

Social Care in Crisis – the Need for Reform

The Learning Disability Coalition Annual Survey 2012

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Anthea Sully
Rachel Bowen



The Learning Disability Coalition (LDC) was formed in 2007 to prevent further cuts to funding for people with learning disabilities. We represent 15 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 else¹.

www.learningdisabilitycoalition.org.uk

¹ LDC members are: Association for Real Change, British Institute of Learning Disabilities, Down's Syndrome Association, Foundation for People with Learning Disabilities, The Hesley Group, 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.

The LDC is a member of the Care and Support Alliance
<http://careandsupportalliance.wordpress.com/>

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Summary

In January and February 2012 the Learning Disability Coalition carried out surveys of local authorities, people with learning disabilities and service providers. The consequences of the budget restraints that local authorities are facing were clearly demonstrated in the survey responses which showed the impact on the quality and availability of services for people with a learning disability. Despite the best intentions of local authorities and providers to manage the situation by making efficiency savings, the consistent message is of a struggle to maintain services and people receiving insufficient support, making it a challenge for people with a learning disability to live the lives they want to lead.

Respondents

- 46% of social care providing local authorities, supporting 69,000 people with learning disabilities.
- 312 people with learning disabilities, their families and carers.
- 61 service providing organisations from a wide geographic area.

Local authorities

- 77% of local authorities are facing difficulties in funding services for people with learning disabilities and are either making cuts to services or efficiency savings.
- Over the last year 13% of local authorities surveyed had tightened their eligibility criteria, with a further 7% considering it as an action for the next financial year.
- Nearly half of local authorities had increased their service charges and 13% said that they had to cut services over the last year.

People with learning disabilities

- Over the last year, 17% of people with learning disabilities have seen a reduction in their number of hours of support and 13% have been given less money to spend on their support.
- 18% have had their service charges increased.
- 2% of people who responded had lost their support entirely due to their local authority changing its eligibility criteria.

Service providing organisations

- 90% of service providers described the funding situation for support for people with learning disabilities as difficult, with 72% saying that funding for their services from local authorities had been cut over the last year.
- Over half said that services for people with learning disabilities in the local authorities that they work had been cut over the last year.
- Two thirds are now being expected to provide additional support to people within an existing contract, but without any extra funding.

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Detailed Report

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The financial outlook

In the 2010 Comprehensive Spending Review, the Government allocated £7.2 billion for social care services over the period of the review. This was in recognition of the increasing demand for social care services. It was also an acknowledgement of the very difficult financial position local authorities were put in as they were expected to make cuts of around 28% across their services, over the five years of the review. This cushion of money for social care was expected to prevent any significant cuts to social care. However, the lack of ringfencing for this funding and the fact that social care has been underfunded and in crisis for many years has meant that this extra funding has done little more than prevent the system from entirely collapsing.

The survey results of service providing organisations and people with learning disabilities show that social care is underfunded and in crisis. People are experiencing cuts to services and are being left isolated and without support – often resulting in costs being transferred to the health system or judicial system as people reach a crisis situation. Local authorities are trying to ensure that an increasing number of people are getting the support they need through a system which is not working for anyone. The message is clear – the system is in crisis and we can't afford not to reform it.

Local authorities

When asked how they would describe the situation in relation to Government funding for learning disability services in their area, only 4% of local authorities said that they were well funded whilst 77% said that the situation was difficult with either efficiency savings or cuts to support being made.

“2012/13 will be difficult to maintain services as the number of people with a learning disability increases. 2013/14 will again be challenging with expected cuts to frontline services.” local authority

When asked which areas of support were most affected, 4 out of 10 councils said support for people with mild to moderate needs, 43% said daytime activities and 39%, supported living services. A further 29% said that residential care services were being affected and over a quarter of local authorities said that employment services were facing financial difficulties.

“We are seeking efficiencies throughout all aspects of support. This includes contracts, commissioning and service provision. The council has to save 28% of its budget and this will impact all care groups.” local authority

“Increase [in] demand due to demographics but funding and resources not keeping pace with demand.”
local authority

We asked local authorities how social care support for people with learning disabilities in their area had changed over the last year. Only 4% said that there had been no change at all. 3% said that their service charges had decreased whilst 44% said that they were making further investment in services – mostly to meet the demographic demand of providing support to people with more complex needs and the high number of people coming through from children's services who need support.

More than 1 in 10 councils said that they had tightened their eligibility criteria and 13% said that they were reducing the services available. Nearly half had increased their service charges. One local authority commented that all areas of service provision would be “affected as we try to rationalise all levels of services within the resources available.”

