



**Learning
Disability Coalition**

THE CASE FOR REAL CHANGE

**Submission to the consultation on ‘The Case
for Change – why England needs a new care
and support system’**

Learning Disability Coalition

28th November 2008

Summary: The Case for Real Change

Question 1: What more is needed to make independence, choice and control a reality?

- i) Policy and practice must respect the human rights of people with learning disabilities.
- ii) Funding should reflect increased demand.
- iii) Individual budgets should be truly person centred and not an excuse for cost cutting.
- iv) The specific needs of certain segments of the population, e.g. young people in transition, should be met.

i) Human Rights

- Practical steps should be taken at a local level to safeguard the human rights of people with learning disabilities.
- Public authorities should have a positive duty to respect the human rights of adults with learning disabilities.
- The Government should ensure that every local authority understands its responsibilities to deliver and promote people's human rights, backed up by adequate funding.
- The Equalities and Human Rights Commission (ECHR) should monitor how human rights are being upheld by the social care system.
- The Government should explore with the ECHR how to introduce a rights based approach to all aspects of people's lives.

ii) Funding

- Funding is inadequate.
- New research shows demand for adult services will grow 3.2 per cent to 5.5 per cent per annum compared to the Government's previous estimates of 1 per cent.
- 34 per cent of respondents to our survey *Tell it like it is* said that their daytime activities had been cut.
- In spite of additional funding, three quarters of councils' social care budgets are under pressure.
- The previous National Director for Learning Disabilities said that at least an extra £1.5 billion would be needed over the next 10 years for services for people with learning disabilities.
- Improved statistics are required, particularly relating to the number of people with profound and multiple disabilities, to ensure sufficient resources are directed to services for people with learning disabilities.

iii) Individual Budgets

- Individual budgets can make a difference to the quality of people's lives, and should be available to all who want them.
- They must be properly funded, with no capping at an arbitrary level.
- Individual budgets need to be holistic and cover all areas of a person's life.
- The roll out of individual budgets must be accompanied by a carefully planned and accessible communications and information strategy.
- Independent research is needed into whether and how assessments and payments for benefits, such as the Disability Living Allowance and Individual Budgets should be co-ordinated.

iv) Segmental Analysis

Transition for young people

- Young people should be entitled to a minimum level of support up to the age of 25. This should be set out in a holistic, person-centred transition plan.
- Every local authority should have a lead professional dedicated to overseeing and co-ordinating their work with young people with learning disabilities going through transition.
- The next set of Public Service Agreements should include a national indicator for transition.
- Councils should be required to prepare plans to show how they will manage their new responsibilities for Connexions and learning and skills and integrate them with their social care transformation programme. This is important to ensure that young people with a learning disability receive high quality support during transition.

Transition for people later in life

Local authorities should be required to identify people with learning disabilities who have older carers, and ensure adequate advance planning for when their families are no longer able to support them and need to find alternative accommodation and support.

People with moderate and mild learning disabilities

- Much more information is needed about the numbers, characteristics and needs of people with profound and multiple learning disabilities to make sure that they receive the quality support they are entitled to.
- The Government should explore whether a new system to provide core central funding to people with the highest needs would be effective.

People with challenging behaviour

Local councils must be improve their planning and commissioning so that good local services are developed for this group of people and to reduce the need for costly out of area placements.

People with severe learning disabilities

People with severe learning disabilities have been in the front line for suffering from funding cuts and their human rights are consequently jeopardized.

Lifelong carers

Carers should be supported to make decisions about how much care they can, and are prepared, to provide to their loved ones. Due care and attention should be paid to their own human rights, independence, choice and control.

Black and Minority Ethnic Communities

Local councils need to be more proactive and flexible when dealing with hard to reach communities and responsive to different cultures.

Question 2: What should the balance of responsibility be between the family, the individual and the state?

- Most of the public discussion on this issue has been about how much older people should pay towards their social care and how much the state should contribute.
- This is not necessarily relevant for people with a learning disability who have not had the opportunity to work and build up assets to contribute towards the cost of their care. Therefore co-payment is not an option.
- The state has a responsibility to provide funding and services to meet the human rights and needs of people with a learning disability.
- Carers make a huge contribution in time and money to help the Government to discharge this responsibility.
- It should not be assumed that family carers can or will provide all of a person's care and support.
- People with learning disabilities should be given the opportunity to make a contribution to mainstream society through volunteering or employment.

Question 3: Should the system be the same for everybody or should we consider varying the ways we allocate government funding according to certain principles?

- Entitlement to care and support should be based on fundamental principles of human rights.
- The system should reflect the fact that learning disability is life-long and care should be for life rather than at the end of life.
- Care and support packages need to be holistic, and acknowledge that co-payment is not an option for people with learning disabilities as they many not have had the opportunity to build up assets.
- People with learning disabilities should have the right to:
 - accessible, visible and inclusive advice and information about their rights and entitlements
 - advocacy which is independent of the local authority providing services, according to need
 - an assessment, irrespective of eligibility or income
 - effective planning for their transition from childhood to living in the community as an adult, with support available until the age of 25
 - an individual budget which reflects the whole of their life needs and which reduces the number of assessments and different funding streams
 - sufficient financial support to make the Government's objectives of independence choice and control a reality
- The role of local councils will be more of an enabling and commissioning one.
- They will also have a statutory duty to make sure that there are independent advocacy and brokerage services as individual budgets develop.

