



# Learning Disability Coalition

## Submission to the Comprehensive Spending Review 2007

### 1. Introduction

The Learning Disability Coalition (LDC), comprising ten major charities,<sup>1</sup> was launched in May 2007. Its aim is to provide a unified voice to raise awareness of the increasing gap between policy and the provision of sufficient public funding so that people with learning disabilities have the same chances and choices as every one else.

The LDC intends to develop a substantive case over the next year for additional funding to meet the rights and needs of people with learning disabilities. In the interim, we are submitting these comments so that Government is alerted to the fact that services for people with learning disabilities are not reaching those in need of support.

Cuts to services at local level have been increasing over the last twelve months in spite of an increase of in expenditure of 7.3<sup>2</sup> per cent per annum in real terms by local authorities. Local authorities are restricting access to services by tightening eligibility criteria. Insufficient resources are allocated to deliver the policy objectives that Government has set out for people with a learning disability.<sup>3</sup> The LDC is in the process of gathering information from its membership to demonstrate the extent of these cuts.

The National Director for Learning Disabilities has stated that an estimated additional £1m for each English local council will be needed over each of the next ten years to provide good quality social care to support people's right to a life based on independence and dignity. That amounts to an extra £1.5 billion<sup>4</sup> above the current expenditure.

Recent demographic, social and health trends are having a significant impact on the demand for services for people with a learning disability. The LDC is concerned that little if any financial modelling has taken place to assess current and future demand and the resources needed to meet that demand.

### 2. The Policy Framework

The policy framework provided by Government sets out a number of positive goals for the lives of people with learning disabilities.

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<sup>1</sup> Association for Real Change, British Institute of Learning Disabilities, Down's Syndrome Association, Foundation for People with Learning Disabilities, Mencap, National Forum for People with Learning Difficulties, People First (Self Advocacy), SENSE, Turning Point, United Response

<sup>2</sup> CSCI The state of social care in England 2005-2006 Page 19 2003/04-2004/05

<sup>3</sup> "Valuing People" 2001 and "Improving the Life Chances of Disabled People" 2005

<sup>4</sup> Community Care 24<sup>th</sup> May 2007

Valuing People<sup>5</sup> defined this framework as “rights, independence, choice and inclusion”. Improving the Life Chances of Disabled People<sup>6</sup> set out the goal of achieving equality for all disabled people by 2025. These in turn are based on the Human Rights Act of 1998 and the Disability Discrimination Act 1995 and 2005 (in particular the Disability Equality Duty). The Mental Capacity Act 2005 further enhances this framework.

In practice, if people with a learning disability are to enjoy their full human rights and live as members of the community, they are entitled to support and choice in the following areas:

- Accommodation: - in supported or independent living, residential care, shared ownership or with their families and friends, and provided with suitable support, such as short breaks;
- Independent living: - personal care e.g. washing and dressing, budgeting, shopping, travel, cleaning, gardening, keeping safe and enabling them to do the things that other people do.
- Healthcare:- physical or mental health needs, and access to primary and secondary health care that is adjusted as required to meet individual needs;
- Social needs:- making and keeping friendships and relationships, leisure and cultural activities, daytime activities;
- Employment- getting and keeping a real paid job or having their own business;
- Education- further or adult education to support independent living and vocational skills;
- Finance- welfare benefits and the development of financial capability;
- Families – living in a family context and facilities for short breaks for the person and their family;
- In transition – to maximise their independence when they leave children’s services for adult life.

These services are financed by a number of funding streams across different Government departments. They inter-relate and a reduction in one area, such as closing a further education course without providing alternative day time activity, can have an immediate and adverse effect on the quality of life for a person with a learning disability.

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<sup>5</sup> Valuing People 2001

<sup>6</sup> Improving the Life Chances 2005

### **3. Pressure on Services**

#### **a) Demographics**

Significant demographic changes are taking place but there is inadequate information to assess accurately the current population of people with a learning disability and the extent of the growth in the population.