“Transport for clients no longer provided. Charges for services increased. Day services [are] being reviewed with a view to closing some of these and replacing with community options e.g. groups based in leisure centres. Not obvious cuts but involves significant change for many individuals.”

local authority

The message from local authorities is clear – they are facing significant difficulties in funding services for people with learning disabilities and are trying to find new ways of working to order to continue to provide some support for people. A number of local authorities noted that they are undergoing a policy of modernising services, increasing the use of personalised budgets and closing traditional services. Whilst this appears to be very much in line with the aims and aspirations set out in Valuing People Now, the speed at which these changes are being made and the surrounding financial circumstances raise questions about whether these decisions are always producing the best outcomes for people with learning disabilities.²

“Over the past year we have moved from making efficiency savings to some actual cuts - stopping client transport is the most obvious. At this stage cuts are mostly small in relation to the whole service, but it does feel like a significant change.” local authority

Providers

The decisions that local authorities have made in relation to funding is severely impacting on the support service providing organisations are delivering and the people they support. Over half of service providers told us that the funding situation for people with learning disabilities in the local authorities that they work in is difficult, with services being cut. A further 36% said that the situation was difficult but that it was being controlled through efficiency savings. Consequently, many provider organisations felt that the people they support were not getting the hours they needed which increased pressures on family carers. The reduction in hours of support is leading to people becoming more vulnerable and often results in transferring costs to other services, particularly health and the judicial system.

When asked which aspects of learning disability services are being most affected by the difficult funding situation, service providing organisations overwhelmingly identified daytime activities, support for people with mild to moderate needs and most concerningly, support for people with profound and multiple learning disabilities. It was clear that service providing organisations felt that some of the changes identified by local authorities as ‘efficiency savings’ were in fact cuts.

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Others stated that they felt all service areas were being impacted by the current financial climate and that this was storing up problems for the future in terms of family breakdown.

One service provider noted that “arbitrary decisions [are] being made about funding transport and activity costs.”

Another said that “our community support service has seen drastic cuts to people's hours and many [are] losing them altogether.”

The effects of local authority budget tightening are also being felt by the service providers themselves. When asked about how the funding for their services has changed over the last year year, Whilst 72% stated that services had been cut only 2% of providers said that they were better funded. A further 28% had experienced a freeze in funding from local authorities.

“25% cut via the CSR over 2 years in the context of high levels of growth in demand.”
provider

One organisation stated that “‘no change’ is what the local authority would claim - though, when taking inflation into account, this in practice amounts to a cut.”

Not all changes to services have been as clear cut as a reduction in funding. Two thirds of providers said that the local authorities they work with expect them to provide additional support from within existing contracts without any additional funding. A common example of this is for local authorities to cease funding day time activities for people living in residential care, leaving the residential care provider with the responsibility of delivering activities during the day, without any extra funding. 38% of providers have had to increase the amount that they charge clients for services in order to make up the shortfall in funding from local authorities.

“As a voluntary sector provider of community-based day activities we are finding that funding is no longer available for individuals who live in registered care homes (or, in some cases, supported living) as their 'care package' is deemed to be 24 hour and therefore day activities are argued to be the responsibility of care home providers. The care home providers can't or won't pay for external day activities, so we either allow people to access our services for free or have to live with the knowledge that people are sitting indoors all day doing nothing.” provider

In spite of the emphasis on personalisation of services and the Government's interest in the use of telecare products, whereby new technology can enable people to live more independently, only 14% of service provider organisations said that they had been given extra funding to support innovation or development.

People with learning disabilities and their families

“They discharged my daughter as not under their criteria.” parent

The financial situation for both local authorities and service providing organisations is very difficult, but the most important factor is how this then impacts on the lives of people with learning disabilities and their families. The picture that emerges from our survey of people with learning disabilities and their families is one of significant change to people’s lives. When asked whether their support had changed over the last year only 7% of people said that they had seen positive changes such as having more hours of support, having more money to spend on buying their support or being charged less for services. However, a staggering 50% of people had experienced negative changes to their support:

- 17% had fewer hours of support
- More than 1 in 10 people had less money to spend on buying their support
- 1 in 5 people were being charged more for their services
- 2% said that their local authority had changed their eligibility criteria and they were no longer eligible for any services

“My local authority has changed their eligibility criteria and this has reduced my support hours.” person with a learning disability

“I don’t get the level of support noted in my Community Care Assessment. My local authority are stopping my access to local day services and my residential care provider will have to offer these- with no extra money.” person with a learning disability

One of the most common comments was that rather than having their services directly cut, local authorities were no longer providing transport to and from services. One person noted that they never used to have to pay for transport and it is now taking “a lot out of my personal allowance.” Another said that she used to be able to walk to her local day centre, but as this has now closed, she has to pay for a very expensive taxi each day to go to another centre. At a time when many people are struggling to pay for basic items, having to find the extra money to pay for transport costs puts them in a very difficult financial situation.