The Case for Real Change: Submission to the consultation on ‘The Case for Change – why England needs a new care and support system’

Introduction

The Learning Disability Coalition, comprising ten major charities,¹ was set up to make sure there is sufficient public funding for people with learning disabilities to have the same chances and choices as everyone else.

In any over-arching review of the future funding of adult social care it is important to remember that:

- A learning disability is life-long and support is likely to be for life.
- Learning disability takes many different forms and “one size fits all” will not reflect the wide variety of conditions and needs of people with learning disabilities.
- Packages of care and support must be holistic. They should include education, employment, health, leisure and housing.
- Co-payment between the state and the individual to meet the cost of social care is rarely an option for people with learning disabilities who have not had the chance to build up assets to help pay for their care.
- The issue for many individuals and their families is what happens to them when their parents die or become unable to support them.

Reforming social care and support and its funding for the long term is an ongoing and iterative process, and the recommendations in this document, both on policy and funding issues, will be developed and costed as the debate continues, and for the forthcoming Comprehensive Spending Review.

Policy Background

“By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society².”

We support the Government’s vision to enable people with learning disabilities to become equal citizens, with independence, choice and control over their own lives.³ The current funding crisis in

¹Association for Real Change, British Institute of People with Learning Disabilities, Down’s Syndrome Association, Foundation for People with Learning Disabilities, Mencap National Forum of People with Learning Difficulties, People First, Sense, Turning Point and United Response

²The Prime Minister’s Strategy Unit (2005) *Improving the life chances of disabled people*

adult social care directly threatens the stability and success of Government policy as well as the human rights of adults with learning disabilities. 34 per cent of the respondents to the survey we recently carried out told us that they had had their daytime activities cut.⁴ The Commission for Social Care Inspection states that many people's lives are impoverished when they are excluded from services because councils have tightened their eligibility criteria.⁵ And the needs of those with mild and moderate learning disabilities have been almost totally neglected.

³ Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century* (CM5086) & Department of Health (2007) *Valuing People Now: from progress to transformation*

⁴ Learning Disability Coalition (2008) *Tell it like it is*

⁵ CSCI (2008) *The State of Social Care in England 2006-07*

Question 1: What more is needed to make independence, choice and control a reality?

Independence, choice and control will only become a reality if:

- i) Policy and practice respect the human rights of people with learning disabilities
- ii) There is adequate funding to meet current need and to meet the expected growth in need over the coming decade
- iii) Individual budgets are truly person centred and not an excuse for cost cutting
- iv) The specific needs of certain segments of the population are met

i) Human Rights

“Real change for adults with learning disabilities will only happen if practical steps are taken to promote a more positive approach to the (human) rights of adults with learning disabilities on the ground, in mainstream public services.”⁶

Understanding, respecting and enforcing the human rights of people with learning disabilities must underpin their care and support in practice. We therefore support the recommendation of the Joint Committee on Human Rights that this requires practical steps at local level.⁷

The Government should require public authorities (Government departments, local authorities and the NHS) to have a positive duty to respect the human rights of adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act 1995 (including their positive duties under the Disability Equality Duty).

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

Government must provide the direction and resources to ensure that every authority understands its responsibilities to deliver and promote people’s human rights. There should be a nationwide communications programme, supported by adequate funding, to provide accessible information for people with learning disability about their human rights and how to get redress if these are not respected. This should be designed to include groups of people who are hard to reach. We therefore welcome Alan Johnson’s statement: “my department will provide more resources to support disability awareness across health and social care.”

The Equality and Human Rights Commission (EHRC) has a responsibility to produce ‘state of the nation’ reports every three years, and to present these to Parliament. These reports should

⁶ JCHR (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. London: Stationery Office

⁷ JCHR (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. London: Stationery Office

crucially cover the extent to which human rights are being respected through the social care system. We encourage the EHRC to use the full range of its powers, including taking legal action on behalf of an individual whose human rights have been abused, and launching a formal investigation if little progress is made in upholding the human rights of people with learning disabilities. The EHRC should also ensure that people with learning disabilities are fully involved in their monitoring work.

The Human Rights Act's effective entrenchment of civil and political rights within the European Convention on Human Rights should not detract from the need to protect economic, social and cultural rights, given that all such rights are interdependent. We want the Government to explore with the ECHR how to introduce a rights based approach for access to health, education, housing, transport, leisure, employment and a reasonable standard of living for people with learning disabilities as well as social care and support so they can truly have the opportunity to live a 'life like any other'.⁸

ii) Funding

Funding Cuts

34 per cent of respondents to our survey, *Tell it like it is*,⁹ said that their daytime activities had been cut.

A large number of people are excluded from social care services, or "lost to the system"¹⁰ because of tightening eligibility criteria. And because of inadequate official data we do not know how many people who are in need of support in fact get none at all. Funding shortages mean that 73 per cent of councils now only support those with critical and substantial needs.¹¹ Those with mild and moderate support needs receive little, if any support.

