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Tell it like it is

*What the crisis in
social care really
means for people with
a learning disability*

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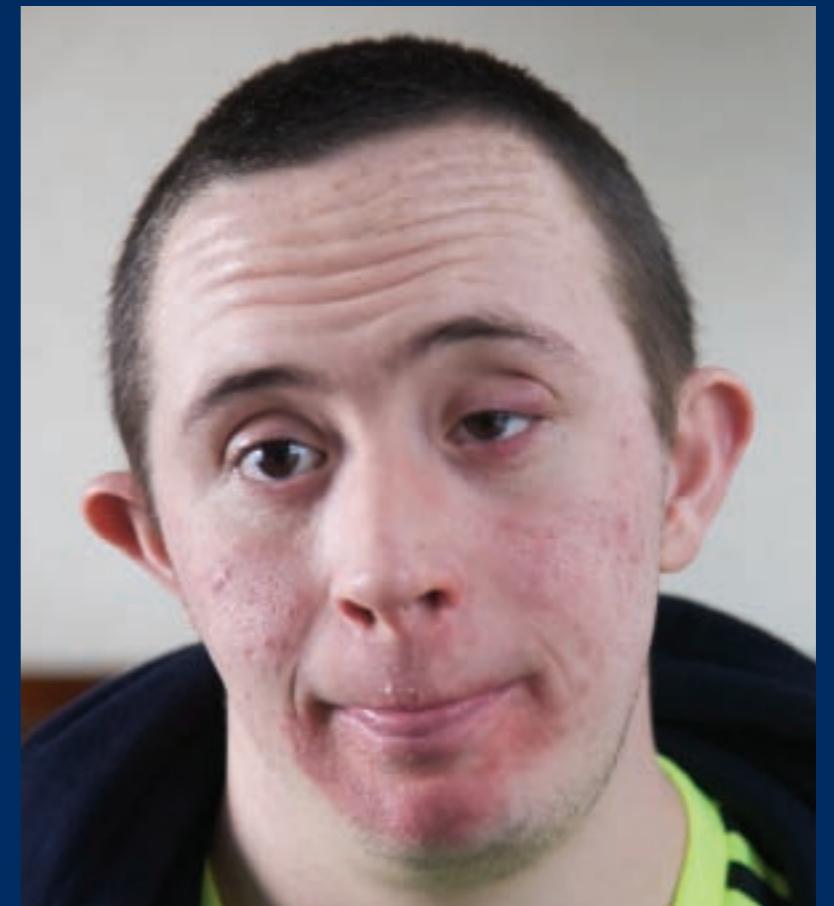
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2001:

“The Government’s objective is to enable people with learning disabilities to have as much **choice and control** as possible over their lives and the services and support they receive.”

Valuing People White Paper¹



2007:

“In the future, we want people to have **maximum choice, control and power** over the support services they receive.”

Putting People First²

2008:

“My daughter had a **nervous breakdown** because her routine was ruined with all the changes. **All of her weekly activities were stopped.** She spent 4 weeks in hospital and was sick at home for 6 months.”

“The government needs to seriously look at the services. **Not keep taking more and more funding away each year.**”

“I used to get services from social services. I wasn’t managing so then I was given Supporting People money instead. All of the money went to one service provider. They came to support me but told me how to live and said **I had to get rid of my cats because I didn’t get much money.** My cats were the only company I had. I didn’t want them to help me. They upset me and I told them to go away, so I ended up getting nothing. **I had nothing to eat and didn’t want to live anymore.**”

“Finally someone helped me and now I get a little bit from social services but **less than what I originally had.** I see someone for 5 hours a week and the rest of the time **I am on my own.**”

“My home is not very clean, **I don’t eat well, have no support to cook my dinner,** can’t go out in the evenings to meet my friends, have no support.”

“Things seem to be getting worse now – **they seem to be making cuts all the time.**”

“...we are only able to alleviate **short-term pressures** and, as you know, in some areas of the country, **only the most severe cases of hardship are receiving any care at all.**”

Alan Johnson MP,
Secretary of State for Health: October 2007³

“We need action now!”