A high number of people said that they were doing less during the week either because they could no longer afford their day time activities, or their day centre was open fewer hours or was closing altogether. Consequently some people are now stuck at home for most of the week and with no day time activities are becoming isolated losing friendships and networks of support.

“There have been cuts to my services. One of the day care centres has closed, the employment service for people with disabilities has shut down and other centres are under threat.” person with a learning disability

“No change only because my mother has appointed a solicitor on my behalf as the local authority wanted to cut my package from 42 hours to 6 hours a week.” person with a learning disability

Others said that the only reason that their support had not changed over the last year was because their families had been fighting to maintain it at its current level. One parent said that “my son’s day centre attendance was reduced from 5 days to 3 days a week but continual fighting has seen it put back to what he has always had.” Several people were concerned that the changes to their support had been implemented very suddenly and that “consultations appear to be a tick box exercise only.”

Personalisation agenda

“Personal budgets are being implemented but there have been some issues with people wanting to maintain their existing services or create something that pushes the cost over their resource allocation. More creative thinking is required to help people find ways to fulfil their support plan with their allocation. More work is also needed to stimulate the market to provide a wider range of options for people to buy with their personal budget.” local authority

One of the Government’s key commitments in the 2010 Coalition Agreement was the “greater roll out of personal budgets to give people and their carers more control and purchasing power.”³ Prior to this, Valuing People Now strongly advocated for more personalised services, commissioned by people with learning disabilities which would allow more choice and independence.⁴ This was in recognition that up to this point, many people with learning disabilities had not been allowed a say in where they lived or what they did.

“[There is a] shift from institutional, residential respite to more flexible community based 'short breaks'. Shift from out dated day services to more inclusive activities and employment opportunities, using personal budgets.” local authority

Although the Valuing People Now programme has now officially finished, many local authorities have continued to work towards the aspirations set out in it. When asked which services they would like to invest in if more money was available, 6 out of 10 councils identified supported living, compared to only 1% who chose residential care. A further two thirds of local authorities said that they wanted to invest in employment services as many people with learning disabilities would like to work. Around a quarter of local authorities wanted to invest further in advocacy services to support people in making choices about their support.

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http://www.cabinetoffice.gov.uk/sites/default/files/resources/coalition_programme_for_government.pdf

⁴ ibid

There is concern that whilst the shift to personalisation is a welcome one for most people with learning disabilities, the actual support people receive is compromised because it is happening at a time of financial strain for most local authorities. In some cases this has led to people receiving a personal budget which means that they are no longer able to afford their current services and in many places, the financial climate for both local authorities and services providers means that people have fewer options of services to buy.

“Services continue to be provided but the chance and flexibility previously offered has been affected.” local authority

It is also concerning that in response to our survey, many local authorities talked about personalisation in the context of making efficiency savings.

“Plans are in place to ensure greater efficiency savings within all aspects of provision.

Examples include:

- **Increasing self-directed support with all service users by promoting access to alternative day opportunities through personal budgets.**
- **Produce a service model that supports people with disabilities into employment through the provision of a range of options and opportunities.**
- **Increase the number of people with learning disabilities who are able to live independently with support providing good quality value for money services.”** local authority

Some local authorities are concerned that personal budgets may initially lead to an increase in spending due to double running of costs as people move from their current services to personal budgets.

Many providers of more traditional services such as residential care or day centres are experiencing difficulties with the shift to personalisation. 4 out of 10 provider organisations said that residential care is affected by funding difficulties and nearly 6 out of 10 said that funding for daytime activities was at risk. But those services which provide more personalised support within the community have also been affected by cuts to funding. One provider told us that “our community support service has seen drastic cuts to people's hours and many losing them altogether.”