Learning disability budgets in three quarters of councils were under pressure in 2005-6¹² and in 2006-7 were overspent by 2.7 per cent.¹³ For example, Hertfordshire Council have told us that despite a cash increase of 7.9 per cent in their 2008/9 budget, including provision for a 4 per cent real terms increase in funding, they are already projecting an overspend and expect overall a 5 per cent increase in expenditure compared to 2007/08.¹⁴

A survey by Leonard Cheshire on the impact of cuts said that 82 per cent of respondents said the changes in their care package had impacted on their well-being and mental health and hindered their ability to engage with their local community and over half (52%) said the shortfall in social care services had led to more accidents, serious illness, suicide attempts and/or more visits to the doctor and hospital. 14% were very concerned that it had also led to illness, accidents and stress in their carers.¹⁵

⁸ JCHR (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. London: Stationery Office

⁹ Learning Disability Coalition (2008) *Tell it like it is July 2008*

¹⁰ CSCI (2008) *The State of Social Care in England 2006-7*

¹¹ CSCI (2008) *The State of Social Care in England 2006-7*

¹² Local Government Association (2006) *Social Services Finance 2005/06*. p.3

¹³ Local Government Association (2008) *Report on Adults Social Services Expenditure 2007-8*

¹⁴ Sarah Pickup Director of Adult care Services Hertfordshire County Council

¹⁵ Leonard Cheshire (2008) *Your Money or Your Life* p7

Increased Demand:

Demand is increasing because of demographic, economic and social changes:

Demographic changes:

- Improved neo-natal care means that babies born with PMLD, many of whom are technology dependent, are now surviving into childhood and beyond.
- Increased longevity due to better social and medical care. Mortality rates have dropped significantly.¹⁶ This means that many people with learning disabilities are now living to an age when their parents are no longer able to support them and they need to be accommodated and supported in the community.
- An increase in the proportion of English born babies from a South Asian ethnic origin where there may be a two to threefold increase in severe learning disability.¹⁷
- Possible increased incidence of babies born with foetal alcohol syndrome. The Government does not keep reliable figures on this. However it is estimated, worldwide, to affect between one and three in every 1000 births.¹⁸
- Increase in the number of babies born with Down's Syndrome because of an increase in the number of older mothers.¹⁹

Economic and Social Changes:

There is a reduction in the number of family carers who are able and willing to provide a lifetime of care for people with learning disabilities, thus increasing the demand for paid support in the community.

- 60 per cent of adults with learning disabilities live with their families and get most of their support and care from family members.²⁰
- One third of adults with a learning disability living in the family home are supported by a relative over the age of 70.²¹
- Over 40 per cent of parents caring for a son or daughter with a learning disability are over the age of 60.²²

¹⁶ Emerson & Hatton (2004) *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England*. Lancaster University. p.6

¹⁷ Darr and Modell (2002) Genetic Counselling and customary consanguineous marriage. *Nature Reviews: Genetics*, Vol 3

¹⁸ Stated in a parliamentary debate in the House of Lords:

<http://www.publications.parliament.uk/pa/ld200304/ldhansrd/vo041018/text/41018-25.htm>

¹⁹ National Down Syndrome Cytogenetic Register (2006) *2006 Annual Report*. Wolfson Institute of Preventive Medicine. P.6

²⁰ Fitzpatrick, J & Wood, A (2007) *Short Breaks: Supporting family carers and people with learning disabilities to have short breaks that work for them*, Paradigm/Valuing People Support Team. P.6

²¹ Mencap (2002), *The Housing Timebomb*. P.5

²² Mencap (2002), *The Housing Timebomb*. P.5

- 30 per cent of children and adolescents with learning disabilities are cared for by a single parent, compared to 23 per cent of people without a learning disability.²³

Changing Expectations:

- As a result of Valuing People and Government policies promoting independent living.
- Many young adults going through transition expect similar support to that which they had in children's services - and are bitterly disappointed.
- Family carers are less likely to be willing to devote themselves to a lifetime's caring responsibilities.

Lack of sound evidence:

A fundamental issue in determining the resources needed for services for people with learning disabilities is to recognise that there are no accurate figures about current and future numbers.²⁴

Two estimates are currently used for the number of people with learning disabilities in England. The 2001 White Paper *Valuing People* gave a figure of 1.4 million for children and adults.²⁵ Emerson & Hatton's work at the University of Lancaster has estimated that there are 830,000 adults.²⁶ Both are acknowledged to be approximate and based on an estimate of prevalence rather than actual figures. There are around 145,000 people with severe or profound learning disabilities who would generally be expected to receive services.²⁷

We do know that around 103,000 people received community care services.²⁸

Estimates of growth:

The increase in numbers of people with learning disabilities has been estimated to be around 1 per cent per annum. This would mean that the "true" number of people with learning disabilities in England would rise by 15 per cent from 2001-2011 and 20 per cent between 2001-2021.²⁹

The Personal Social Services Research Unit (PSSRU)³⁰ has predicted that the numbers of adults with a learning disability aged 18-64 will rise by 20.6 per cent between 2005 and 2041.

²³ Emerson & Hatton (2007) *The Mental Health of Children and Adolescents with Learning Disabilities in Britain*. Lancaster University/Foundation for People with Learning Disabilities. p. 8

²⁴ Emerson, E and Hatton, C (2007) *People with Learning Disabilities in England*. Centre For Disability Research; Lancaster University. p 3

²⁵ Department of Health (2001) *Valuing People, a New Strategy for Learning Disability for the 21st Century*. p15

²⁶ Emerson, E and Hatton, C (2007) *People with Learning Disabilities in England*. Centre For Disability Research; Lancaster University

²⁷ Department of Health (2001) *Valuing People, a New Strategy for Learning Disability for the 21st Century*. P.16 Eric 2008

²⁸ Emerson & Hatton (2008) *People with Learning Disabilities in England*. Lancaster University. p.vi

²⁹ Emerson & Hatton (2008) *People with Learning Disabilities in England*. Lancaster University. p.5

³⁰ Wittenberg et al (2008) *Future Demand for Social Care, 2005 to 2041: Projections of Demand for Social Care and Disability Benefits for Younger People in England*, PSSRU. P.10

However, Emerson has recently estimated that there will be a growth in the number of adult social care users in a range between 2 and 5 per cent, or 19 to 38 per cent over a 6-8 year period in two more recent local studies in Manchester³¹ and Stockport.³²

Both of these studies suggest that previous figures, based on prevalence, may underestimate future growth in need. The number of older service users will increase in a range between 36 and 38 per cent, and younger service users aged 18-29 between 70 and 129 per cent. These figures reflect other research undertaken in Sheffield.³³ Over the last decade the number of those with severe or complex needs in Sheffield has increased by 70 per cent suggesting a large increase in the number of high cost packages of care in the near future.