In 2001<sup>7</sup> Valuing People estimated that there were over 1.4 million people with some form of learning disability of whom 1.2 million (2.5 per cent of the population) have mild to moderate learning disabilities and 210,000 (0.4 per cent of the population) have profound and multiple learning disabilities. Of these 65, 000 were children and young people, 120,000 adults and 25,000 over 65 years old. (But there are no accurate figures. A report in 2004 by Emerson<sup>8</sup> did give a lower estimate which he described as being based on an extremely conservative assumption.)

Only 20 per cent of adults with learning disabilities are known to learning disability services. Most of the remaining 80 per cent of adults with learning disabilities will not be users of generic social care services<sup>9</sup>.

The number of people with learning disabilities is increasing, with various estimates as to how much. From the limited information available the annual increase is at least one per cent per annum<sup>10</sup> because:

- Medical advances and preventative care mean that more babies with complex and multiple needs are surviving to become adults;
- More adults are living longer as mortality rates decline. (The Local Government Association (LGA) calculates that there will be a 41 per cent increase in people with learning disability between 60-79 by 2011 and a 56 per cent increase in those over 80<sup>11</sup>);
- A greater prevalence of younger people with higher support needs from South Asian ethnic minorities.

However the LGA has calculated that there will be 15,000 (4 per cent per annum) extra people requiring social care by 2011. In part this can be attributed to the numbers of people with learning disabilities currently living with elderly parents, who will need to be found alternative accommodation and support.

Another estimate from the Learning Disability Task Force estimated an 11 per cent increase in the number of people with learning disabilities between 2001 and 2021, with those over 60 increasing by 36 per cent.<sup>12</sup>

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<sup>7</sup> Valuing People A New Strategy for Learning Disability 2001 Cm 5086

<sup>8</sup> (Emerson, E & Hatton, C (2004). *Estimating the Current Need/Demand for Support for People with Learning Disabilities in England*. Lancaster: Institute for Health Research, Lancaster University)

<sup>9</sup> Emerson, E & Hatton, C (2004). *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England*. Lancaster: Institute for Health Research, Lancaster University

<sup>10</sup> Valuing People Cm 5086

<sup>11</sup> LGA Service Working Group-Adults and older people services Submission to CSR2007

<sup>12</sup> Transforming the Quality of People's Lives- Report of the learning disability task Force 2004

Information provided by the Sheffield register<sup>13</sup> for people with a learning disability provides some valuable, illustrative information about demographic trends and future demand.

In the last 5 years there has been an increase of 57 per cent in the number of young people with learning disabilities aged 15-19 and a 74 per cent increase in numbers aged 10-14.

Of the 262 people aged 15-19, 120 have the most severe levels of disability (this includes severe physical, continence and/or behavioural difficulties), compared to 89 in 2001. This is 22 per cent higher than the number of 20-24 year olds with severe disability. (A further 70 of the 15-19 age group have not yet had their level of disability assessed). Not all those in the 10-14 age group have been assessed yet, but it is likely that an even higher proportion will have severe disabilities

If current levels of service entitlement are to be maintained public expenditure needs to rise significantly.

#### b) Financial pressures on local authorities leading to cuts

In spite of the fact that spending on services for adults with a learning disability has increased by 7.3 per cent in real terms, from £3,039m to £3,373m between the years 2003/04 - 2004/05, services have been cut<sup>14</sup>. Both the LGA and the Association of Directors of Adult Social Services (ADASS) have made it abundantly clear that public expenditure does not meet the increasing demand.

The "Survey on Social Services Finance 2005/6" reported that three quarters of local authorities faced cost pressures in learning disability services with a total overspend amounting to £81m.<sup>15</sup> These pressures are due, in part, to the demographic changes described above. They also result from the transfer of responsibility for long stay patients from the NHS into the community without the allocation of sufficient resources to local authorities. Whilst the ADSS report showed significant increases in local authority spending on learning disability services, NHS spending remained more or less constant.

The requirement for local authorities to achieve efficiency savings of 2.86 per cent in Supporting People funding for learning difficulties<sup>16</sup> contributes to the pressure at a time when demand is increasing.