Tell it like it is - Introduction

Dame Jo Williams



Across the country people with a learning disability and their family carers are suffering because of cuts to services and rationing of social care.

73 per cent of local councils will only support people whose needs have been assessed as 'substantial' or 'critical',⁴ leaving people with mild and moderate learning disabilities out in the cold.

And despite the huge issues faced by people with a learning disability, most of the current debate on the future of social care has, up till now, focussed largely on older people. But however pressing their needs undoubtedly are, the Government must not forget people with a learning disability and their family carers, many of whom are experiencing considerable hardship.

Indeed, the report of the Joint Committee on Human Rights, *A Life Like Any Other*⁵, found that the rights of people with a learning disability are routinely ignored.

Our report reflects the experiences of a group of people who are often unheard, and for whom reality does not match up to the very many promises that have been made.

Reading the responses to our questionnaire was heart wrenching.

It is no exaggeration to say that the under-funding of social care is wrecking lives.

But we remain hopeful. The Government's policies are moving in the right direction. In particular, the drive towards personalised services has the potential to bring about unprecedented transformation in people's lives.

One thing is clear though: there is just not enough money to provide the services that people really need.

The Government says that rights, independence, choice and inclusion are the four key principles that underline their vision for people with a learning disability.⁶ However, it is clear that services are under great pressure and that people are seeing a reduction in provision in all areas of their life.

We call on the Government to take the chance offered by the forthcoming Green Paper on social care to match resources to promises and to put an end to the indignities caused by lack of proper funding.

Dame Jo Williams DBE
Co-Chair, Learning Disability Coalition
& Chief Executive, Mencap.

Karen Flood



It is about time the public knew more about what a terrible time some people with learning difficulties and their families are having. We just want a decent life like anyone

else. We've got a lot to offer, given the chance. Just a little bit of help can make the difference between sitting at home every day or getting to a keep fit class or college.

I'm angry about the cuts to services that are going on around the country.

It seems very hard to get the message over about what a serious issue this is, and how it's affecting people's lives.

The tightening of eligibility criteria means that people who need help are not getting it. This puts pressure on people with learning difficulties and their families, which can lead to physical and mental health problems.

In some families people have to give up their jobs to look after their family members with a learning difficulty. We can't wait until all the talking about the Green Paper has finished. **We need action now!**

Karen Flood
Co-Chair, Learning Disability Coalition
& Co-Chair, National Forum of People with Learning Difficulties.

The Coalition was launched in May 2007. Our aim is to make sure there is enough public funding for people with a learning disability so they have the same life chances and choices as everyone else.

From January to March this year we distributed a questionnaire through our member organisations to find out the effects that cuts to services and extra charges were having on people with a learning disability and their families.

Daytime Activities

34% of people told us that they have had their day time activities cut.ⁱ

What people told us:

*“I had my four days attendance at a day-centre withdrawn. After **18 months** of my mother fighting for me, I have had **one day** reinstated.”*

*“**Don’t do much at the centre.** Too much Bingo, lots of watching TV and DVDs. **No more outings.** Programmes are ignored – staff shortage blamed. It is a multipurpose day centre and **the elderly take priority** over people with learning disabilities for staff time.”*

*“Because they split up and closed a day centre in my own town, **I could only have a place in a town about 10 miles away.** They have recently announced that **2 day centres in other nearby towns are to close,** plus a respite centre closed last year.”*

*“Very little provision once I left college. **Assessment criteria has been raised; so little help for people with Down’s Syndrome – they’re too able!**”*

Context:

Valuing People proposed major changes to day services, including moving people from traditional day centres towards more community based services and into work.⁷ This policy is welcome. People with a learning disability should have choice over how they spend their time.

As part of this modernisation process, some day centres were closed as part of an overall restructuring of daytime activities.

However, a number of local authorities have used the modernisation agenda as an excuse to close more costly day centres prematurely, failing to replace them with adequate or meaningful daytime activities. This has been particularly true for services for people with profound and multiple learning disabilities.

Many councils have not thought through the outcomes of the changes they have made. In some cases replacement services have not been immediately available when day centres are closed, leaving people with little choice but to stay at home; in others, daytime support has been reduced.