In new research using the spring 2008 School Census released by the Department of Children, Schools and Families, Emerson and Hatton state that the average estimated annual increase in new entrants to services will be in a range of 3.2 per cent to 5.5 per cent per annum between 2009 and 2026.* This is the middle one of three scenarios which reflect the different number of eligible service users, and the results are very similar to those found in Manchester and Stockport, quoted above.

How much funding is needed?

To answer this question we need a more accurate figure for the number of people with learning disabilities and the trends in growth in demand.

Changes in the prevalence of learning disability on total public spending can be significant. The PSSRU has estimated that a reduction or increase in the prevalence of learning disability of 0.5 per cent per year would translate into a reduction or an increase in total net public spending of £1,400 million and £945 million, respectively, by 2041.³⁴

If the current levels of service provision only are to be maintained, funding must be increased to reflect the demographic, economic and social trends indicated above. And unless extra funding is available the Government's vision of independence, choice and control will not be delivered.

The previous National Director for Learning Disabilities 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 billion³⁵ above the current level of expenditure.

³¹ Emerson, E (2007) *Estimating Future Need for Services for Adults with Learning Disabilities in Manchester* pii

³² Emerson, E (2008) *Estimating Future Need for Services for Adults with Learning Disabilities in Stockport* pii.

³³ Parrott, R (2008) *People with complex needs and profound and multiple learning disabilities in Sheffield* p5

³⁴ Wittenberg et al (2008) *Future Demand for Social Care, 2005 to 2041: Projections of Demand for Social Care and Disability Benefits for Younger People in England*, PSSRU p.13

³⁵ Community Care 24th May 2007

* forthcoming research commissioned by Mencap and seen by the Learning Disability Coalition

The Department of Health have said that there will be a £6 billion funding gap for social care in 20 years time.³⁶ However, this figure, based on work by the PSSRU,³⁷ could be a significant underestimate. The PSSRU assumes a 2 per cent per annum rate of growth of GDP, mirrored by a 2 per cent growth in investment in social care. This latter increase is unlikely, and the Government has made no commitment to this level of investment. Last year, the Government increased spending on social care by only 1 per cent.

The Government has regularly stated that services must be provided from the same financial envelope and envisage 3 per cent in efficiency savings. But efficiency should not be achieved by pushing down prices to minimum wage levels at the expense of the specialised and quality care needed by many people.

iii) Individual Budgets

Individual budgets have the potential to improve people's lives and they must be available to all, and not just to well informed and assertive individuals or carers.

Some families are understandably protective of their children, and the introduction and development of individual budgets must be accompanied by a carefully planned and accessible communications and information strategy for individuals and their families. They must be facilitated by properly trained staff, whether these are social workers, advisors, brokers or advocates, who should know what services are available and how they work, e.g. understanding housing options. In addition individuals and families must have support throughout the process, and the individual budget must be adaptable as people's needs change. In particular, people with PMLD and those with high support needs and their families should receive enough support to enable them also to enjoy the benefits of individual budgets.

Individual budgets will not suit everyone so they must be voluntary, and available to everyone, including people in residential care settings. This type of accommodation will remain the preferred choice for some people.

In spite of the reported difficulties of amalgamating or co-ordinating different funding streams, individual budgets must be comprehensive, or 'holistic', covering all aspects of an individual's needs i.e. housing, training and education, support to find and sustain work, positive day time activities, leisure activities as well as social care. They should include appropriate elements of health funding, including NHS continuing care funding.

There should be thorough and independent research (including the views of people with learning disabilities and their families) into whether and how assessments and payments for benefits, such as the Disability Living Allowance and Individual Budgets, might be co-ordinated. This research needs to address services from other funding streams such as further education and employment support.

³⁶ Department of Health press release, 12th May 2008

<http://nds.coi.gov.uk/environment/fullDetail.asp?ReleaseID=367176&NewsAreaID=2&NavigatedFromDepartment=False>

Details of calculations: <http://www.careandsupport.direct.gov.uk/wp-content/uploads/2008/07/technical-funding-doc-080708.pdf>

³⁷ Wittenberg et al (2008) *Future Demand for Social Care, 2005 to 2041: Projections of Demand for Social Care and Disability Benefits for Younger People in England*, PSSRU.

Individual budgets must be properly funded, with no capping. Support should be provided on the basis of need, not on the basis of arbitrary cash limited entitlements. Early reports that individual budgets could make substantial cost savings to the Exchequer were misleading, failing to reflect that a saving in one budget will often be a cost in another and that the provision of quality care requires adequate funding. Where individual budgets have been set too low they not only fail to provide the care and support necessary, but also push wage rates down and reduce the availability of specialised staff.

