, People with Learning Disabilities in England 2010, (January 2011)



There was a clear recognition amongst local authorities of the importance of providing good employment services, as 54% responded that if they had more money, the would invest it here. Several authorities noted that many people with learning disabilities were very keen to get into work, which increased the urgency for high quality employment services.

"Promoting employment opportunities for people who can access work is a route out of dependence on social care." Local authority

Day services

Day time activities other than employment were another area of concern, as 48% of local authorities said that they were likely to be cut.

Families are very concerned about the implications of cuts to daytime activities, especially if their relative has less severe learning disabilities, as many will no longer be eligible for any form of local authority support. This will result in many people having to stay at home, and being further dependent on family care and support.

"We are also moving away from large day centres to mainstream venues to support people in the day such as leisure centres." Local authority

"Major renew of day opportunities will result in services thresholds at highest need only." Local authority

A significant number of people with a learning disability, their parents and carers who responded to our survey said that their local day centre had either closed, or was under threat of closure. Others said that their transport to the local day centre had been cancelled, which meant that they were no longer able to access it.

"Our local authority is closing down one of only two day centres in [our city], hitting the most vulnerable in society and putting more pressure on carers." Carer of a person with a learning disability

Residential care and supported living

Not only are cuts to services affecting people with more mild to moderate needs, but people with more severe disabilities are suffering the effects too. 36% of local authorities replied that residential care services were likely to be affected, and 44% thought that supported living services would be cut.

"Traditional services not being available will put additional pressure upon carers and families." Local authority



Cuts to residential care services are particularly concerning as many parents and carers who responded to our survey felt that as social care provision and support from the local authority are reduced, the likelihood of their children needing high cost residential care in the immediate future was vastly increased.

"Many carers will be left unable to cope with the additional demands as their role intensifies, which will lead to an even higher demand for services and high cost residential placements which the government will not be able to fund! Social care funding keeps families together and helps safeguard the vulnerable amongst many other things." Parent of a person with a learning disability

By contrast, 64% of local authorities said that they would make further investment in supported living services, if they had the money available.

"There is still an over reliance on residential care. We need to continue to invest in supported living and other models that increase people's independence. The 'hotel nature' of the residential model rarely encourages independence." Local authority

Profound and multiple learning disabilities, and challenging behaviour

Due to reduced funding, most councils are now having to focus their remaining resources on support for people with higher needs, but there was a general consensus that more money is still needed for this group of people. 41% of local authorities would improve services for people with profound and multiple learning disabilities. The demographic pressure of the increasing number of people with profound and multiple learning disabilities is clearly putting strain on local authorities, who recognise that there is still more to be done in this area.

"In many cases there is also a lack of skilled providers and community provision for people with complex or challenging needs with the risk that people will continue to 'choose' residential care to meet their complex needs because there is no other realistic option." Local authority

"People with more profound needs...have only recently been supported to make connections with their local communities.... – this could quickly cease if there was need for any staff reductions." Local authority



A further 34% of local authorities would improve support for people with challenging behaviour, as many councils recognise that with proper support, challenging behaviour can be better managed.

"Behaviours that challenge: we need to ensure that we are offering the right support to people whose behaviours challenge us - ensuring that people are in the right place with the people and support they want can very often lead to reductions in the costs of support packages, i.e. if people don't have to live with people they don't like they are less likely to hit out at them." Local authority

Advocacy support

A further 20% of local authorities would provide more funding for advocacy services, as they believe that this will help people with learning disabilities to have their voices heard and to get the services that they need.

"The drive to shaping services for the future has to be through service users and the spending power of their personal budgets. Advocacy is essential to supporting people to develop the confidence to take on this role at an individual and strategic level." Local authority



Conclusion

The results of our two surveys indicate that both people with a learning disability and local authorities are describing a worsening situation in the funding of social care support over the last year.

In 2011 twice as many councils are making cuts to services, the effects of which are already being felt by people with learning disabilities and their families. People with learning disabilities and their families are very afraid for their futures.

At a time when the numbers of people needing support are increasing, the benefits system is being overhauled and more people are being pushed into searching for work without appropriate support this is deeply worrying.