The Lyons Inquiry into Local Government<sup>17</sup> says that the "analysis of pressures raises important questions about the adequacy of national funding, and the degree to which local government can achieve efficiency savings." And, "if Government makes a 'national promise' about future adult social care, local government must be adequately funded to enable it to deliver." Of course it is important to continue to achieve better value from existing funding, as it is likely that much money is tied up in the wrong kinds of services.

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<sup>13</sup> 2006 report from Sheffield Young people with profound and multiple learning disabilities: implications for adult services.

<sup>14</sup> CSCI The state of social care in England 2005-2006

<sup>15</sup> Social Services Finance 2005/2006-LGA, ADSS, Society of County Treasurers. March 2006

<sup>16</sup> Social Services Finance 2005/2006

<sup>17</sup> The Lyons Inquiry into Local Government. Paragraphs 30 and 94 of the executive summary

### c) Pressures on People

Over the last year members of the Learning Disability Coalition have received a significant and increasing number of complaints about cuts to services that support independent living for people with a learning disability. We are systematically accumulating evidence of these cuts and commissioning in-depth research into a selected number of local authorities to explore the nature of the cuts and the reason they are happening.

For example, day services have been cut, the number of hours of personal support has been cut, the number of days of daytime activities has been cut, further education courses have been cut and charges to service users have increased.

Council funding to small local voluntary organisations is also being cut, resulting in a loss of creative local services that will be very hard to replace.

### d) Eligibility Criteria

According to the LGA seven out of ten people now only receive support if their needs are “substantial” or “critical” as defined under the Fair Access to Care (FAC) guidelines, and eighty per cent of local authorities intend to tighten their eligibility criteria.

In practical terms this means that local authorities will only provide care if:

- Someone’s life is, or will be, threatened or who has little or no choice or control over their lives” (critical needs<sup>18</sup>) or:
- Someone has only partial choice or control over their immediate environment, is liable to abuse or neglect, and who is unable to carry out the majority of their personal care needs or domestic regimes (substantial needs).

Restricting eligibility for care services to these two bands means that a large number of people who are “or will be unable to carry out several personal care or domestic routines” such as, washing themselves and cooking a meal (moderate needs), will be excluded from funded care. What will happen to such people? Where is the army of unpaid carers that is expected to step in and what are the implications for families?

Those people, whose needs are categorised as “low”, may have their ability to live with independence and dignity in the community restricted through lack of support. (Although FACS encouraged authorities to invest in low level preventive supports)

And are those local authorities, who are contemplating limiting care only to those with critical needs, really accepting that some of their residents could be liable to abuse or neglect?

### e) People’s Expectations

As in other areas of social provision, expectations amongst people with learning disabilities for an independent life have increased. This is as a result of Valuing People and Improving

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<sup>18</sup> [www.dh.gov.uk.en.publications](http://www.dh.gov.uk/en/publications) and statistics/publications/PublicationsPolicy and guidance/DH-4009653

the Life Chances of Disabled People. Alongside these, social changes mean that families and carers have different expectations of the level of support they should be expected to provide.

Families may not be prepared to take on a life time of commitment of care for their child when s/he leaves school or college. There are more single parent families, more women work or do not expect to stay at home as a carer and, as more people with learning disabilities survive longer, the pressure on their older parents becomes greater.

People with learning disabilities are increasingly going to mainstream schools. Being educated alongside their peers will mean that their expectations of finding a job, having a relationship and a home of their own when they leave school, are so much higher. What will be the impact on them when their hopes are dashed?

#### f) Policy Changes

Some policy changes intended to improve the lives of people with learning disabilities have had unintended consequences.

- The modernisation of day care services has led to the closure of day centres. Many were old fashioned, offered little stimulation and did little more than “warehouse” people. However individual tailored support packages in the community, where appropriate activities are not already available, take time to set up. Indeed many people with learning disabilities are finding that opportunities for day time activities are either inferior or provide significantly fewer days of activity outside the home than previously.
- Government priorities in further education focus around young people aged 16 - 18 years old and learners developing basic skills at level 2 or above. This is having an unforeseen affect on funding for courses for people with a learning disability. Courses for people with a learning disability are often below basic skill level 2 and do not lead to accredited qualifications. A recent survey by the Learning and Skills Council (LSC) showed a 15 per cent reduction in places within further education for people with a learning disability. The LSC does talk about finding more sophisticated ways of measuring progress, even for people with severe disabilities. There are indeed promises of additional funding. But what this means, today, is that another area of potential daytime activities is cut.