There should be a simple, swift and robust appeals system designed specifically to respond to the needs of people with learning disabilities. Issues of equity in access, uptake and outcomes need to be carefully monitored.

iv. Segmental Analysis

For certain segments of the population there are specific issues that need to be addressed if they are to have choice, independence, and control. These are our current views in advance of the publication of Valuing People Now.

Transition for young people

There is a huge gap between the support which many young people with learning disabilities³⁸ have had as children and the yawning void for those who do not meet the thresholds for adult services when they leave school. And yet, just like anyone else, the period in life between the ages of 16 and 25 of a person with a learning disability is crucial for future development. We attach a short comparison of two case studies at the end of this document which vividly demonstrates the cost in human and financial terms of inadequate transition planning.

If young people with learning disabilities are to have a chance for choice, independence and control they must receive the care and help they need. Too often the family and the individual are left to fend for themselves. Therefore young people with learning disabilities leaving school or college should be entitled a minimum level of care and support until the age of 25, set out in holistic person centred transition plans which meet their specific needs. These will include suitable accommodation and support to live independently and acquire life skills. It will include advice and facilitation of properly designed and funded further education and training courses and help with looking for employment.

Every local authority should have a lead professional dedicated to overseeing and co-ordinating their work with young people with learning disabilities going through transition. This person would understand the issues that affect people with learning disabilities. They should be familiar with child and adult care, support and health services, opportunities in training and education and options for finding employment. They should also understand the different budget heads and how to access them and the benefit options that are available. Local Authorities should also ensure that the required planning processes are in place for these young people, starting in Year 9.

³⁸ With a statement of special educational needs

We recommend that when the next set of Public Service Agreements is negotiated there should be a national indicator relating to transition. It might, for example, cover the number of people with learning disabilities aged 16-25 not in education, employment or training (NEET). Local authorities should have a statutory duty to support those young people leaving school with learning disabilities (who have had a statement of special educational needs) up to the age of 25.

Education and training, so vital to achieving an individual's work potential and ability to live independently, is often poor and often unrelated to their needs and realistic job prospects.

There has been a 15 per cent cut in courses for people with learning disabilities, affecting 3000 people and currently, people with learning disabilities and difficulties are twice as likely to be Not in Education Employment or Training.³⁹

There is no entitlement for learners with learning difficulties and/or disabilities to receive free education up to aged 25. If a disabled person claims an income related benefit, such as income support they will be entitled to a fee waiver under current rules. However, if they claim Incapacity Benefit not Income Support they will not have their course fees waived.

Fee waivers are discretionary and further education providers can make the decision to offer free education to disabled learners. In reality the absence of a legal duty means that colleges are loathe to spend their already stretched budgets on fee waivers, particularly for learners on pre entry and entry level courses who will not contribute to their targets or government priorities.

Local authorities will soon be responsible for many of the elements of a transition plan e.g. the Connexions service, and funding for further education will be transferred from the Learning and Skills Council. At the same time they are managing personalisation and the introduction of individual budgets. All this is potentially very helpful and we welcome the "Getting A Life" project.

We would like to see a clear, co-ordinated plan for the role that local councils will be playing in delivering improved transition.

Transition for people later in life

Transition does not only affect young people. The number of people with learning disabilities living with older carers is increasing as people are living longer. Inevitably the time comes when carers are unable to continue caring for their family member through old age, infirmity or death. At this point the state takes over their child's support, if they are eligible. All too often, the death of a family carer triggers a crisis situation as little or no planning for this eventuality has taken place.

Families are not supported to make plans for the future, and the shortage of suitable housing means that those with a lower priority of need (i.e. those still living with older carers, and with a low eligibility criteria) receive little or no help.

³⁹ DCSF (2004) *Reducing the number of young people not in education, employment or training (NEET)*. DCSF Publications. p3

Local authorities should be required to identify those people with learning disabilities who are cared for by older family carers, so they can plan the support they will need, and gradually introduce the choice of other living environments. This will avoid crises, and the stress and anxiety of having to move into unfamiliar accommodation following the death or illness of a close family member.

People with moderate and mild learning disabilities

We do not know how many people there are in England with moderate and mild learning disabilities. The number is probably around 800,000. Most are unknown to services unless their vulnerability has been identified and their needs classified as critical or substantial.

The Commission for Social Care Inspection, in its latest annual review, stated that there is an increasingly sharp divide between those who are and those who are not supported by the system.⁴⁰

There is a strong correlation between mild and moderate learning disability and poverty and social deprivation.⁴¹ This has significant implications for people's exposure to health and social risks.

Only 28 per cent of people with moderate and mild learning disability are in employment compared to 50 per cent for disabled people generally.

7 per cent of the prison population are people with learning disabilities.

25-40 per cent of people with learning disabilities have mental health problems,⁴² often associated with the low esteem from being unemployed and from insufficient positive daytime activities. 75 per cent of a people with learning disability in a survey into substance abuse had no structured daytime activities at all.⁴³

High profile cases of people with learning disabilities who have been abused, and even murdered, highlight the very vulnerable situations that people can find themselves in if some level of support is not available.

Very little research has been undertaken into the characteristics of this group of people. We recommend that this should be undertaken examining their characteristics and needs, and the benefits to the individual, the family and the Exchequer of certain interventions. As well as medical interventions such as the availability of psychiatric care, this will include better transition planning, better training and education including life skills training, employment support initiatives, mentoring, and what constitutes positive daytime activities.