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

“Particularly hit was day services where providers just provide warehousing and very little stimulation. Residential providers whose fees were low as clients were out during the day now have 24hr care and placements are breaking down due to no stimulus and loss of friendships etc.” provider

Several people with learning disabilities told us about the difficulties they have faced in getting a personal budget and the problems they have had in finding an appropriate service when they have been allocated a personal budget. Some people told us that they wanted to use their personal budgets to buy more traditional services, such as residential care or a placement in an 'intentional community' but were finding it difficult to do so either because their local authority would not fund an out of county placement or their personal budget did not give them enough funds to cover the cost of a residential place.

Service provider organisations also noted that more traditional services would be affected by personal budgets as people would be unable to buy them as the economies of scale would make them too expensive. Nearly 4 out of 10 service providing organisations told us that over the last year they have increased charges for services. The loss of services such as day centres is leaving people isolated as it becomes almost impossible to maintain contact with their friends. One service provider said that the loss of day services also makes it much harder for people with learning disabilities to have a regular health check which is often leading to people having problems with their teeth or feet as there is no one to monitor their health and well being. Whilst personalisation has brought significant improvements to the lives of people with learning disabilities, in many areas it seems that traditional services are being closed before alternatives have been put into place.

“I have been reviewed for a personal budget twice but have never had the results. I am told my day service is closing by December this year and I will have to buy a lesser service but I cannot find the service I need in the private sector. The council want me take up college and adult learning courses or go to work. College stopped my courses a long time ago as I cannot cope with them and I don't want to do this. I would love to have a job and be normal but that will never happen as I have such severe learning disability, I need full support. Why do the council want to get rid of me?”
person with a learning disability

Mild and moderate needs

“People at the less severe end of the spectrum struggle to get any services, even though these are people who typically - without support - will end up in crisis situations and expensive, unnecessary provision. Thinking is very short-term.” provider

4 out of 10 local authorities identified support for people with mild and moderate needs as facing difficulties in funding. More than 5 out of 10 service providing organisations said that funding for people with mild and moderate needs was difficult. It is concerning that people with mild to moderate needs are finding it harder to access social care support at a time when it is difficult to find a job – recent statistics show that although 65% of people with learning disabilities want to work, less than 2 out of 10 people with a learning disability are in employment.⁵ There is also a risk that people with mild to moderate needs will lose out on welfare support as the Government intends to target the new Personal Independent Payment on people with higher needs. This increases the chance that people assessed as having mild to moderate needs will fall through the net of support and may end up in a crisis situation.

“We would like to increase the resources for prevention and early intervention services – especially for people who are potentially just below our FACS eligibility threshold, with a view to reducing the demand on community care funding.”

Employment is a key area in which we would like to invest further and also forms a key strand of our prevention strategy – the current global economic climate makes the expansion of job opportunities more challenging.” local authority

Nearly 3 out of 10 local authorities said that employment services were being affected by efficiency savings and cuts, but when asked which areas they would like to invest in further, if money was available, two thirds of local authorities identified employment support services.

A further 21% identified support for people with mild and moderate needs would be somewhere they would like to invest more money, often saying that preventative services would help to ensure that situations do not become a crisis, requiring much more intensive intervention in the future.

“Clients with moderate needs who were being supported now will fall outside fair access criteria so now have no support and will get into problems. More pressure going on to specialist health teams to support these clients.”
provider

“There have been cuts to my services. One of the day care centres has closed, the employment service for people with disabilities has shut down and other centres are under threat.” person with a learning disability

⁵ http://eprints.lancs.ac.uk/9515/1/CeDR_2008-1_People_with_Learning_Disabilities_in_England.pdf
p8

Effects on families and carers

“My mum does a lot of support as I don’t have enough money to pay support staff for 24 hour care from my budget.” person with a learning disability

“I receive no support from the government apart from my DLA payments. My parents’ whole life is devoted to giving me the kind of life any young person would enjoy, with lots of activities and as much independence as I can manage safely.” person with a learning disability

“We support many people who do not get the hours they need and many older carers struggling with only 5 hours per week respite through support.” provider

There are around five million carers in England, who save the economy an estimated £119 billion per year. Caring for someone with a learning disability is often a life long commitment and of the people who responded to our survey, 56% of people needed more than 50 hours of care per week, which was usually provided by family members. Respite care and services for carers are key to enabling families to continue their caring roles, but respite services are one of the areas facing financial difficulties. Several local authorities mentioned that they were looking at changing the way they provided respite care.