Often, the alternative services offered by the local authority do not meet people’s individual needs and provide them with little or no choice over their own lives.

ⁱ This is the percentage of people who answered yes to any of the following questions: ‘has your day centre closed?’, ‘has your college course been cut?’ or told us that the cost of their services has risen.

College Courses

37% of people whose courses were cut are now staying at home.

What people told us:

*“Community activities such as keep fit sessions and yoga run by the Learning and Skills Council **no longer happen due to funding problems.** Some people can join in day classes or activities run for all, but I need a slower pace and small groups – **I want to join activities with my peers.**”*

*“My course that was cut was **4 days a week** – now my new course is only **1 day a week.**”*

*“**The college courses have been cut.** We are told that **the day centres are all full.** So our daughter has just the one day at the café; which is lovely but not enough.”*

*“We managed to find another course (when the existing course was cut). It runs three days a week only. **Cost was increased steeply from £20 to over £250!!**”*

*“When I finished in the Basic Education Class at my local college in 2007 **I was not offered a place in any day centre;** not even allowed to look around one as most of these were going to be closed or rationalised in the next few months. I was lucky enough to find a place in a private centre which was then financed by the council. But we have now heard that this too will be closing soon to come in line with the proposals of the Council for provision for people with learning disabilities. I have no idea what I will do then.”*

Context:

These results are not surprising considering that, across the country, there has been a 15 per cent cut in courses for people with a learning disability, affecting 3000 people.⁸

The closure of these courses is often attributed to the poor quality of the course or lack of progression on the part of the pupils. In some cases, it is claimed that courses are more about providing something for pupils to do during the day than education. This may be true sometimes. The real scandal is that services are cut before new provision is available.

In a number of areas, day services are being cut in parallel with cuts to further education. This will lead to an increase in the 37 per cent of people who, according to our questionnaire, now stay at home following cuts to their courses.

Employment

34% of people had access to a service that helped them to find a job in the past.

17% of these people said that the service was no longer functioning.

What people told us:

“No constructive support to help look for and get employment. Parents still having to make all enquiries.”

“There is a desperate need for lifelong learning and proper access to employment even for a few half days per week. We have had to fight for a social worker to help us and still do not have one. They deal with crisis management in our area and as we are not in crisis we get left behind.”

“Not enough opportunities for working/training.”

“No support to have a job. I would like regular part time work but get no help from the Government to achieve this.”

Context:

Around 17 per cent⁹ of people with a learning disability are in paid employment (and for those known to services, the figure is just 10 per cent¹⁰), as compared to 47 per cent¹¹ of all disabled people. But at least 65 per cent¹² would like to work. There is much evidence that people with a learning disability make highly valued employees when given the right support.

Employment services for people with a learning disability are surviving on piecemeal, short-term funding. There is a tendency to award contracts to large pan-disability organisations at the expense of specialist providers.

There are very specific factors involved with working with people with a learning disability. There should therefore be an employment programme focusing exclusively on this group. It needs to be properly funded, specific to learning disability and with no rationing of services based on eligibility criteria or similar restrictions.

Transport

Although we did not ask specific questions about transport, we had a large number of unprompted comments about it.

11% of respondents told us about their transport services, with 77 per cent of these people making negative statements about them.ⁱⁱ

What people told us

“Cuts to transport have meant centre session times are much shorter as minibuses double up or people arrive late and leave early.”

“I used to go out once a week for coffee/lunch. Now all I get is a walk in my wheelchair to our local Asda store just a few minutes from our centre.”

“No transport means aged mother has to take daughter to new private day centre for a journey that takes 45 minutes twice a day.”

“I live in a rural area with no services. I have to have support to travel and access local mainstream services. It made me very worried about having no money left to go out and do activities. I have to pay for meals and drinks. The local council did not take these expenses into account. I had to write many letters complaining about this. I wrote to the minister – he didn’t do anything.”

Context:

Most people with a learning disability cannot drive. Half of all families with a disabled child do not have a car.¹³ Many people with a learning disability are completely reliant on public transport.