⁴⁰ CSCI (2008) *State of Social Care in England 2006-07* p. xiii

⁴¹ Leonard Cheshire Disability (2008) *Disability Poverty in the UK* p18

⁴² Mind Fact Sheet (July 2007) *Learning Disabilities and Mental Health Problems*
<http://www.mind.org.uk/Information/Factsheets/Learning%2Bdisabilities/>

⁴³ Northern Ireland Alcohol and Substance Misuse group November 2004

People with Profound and Multiple Learning Disabilities

People with PMLD have great difficulty communicating and need high levels of support. Some people with PMLD will require as many as three supporters working with them 24 hours a day. They may be technology dependent, requiring oxygen, tube feeding or suctioning equipment to survive. Their behaviour may be challenging. They are often excluded from the community and have difficulty in accessing their human rights.

Care and support will be life-long and is likely to be amongst the most expensive: support will often cost more than £100,000 and sometimes as much as £500,000 per annum. The expense of supporting people with PMLD can have a great impact on local authority social care budgets. We are therefore concerned about the lack of accurate figures in regard to this group of people. Government and others use a combined estimate of 145,000 for adults with both PMLD and severe learning disabilities. This estimate has been shown to be inadequate; and at any rate, figures for these two groups should be reported separately, as their needs are very different.⁴⁴

Research is urgently needed to show how many people there are with PMLD, what their characteristics are, what good quality support would look like for them in a range of settings and what this will cost. The Government should undertake this research as a means of ensuring adequate funding in the next Comprehensive Spending Review.

Community facilities should be designed and equipped to meet the health and social care needs of people with PMLD. An example would be constructing more Changing Places toilets. And services specifically needed by people with PMLD due to the associated medical conditions they may have, for example hydrotherapy pools, should be designed in such a way that they can be shared with other members of the community, such as those with severe arthritis, where appropriate.

A skilled and committed workforce is crucial. There are not enough staff available with the necessary combined health and social care training to meet the complex health care and communication needs of people with PMLD. Therefore, training needs to be redesigned to provide a workforce with these additional and highly valued skills.

Reports from families suggest that many local authorities are applying arbitrary caps to individual budgets for people with PMLD. This causes great distress to families and individuals who often have no choice but to take recourse through judicial review or by referring their case to the Ombudsman. Many people find this extremely difficult and distressing, and as such this route is, in practice, available to only a small minority of service users and their carers.

Because of the high cost and complexity of the packages of care for people with PMLD, and the enormous struggle many families face to obtain adequate funding, we recommend researching a new system of core central funding for those individuals with the highest and most complex needs.

⁴⁴ Emerson & Hatton (2008) *People with Learning Disabilities in England*. Lancaster University. p. i

People with challenging behaviour

The first report by Professor Jim Mansell, in 1992, said that challenging behaviour was the acid test of the policy of community care.⁴⁵ Fourteen years later he says that there is still a long way to go.⁴⁶

There are over 12,000 people with learning disabilities in England whose behaviour presents a serious challenge at any one time.

The lack of support offered to families often means that they are unable to continue their caring role and people with people with challenging behaviour may have to leave home and find residential accommodation.

The lack of local facilities means that challenging behaviour is a common reason for out of area placements by local authorities in England.⁴⁷ These can be very expensive⁴⁸ and the increasing number of such placements may contribute to the rise in social services expenditure on learning disability services.⁴⁹

Local councils must be required to improve their planning and commissioning so that good local services are developed for this group of people. The services will not necessarily be cheaper, overall, than institutional care, but will be better value for money.

People with severe learning disabilities

People with severe learning disabilities probably constitute the largest number of people with learning disabilities who receive services. Their packages of care are rarely as much as for people with PMLD.

This group of people and their family carers face daily the impact of councils' cutting and reducing services because of funding shortages.

34% of people who responded to our recent survey *Tell it like it is* had experienced cuts to their day time activities. Their quality of life is jeopardised and their human rights ignored. This group of people is rarely vocal, often because of the sheer effort of survival.

These are some of the comments that we received in response to our survey:

"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."

⁴⁵ Mansell, J (1992) Services for people with learning disabilities and challenging behaviour or mental health needs. London, the Stationery Office

⁴⁶ Services for people with learning disabilities and Challenging behaviour or mental health needs : Report of a project group "Mansell 2" 2007

⁴⁷ Emerson, E & Robertson, J (2008) Commissioning person-centred, cost-effective, local support for people with learning disabilities. SCIE. P.5

⁴⁸ Services for people with learning disabilities and Challenging behaviour or mental health needs : Report of a project group "Mansell2"

⁴⁹ Emerson, E & Robertson, J (2008) *Commissioning person-centred, cost-effective, local support for people with learning disabilities*. SCIE. pp.vii - x

“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.”⁵⁰

Funding must be made available to meet the rights and needs of this section of the population.

Lifelong carers

Caring for people with learning disabilities is often life-long. 64 per cent of people with a learning disability live with their families. 30 per cent of carers are over 70.⁵¹

The recent carers’ strategy is welcome but does not pay enough attention to the needs of lifelong carers for financial and emotional support.

Furthermore the principles contrast sharply with what is happening on the ground. Over a third of people with a learning disability have had their day time activities cut.⁵² This is putting an unbearable pressure on the millions of unpaid carers who are left without the support they need to go on caring within the family home.

8 out of 10 of those caring for someone with learning disabilities have reached breaking point - an emotional and physical breakdown that leads to carers feeling that they cannot care for their son or daughter any more.⁵³

The Government should not expect carers to provide so much support that they neglect their own lives and needs. There should be no presumption that families will provide the necessary care for a person with learning disabilities. The social care system must be sturdy enough to manage the care of people with learning disabilities if their family carers are no longer able or willing to continue in this role.