“[We] won’t know [if our support has changed] till we start pestering for this year’s respite, it was a struggle to get it last year.” parent

We asked people with learning disabilities whether they could afford certain items, such as clothes, food, heating or a hobby. Nearly 1 in 5 people told us that without extra financial support from their families, they would not be able to afford these things. This means that as well as providing caring support, families are often providing extra financial support, despite the fact that many may no longer have the time to work.

“I get some financial support from the government but it would not be enough to live on. I am only ok because my parents support me. I do not have a social worker and my parents are not recognised carers so they get no support from outside the family and they get no respite...I don’t think the government cares that much about me or people like me.” person with a learning disability

In addition to caring or coordinating care and providing financial support, many families are heavily involved in fighting for the support that their children or siblings need.

“No change so far, but my parents have been struggling for over a year with social services to maintain the current level of professional support.” person with a learning disability

The future for service providers

72% of service providers told us that they had experienced a reduction in local authority funding over the last year, with over half cutting services. A further 28% had seen a freeze in local authority funding which, as many service providers told us, effectively means a real terms cut in funding owing to the increase in inflation and expenditure. Two thirds of service providers said that they were expected to provide additional support from within existing contracts but without additional funding which creates significant additional demands on provider organisations.

“For the existing service users funding has remained the same, but for any vacancies we have the funding has been drastically reduced.” provider

“No uplift for the year ending 31/3/12 has meant that our fees have reduced in real terms due to inflation and the high cost of energy.”
provider

The reduction in funding from local authorities has meant that provider organisations have had to find other ways of increasing their income, which has resulted in 38% of service-providing organisations increasing their charges for people who use their services.

“Our local authority has moved to critical and substantial and dropped high moderate and is supporting those in high moderate until alternate services can be found. Funding to voluntary sector has been maintained and ring-fenced but grants and contracts are being recycled into new contracts which mean local groups lose funding as larger charities coming in from outside the borough get the tenders.” provider

A high number of people with learning disabilities told us that their residential care home or day centre was closing and that they were unable to access the right kind of support within the community. This suggests that providers of more traditional services are being hit hard by the current funding crisis and that, as yet, there are not enough organisations that are able to provide more community based services. Recent statistics show that the number of health and social care providing organisations that went into administration during 2011 increased by 9%.⁶

Local authorities told us that if more money were available, they would chose to spend it on services which enhance personalisation such as supported living, employment support or advocacy. Only 1% said that they would make further investment in residential care and 21% in daytime activities, other than employment. This demonstrates the increasing demand for more community based services.

⁶ https://www.deloitte.com/view/en_GB/uk/news/news-releases/3c004b41857c4310VgnVCM2000001b56f00aRCRD.htm

Conclusion - the need for reform

“I am being reassessed with a system that is fundamentally flawed”
person with a learning disability

The evidence from our three surveys shows a system in crisis and in desperate need of reform in order to meet the need for support in a growing population. As our previous surveys show, local authorities have been forced to make efficiency savings and cuts for several years and 9 out of 10 councils are anticipating making further efficiency savings in the coming year. Nearly a third expects to increase service charges – building on nearly half of local authorities who have done so this year, and 6% are considering tightening their eligibility criteria. Despite the assurances from the Government that they have provided enough money to prevent cuts to services, the evidence suggests that this is not the case. As one local authority told us, “providing more for less for an interim period is manageable but not sustainable in the long term.”

“Social care needs reforming to enable departments to work more effectively to meet need. This should be about efficiency, not having a focus on doing this to save money.” local authority

2012 will see the publication of the widely anticipated white paper on social care, which will draw together the recommendations from the Law Commission’s report into adult social care and the Dilnot Commission. This represents a real chance to reform the social care system and to create a system which works for everyone – people with disabilities, older people and carers. When asked what was going to be the most important factor in changing social care, 97% of local authorities said that a reformed social care system was key, with 57% saying that more money would also be vital to making it work. Service provider organisations overwhelmingly agreed, with 84% saying that reform was vital to changing social care and 62% saying that more money was needed to implement reform.

“Though there are efficiencies in personalisation of services and close integration of health and social care services the long term population trends are unlikely to be met without mechanisms to get more money into health and social care.” provider

For too long, support for people with learning disabilities has not been seen as a significant part of social care, despite 24% of the social care budget being spent on people with learning disabilities, much of the attention is on older people.⁷ There is a real need to create a social care system which works for all people with disabilities of working age, just as much as for older people.

“[We need] better funding, to enable a perfect personalised support and for people with learning disabilities to have a normal life style like every one else.” provider

⁷ NHS info centre

www.learningdisabilitycoalition.org.uk