#### g) Missed Opportunity

- There are around 800,000 people with a learning disability of working age in the UK. They are the disabled group most excluded from the workforce with an estimated 90 per cent unemployment rate<sup>19</sup> compared to 51 per cent of disabled people as a whole. Yet 65 per cent of people with a learning disability want to work. Employment is an important source of independence, self esteem and inclusion for everyone and is particularly important for people with a learning disability. They want to contribute to society, become more independent and take greater control of their own lives. Increasing the number in work represents scope for significant financial savings.

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<sup>19</sup> Valuing People p.84

- Government should invest in a supported employment programme geared towards people with a learning disability and employers should be encouraged to discuss how to increase their recruitment and retention, including better promotion of programmes such as Access to Work.

## **Consequences**

1. Cuts in services mean that people with learning disabilities have a worse quality of life. They lose more and more of their ability to live independently. Indeed the state may not be meeting their fundamental human rights, as set out in the European Convention on Human Rights, currently under investigation by the Joint Committee on Human Rights. At the very least, we are failing to live up to the aspirations of Valuing People.
2. The prevention agenda is jeopardised and care costs will rise as a result. For example people with Downs Syndrome who do not receive sufficient stimulation in their day time activities are more likely to develop mental health problems and experience an early onset of dementia. Insufficient care and meaningful day time activity will increase challenging behaviour, cause mental health problems and put intolerable strain on the carers of people with learning disabilities. This will increase costs in the medium to long term.
3. Government's admirable policy objectives, of choice, rights, independence and inclusion, will not be met as immediate funding crises in local authorities cut vital services.
4. Restricted support to carers, such as short breaks, will cause health and family breakdown. Some might have to give up caring for their children. This will exacerbate the pressure on health and social care budgets.
5. Pressures on providers to lower costs put at risk the delivery of high quality services to support independent living. Cuts to learning disability services will exacerbate the difficulty in attracting, training and retaining sufficient high quality staff. This is an ongoing problem across the social care sector as a whole. Salaries fail to reflect the demands of the job. Indeed, demands on frontline staff are increasing with the growing emphasis on lone working and self directed support and the additional responsibility that this carries.
6. The outcomes of the investment programme of £340m, recently announced by the Government for disabled children,<sup>20</sup> will be short lived if sufficient resources are not allocated to continue the good work when children become adults.

## **7. Recommendations**

1. As it has done for children, the Government should acknowledge that there is insufficient data to make an accurate assessment of the level of services needed for adults with learning disabilities<sup>21</sup>. The Treasury should therefore use this CSR to

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<sup>20</sup> Aiming high for disabled children: better support for families HMT DES May 2007

<sup>21</sup> Page 29 "Aiming High"

provide additional funding for adult social care services that mirrors that made for children. This would be in the nature of a down payment until the Government has carried out a thorough evaluation of resource requirements of people with learning disabilities. We have quoted various sources in this document that make the case for additional public expenditure on these services. The LDC's direct experience of what is happening on the ground backs up these sources and tells us that the situation is deteriorating.

2. Ensure that the "Refreshing Valuing People" exercise announced by Ivan Lewis MP, the Care Services Minister on 16<sup>th</sup> May, includes financial modelling about the resources needed to meet the Government's policy objectives.
3. Instigate a strategic review, like one of those conducted by Sir Derek Wanless. This should assess the demographic, social, economic and health trends that are likely to have an impact on the services needed by people with learning disabilities, and the consequential funding requirements. The review will need to cover meeting the policy objectives set out in Valuing People and Improving the Life Chances of Disabled People.
4. Society has rightly decided to invest in good neonatal intensive care. To follow that policy through we need to make sure that local authorities have adequate funding to ensuring that those people who survive into adulthood can live a decent life.
5. Ensure that CSCI's current research, into the tightening of eligibility criteria by local authorities, fully explores the impact on people with learning disabilities, as well as the impact on the elderly.

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