Carers should be supported in their own right to make decisions about the level and intensity of care they provide, with due care and attention to their human rights, independence, choice and control.

Every family should be entitled to a minimum level of short breaks based on the levels of support needs of the person they care for. For those with the most complex support needs, this entitlement should be based on an expectation that it be not less than a minimum of 52 nights a year.

Breaks must be flexible to meet the needs of the family and the individual and should not necessarily be in a care home.

⁵⁰ Tell It Like It Is Survey by Learning Disability Coalition July 2008

⁵¹ Services for people with learning disabilities and Challenging behaviour or mental health needs : Report of a project group “Mansell 2”

⁵² Learning Disability Coalition (2008) *Tell it like it is*

⁵³ Mencap (2006) *Breaking Point*. Mencap. p.5

Councils should be advised to adopt a more proactive approach to informing family carers about their rights to assessment, advocacy and other services and support.

Many family carers are impoverished because they are unable to work and we would like to see this issue more fully addressed in future work on the carers' strategy.

Black and Minority Ethnic Communities

Many people from black and minority ethnic communities do not receive the support that they need. Demand for care and support is growing as our earlier section on funding demonstrated and this is particularly reflected in the proportion of younger adults requiring services.

There are cultural sensitivities and families may not engage with traditional social care structures, placing greater emphasis on the integrity of the community and its ability to care for people with a learning disability without outside assistance. Learning disability practice must take this into account, and there should not be an assumption that independence means living alone.

Local councils must communicate the options for care and support effectively and may need to be more proactive and flexible when dealing with hard to reach communities. Community workers need to be both well trained in learning disability issues and to be able to understand the communities (including their languages) in which they are operating.

Legislation on race applies to services for people with learning disability, as elsewhere; opportunities such as Race Equality Impact Assessments should be used to monitor change. Lead professionals in diversity should be fully involved in learning disability services.

This is another area where research is needed into the numbers, characteristics and support which this section of the population is needed.

Question 2 What should the balance of responsibility be between the family, the individual and the state?

Most, if not all, of the public discussion on this issue has been about how much older people should pay towards their social care and how much the state should contribute.

The situation is quite different for people with learning disabilities because learning disability is life-long. It is unlikely that people with a learning disability will have had the opportunity to build up enough assets to make a contribution towards the cost of their care. Only 10 per cent of those with severe and 27 per cent with mild and moderate learning disabilities work, and even those who do receive low wages and are often supported through tax credits. Co-payment is therefore not an issue for people with learning disabilities.

The prime responsibility is for the state to provide funding and services to meet the human rights and needs of this section of the population, and to ensure that there is a framework in place to deliver those services at a local level.

Carers make a huge contribution in time and money to help the Government to discharge this responsibility, but they too have a right to a balanced life and respect for their human rights. There should not be a presumption that the family will provide all of a person's care and support.

People with learning disabilities should be given the opportunity to make a contribution to mainstream society by volunteering or earning a living wage and having the opportunity to make financial choices and improvements to their lives.

Question 3 Should the system be the same for everybody or should we consider varying the ways we allocate government funding according to certain principles?

Entitlement to care and support should be based on fundamental principles of human rights - respect for an individual's dignity, personal autonomy and the right to support which will enable independent living. This is in accordance not only with the UK's international commitments under the European Convention on Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights but also its intended commitments under the UN Convention on the Rights of Persons with Disabilities.

For people with learning disabilities the system should reflect the fact that learning disability is life-long and funding for care and support may be for life, rather than at the end of life. Packages of support should be holistic including further education and employment where relevant, and co-payment is rarely an option because people have not had the opportunity, through employment, of building up assets.

Should there be one system for everyone or different systems depending on the type of need for care and support that somebody has?

We do not have a view as to whether there should be one system of funding social care and support, or two. This will be dependent on whether the principles and practice of funding social care and support for disabled working age people and older people are consistent.

Which is more important to us: local flexibility or national consistency?

The current 'postcode lottery' where a person in one area is denied the care and support available to another in a neighbouring council is unjust and should stop.

It follows that there should be a universal set of entitlements for people with learning disabilities (and others). These are:

- the right to the social care and support they require to have independence choice and control that is relevant to their needs, free at the point of support and based on personal outcomes
- the right to accessible, visible and inclusive advice and information about their rights and entitlements
- the right to advocacy, independent of the local authority providing services, according to need
- an enforceable right to an assessment irrespective of eligibility or income
- the right to effective planning for their transition from childhood to living in the community as an adult, with support available until the age of 25
- the right to an individual budget which reflects the whole of their life needs, and not just social care and support, available in a system which reduces the number of assessments and different funding streams
- the right to sufficient financial support to make the Government's objectives of independence choice and control a reality irrespective of where they live and with no artificial capping of the funding available. This will entail increasing the amount of resources for services for people with a learning disability commensurate with population growth.

Government needs to explore, by consultation, the proposal by CSCI⁵⁴ for a transparent national resource allocation system, properly researched and responsive to local costs and circumstances. It is critical that this resource allocation system takes account of people with particularly complex needs (for example, sensory impairments), who will often require particularly skilled and therefore more expensive support.

⁵⁴ CSCI (2008) *Cutting the Cake Fairly: CSCI Review of Eligibility Criteria*

For the longer term we consider that the Government should research the arguments for and against individuals receiving just one package of funding which will include both their individual budget and their benefits.