Concessionary transport is important for many people with a learning disability, particularly to people who use it to travel to college. But many people with a learning disability, including those who attend day centres, are dependent upon transport provided by their council. The response to our questionnaire shows that transport is an area of concern and that services are clearly under pressure.

ⁱⁱ The other responses were either neutral or positive.

Short Breaks

Our questionnaire did not specifically ask about short breaks (or ‘respite care’). However, once again we had a large number of unprompted comments on the subject.

35 people told us about their bad experiences, with only a few positive comments coming in.

The 35 negative comments we received gave us a graphic insight into the pressures caused by the lack of short breaks.

What people told us:

“After 16 years was offered respite care – after a lot of preparation and few day visits it was withdrawn without consulting me or my parents.

Apparently the placement was offered to another person without informing me. No respite care at the moment.”

“Our respite has been cut from 28 days a year to 21 days and there is no flexibility.”

“My respite centre has closed and I have not had a break and nor has my carer.”

“Closure of respite care homes where our grown up children could go and meet friends and socialise in a group. The council are now beginning

to push individual budgets for respite in our homes but **in this rural community it further isolates people.”**

“I have phoned Social Services but to date, no one has contacted us. I have had ME and Fibromyalgia for 7 years and am unable to sustain the amount of support and input I gave to Sarah. My experiences have been the more I do for Sarah, the more I was left to get on with it – even when my late husband was ill and later passed away, and during other family crises. **Will persevere, in the hope that someone will have the good grace to return my calls.”**

“Respite is about to finish this year so my family will have no help at all.”

Context:

Mencap’s report Breaking Point highlighted the importance of short breaks with the following statistics:

- 7 out of ten families provide more than 15 hours of care everyday
- 5 out of 10 families always provide care during the night
- 6 out of 10 family carers who are in poor physical health say it is because of the amount of care they provide¹⁴

Good quality short breaks are invaluable for people with a learning disability and their families.

They offer people with a learning disability choice, independence and a change of routine. And it gives their family carers a chance to rest and recharge their batteries.

The Government’s recently announced carers’ strategy¹⁵ is a step in the right direction but there is still a long way to go...



Charging for Services

What people told us:

“I think councils should not be allowed to charge people with disabilities for services. **The only money we have is benefits** and local authority charges 60% of what they say is disposable income.”

“Charging for transport and for day services and colleges has been **a big problem** for people in my area.”

“Tony’s carer is his father, who has chronic obstructive pulmonary disease and prostate cancer. Up till age 18 Tony received 6 hrs per week with a personal assistant. On his 18th birthday **a fee of £26 per week was demanded** by our local authority. **We cancelled the personal assistant.**”

Context:

The introduction, or increase, in charges for services means that some people will just not be able to afford them and will do without.

Any charges that a council levies for providing social care must be reasonable. Under the Government’s Fairer Charging policy guidance, local authorities are obliged to consider the income of an individual receiving care. However, it is becoming increasingly hard for families to prove the high levels of disability related expenditure and more and more charges are being levied.



It's like this...

At the end of the questionnaire we asked people to let us know about good or bad things that were happening in their community.

400 respondents completed this section, with **256** commenting on good things and **328** on bad (many people commented on both their good and bad experiences).

What people told us:

“Direct payments have **transformed his life**, particularly access to leisure services.”

“The individual budget scheme is excellent. I am just about to start it, and **it will help to make me independent and access the things I want to do.**”

“The introduction of direct payments has given Jane and others **much more freedom** to do what they would like to do, rather than being **told what to do.**”



The Norah Fry Research Centre completed a thematic analysis of the answers, which can be found on our website: www.learningdisabilitycoalition.org.uk.

This is a summary of the analysis, which mirrors many of the findings in the main report:

- There was a lot of enthusiasm for direct payments and individual budgets.
- Although there were many negative comments about day centre closures, people who had experienced modernisation of day services were often very positive.
- People had many good experiences of employment and inclusion in the community – e.g. by using free bus passes.
- There were particular problems for people who were ‘too able’ for services. People were angry that social services react only to crises, and usually meet only critical or substantial needs.
- Families said they were bearing the brunt of all the cuts, and spoke of the problems this caused them, including feelings of isolation and desperation.
- There was a lot of frustration caused by insufficient employment support and learning opportunities, as well as leisure activities.
- It was clear that people want better forward planning and information about services, and better support for people managing their own budgets or direct payments.
- People with a learning disability are a hugely diverse population. One solution will not suit all. A person centred approach, backed by sufficient funding, could make a huge difference to many thousands of lives.