Local authorities must continue to prioritise social care and spend the money allocated on such support. However, this alone will not solve the social care crisis. As recognised by the work of the Dilnot Commission on the Future of Care and Support there is a clear need for significantly higher levels of funding in the system from central Government.

The Learning Disability Coalition believes that people with learning disabilities have the right to live independent lives, with the support that they need. We will continue to campaign to ensure that the Government provides enough public funding so that people with learning disabilities have the same choices and chances as everybody else.

"Services for disabled people are not extras or luxuries, but just help towards enabling [them] to achieve some kind of equality with the activities and lives of the rest of us." Carer of a person with a learning disability

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The Welfare Reform Bill http://www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/welfare-reform-bill-2011/



Appendix 1

Learning Disability Coalition survey of funding of learning disability services in local authorities.

Question 1: How would you describe the situation in relation to Government funding for learning disability support in your local authority?

Well-funded	
Adequately funded	
Situation difficult but maintaining services through efficiency savings	
Situation difficult and services being cut	
Comments (optional)	

Question 2: If the situation is difficult, which services/aspects of learning disability support are most affected? (please tick all which apply)

Residential care	
Supported living	
Day time activities (other than employment)	
Employment support	
Support for people with mild to moderate needs	
Support for people with profound and multiple learning disabilities	
Support for people with challenging behaviour	
Advocacy	
Other (please specify)	



Comments (optional)	
Comments (optional)	
Question 3: How does your local authority's current financial situations compare to this time last year?	ation
Better funded	
No change	
Reduced funding, but managing through efficiency savings	
Reduced funding and cuts are being made	
Other (please specify)	
Comments (optional):	



Question 4: If more resources were available, where would you like to see the money spent? (please tick a maximum of 3)

Residential care	
Supported living	
Improved support for people with profound and multiple needs	
Improved support for people with mild to moderate needs	
Improved support for people with challenging behaviour	
Day time activities (other than employment)	
Employment support	
Advocacy	
Other (please specify)	
Diago evaloin why:	
Please explain why:	

Question 5: How have the changes implemented by the Emergency Budget and Comprehensive Spending Review affected funding for learning disability services in your area?

No change	
Eligibility criteria have been raised or there has been a consultation	
on this option	



Service charges have been increased or there has been a consultation on this option	
Services are being reduced	
Efficiency savings are being made	
Further investment has been made in modernising services	
Other (please specify)	
Comments (optional):	
Question 6: What type of local authority are you?	
Metropolitan district	
London borough	
Other unitary authority	
County council	
Question 7:	
Approximately how many people with a learning disability do you fund?	



Appendix 2

The Learning Disability Coalition survey of people with a learning disability, their parents and carers.

About you

- 1. Who is completing the survey?
- I have a learning disability and I am completing the survey by myself
- I have a learning disability and I am completing the survey with support
- I am the parent or carer of someone with a learning disability, and I am filling out the survey on their behalf
- 2. How old are you? (or the person for whom you are filling out the survey)
 - 18 24 years old
- 25 34 years old
- 35 44 years old
- 45 54 years old
- 55 64 years old
- 65 years old or older
- 3. Do you (or the person for whom you are filling out the survey) live in:
 - a family home
- a residential care home
- supported living
- your own home
- other (please explain)
- 4. Do you (or the person for whom you are filling out the survey) work?
 - a full time paid job
- a part time paid job
- a full time voluntary job
- a part time voluntary job
- I do not have a job
- I do not have a job, but I would like a job

About your care

- 5. On average, how many hours per week of support do you (or the person for whom you are filling out the survey) receive?
- 0 9 hours
- 10 19 hours
- 20 29 hours
- 30 39 hours
- 40 49 hours



50 hours or more

- 6. Who provides the majority of your (or the person for whom you are filling out the survey) care?
- family member or friends
 local authority services
 a private provider
 other (please explain)
- 7. How is the majority of your (or the person for whom you are filling out the survey) care funded?
- I or my family pays (self-funded)
- My local authority pays or gives me a direct payment or individual budget
- Other (please explain)
- 8. Over the last few months has your local authority been in contact with you about any of the following?
- an increase to the amount that they charge for services
- an increase in eligibility criteria
- a reduction in the amount of funding that you receive
- a reduction in the number of hours of care that you receive
- other (please explain)