If you would like to get involved with our campaign to make sure that there is enough funding for services for people with a learning disability, please visit our website: www.learningdisabilitycoalition.org.uk

Further Information

We went directly to people with a learning disability and their supporters to tell us their stories. We used an accessible questionnaire called Tell it like it is.

The questionnaire was designed to help us gather evidence about the effect that cuts to services were having on people with a learning disability.

It was carried out between 1st January and 31st March 2008.

Copies of the questionnaire were circulated by the following means:

- 4249 by Direct Mail to members of the Downs Syndrome Associationⁱⁱⁱ
- 2483 to local Mencap groups
- 304 to other members of the Coalition
- 362 were downloaded from the Coalition's website

Altogether 7398 copies were circulated.

A total of 685 forms were returned – representing 9 per cent of all those sent out. Of these, 520 came from the Downs Syndrome Association, and 165 from the other sources.

Two more forms were returned with none of the questions answered – these are not included in these figures or in the statistics in this report.

We asked the people who responded

whether they were filling in the form for themselves or for someone they cared for.

Only 4 per cent (20 people) stated that they were responding about themselves. 64 per cent (335 people) stated that they were filling the form in for someone with a learning disability. 32 per cent (165 people) did not answer this question.

Of those who stated that they were filling in the form for a person with a learning disability, the overwhelming majority (72%) of people were mothers of people with a learning disability, compared to 16% of fathers. A further 5% described themselves as parents. The rest of the respondents either did not state their relationship to the person they were filling the form in for or had another relationship with them (e.g. support worker, brother, sister).

The Norah Fry Research Centre undertook a thematic analysis of the answers to a question we posed about what people's local circumstances are. This can be found on our website: www.learningdisabilitycoalition.org.uk. You can also see a full set of the comments we received – some of which are distressing to read.

This report is not a definitive analysis of

the problems facing people with a learning disability. It is a glimpse into people's lives, lives which could be made more fulfilling if there was sufficient funding to turn the Government's inspiring policies into reality.

Please note that all the names in this report have been changed.

ⁱⁱⁱ The Down's Syndrome Association sent the form to their members with Down's syndrome who are over 18.

References:

- 1 Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. p4
- 2 HM Government (2007) *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*. p2
- 3 Speech to the Local Government Association/ Association of Directors of Adult Services Annual Conference, by Rt Hon Alan Johnson MP, Secretary of State for Health, 18 October 2007
- 4 '(...) in 2007-08 some 73% of councils plan to operate only at the highest two levels, compared to 58% of councils in 2005-06.' CSCI (2008) *State of Social Care in England 2006-07*. p118
- 5 Joint Committee on Human Rights (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*
- 6 Department of Health (2007) *Valuing People Now: From Progress to Transformation*. p3
- 7 Department of Health (2001) *Valuing People, a New Strategy for Learning Disability for the 21st Century*. p77
- 8 Learning and Skills Council (2007) *Adults with Learning Difficulties and/or Disabilities: Issues from the 2006/07 Planning Round*. p9
- 9 Emerson, E and Hatton, C (2004) (2004) *Estimating Future Need/Demand for Support for Adults with Learning Disabilities in England*. Institute for Health Research; Lancaster University. p4
- 10 Emerson, E and Hatton, C (2008) *People with Learning Disabilities in England*. Centre for Disability Research (2008). p8
- 11 Department of Health (2007) *Valuing People Now: From Progress to Transformation*. p3
- 12 Emerson et al (2005) *Adults with learning difficulties in England 2003/4*, Institute for Health Research, Lancaster University p.52
- 13 Read et al. (2006) *Disabled Children and the Law*. p42
- 14 Mencap (2006) 'Breaking Point - families still need a break'. p7
- 15 HM Government (2008) *Carers at the heart of 21st-century families and communities*.

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