Budgets, both central and local, will need to be pooled if holistic packages of care and support are to be delivered. This is a mammoth undertaking and will require a major overhaul of governmental structures. However the impetus for this has been created by the personalisation agenda and we look forward to the results of the “Getting a Life” project.

The fact of a national entitlement should not diminish the role of local councils. Their role will become more of an enabling and commissioning one. Local councils will carry out assessments (and there will need to be safeguards about whether they take into account the amount of money these assessments will cost).

They will be responsible for strategic commissioning to ensure that services needed are available and that there is a real choice for the individual and their family as to which services they receive.

The local council will co-ordinate the package of support with care and support services, education, employment, health and other services where necessary. They will have a statutory duty to ensure that people with learning disabilities and their families have access to accessible information, advice and support services. Part of this responsibility will be publicising what support people are entitled to.

They will also have a statutory duty to make sure that there are independent advocacy services available, and that, as individual budgets develop, brokerage services are available. They will have statutory duties in relation to transition for young people with learning disabilities between the ages of 18 and 25 as described earlier.

What should the balance be between targeting government resources at those who are least able to pay and having a system that supports those who plan and save?

This question is more relevant to older people and other groups than to people with a learning disability. People with a learning disability very rarely have the resources to contribute towards their own care. It would therefore not be possible for any system based on co-payment to meet the needs of people with learning disabilities.

Annex 1

We have included this case study to demonstrate the practical effects of some of the policy issues we have outlined in this document. It shows the damage that can be caused by councils cutting costs in the short term; in this instance, during transition, which is a critical time for many people with learning disabilities.

Two people's experience of transition: a comparison

At the age of 10, two boys with Down's syndrome were at a local school together. Both A and B had enjoyed their time at school, had made friends and joined in with the general school activities. However, as the time approached for their move to secondary school, decisions had to be made about their next placement.

At the age of 11, the boys both moved to a residential school, as the education authority were unable to place them locally. The boys both developed their skills gradually over the next few years, before moving on to different placements to continue their development.

At the age of 22, the young men had different skill sets. They were now funded by different authorities, due to local changes, and were offered different levels of support to develop their independence and begin their adult life. Their paths took very different routes:

Case A	Case B
<p>A's strengths lay in his compelling interpersonal skills, his caring nature and his well-developed verbal ability. His academic skills regarding money, reading and writing were not as developed and he continued to need a network of support to help him develop his independence. He continues to be reliant on others for guidance.</p>	<p>B had developed much stronger academic skills and was very self-confident. He showed little fear of tackling new situations and seemed more able. B's skills in developing routines and structures for himself, in engaging in beneficial social and recreational activities and in understanding the consequences of his actions need further development.</p>
<p>A was funded by his local authority to live in a supported environment with 24 hours of support a day.</p> <p>Cost to LA: £680 per week (Day activities included)</p>	<p>B was funded by his local authority to live independently in a supported living environment with 23 hours of support a week.</p> <p>Cost to LA: £450 per week (No day activities funded)</p>

<p>A is supported and encouraged to learn skills and confidence through engagement and challenge, both within his living environment and in his daytime activities.</p> <p>A has individualised programmes of learning leading towards the achievement of certificated vocational skills and supporting his independence.</p> <p>Cost £680 per week</p>	<p>B did not have access to the range of friends or formal support that he had when at college, and for much of the time was left to his own devices, with few activities to engage with and few people to socialise with.</p> <p>B had no work, had little structured activity during the day, became bored with his own company, and so began to find things to do.</p> <p>Cost £450 per week</p>
<p>A works on a farm for 2 days a week (unpaid, but is moving towards paid employment) and assists with the birth of calves. He looks after pigs and herds animals. He also works in an office one day a week.</p> <p>In his leisure time, A goes to the pub with his friends, plays pool, football, goes to the gym, cinema and swimming. A is also a member of a samba band.</p> <p>A has support to manage his money, do his shopping and develop his understanding of social rules.</p> <p>A, on occasion, would find himself in an uncomfortable situation and would phone his support worker or family for advice and encouragement. A is quite vulnerable and can be influenced easily by stronger personalities. Staff have developed a programme to support and encourage him to walk away from difficult situations and explore issues of trust.</p> <p>Cost £680 per week</p>	<p>B would go to the pub, buy food and drink for people he didn't know and invite them back to his house for company.</p> <p>He would go into town and attempt to buy things that were very expensive; He was 'helped' by retail staff to buy several different mobile phones and a contract that he did not understand and could not pay for;</p> <p>B experienced difficulties with managing money, shopping for appropriate food, managing his time, observing social rules.</p> <p>B did, on occasion, take the train to towns further afield and not be able to get back home, involving police searches. B became distressed on a number of occasions, and when his housemate went away on holiday, B turned up at a group home, refusing to go back.</p> <p>Cost £450 per week</p>

<p>A is doing well, developing his independence slowly and becoming more confident and outgoing.</p> <p>A is now working towards a more independent life. He has learnt how to travel independently by bus and trains and is becoming more independent – for example, cooking for himself and shopping within his budget for food.</p> <p>A is a popular member of his social group and has been elected by his co-tenants to a residents committee.</p> <p>A is enjoying his social life, developing adult relationships and planning his future with confidence.</p> <p>Cost £680 per week</p>	<p>B has now been assessed by health professionals and is receiving support to help him come to terms with his experience. He is living in residential accommodation with 24 hour care and requires 1-1 support. He has lost confidence in his ability to live outside of this protected environment, and is likely to need this level of support for some time to come. B put on three stone in weight during his short time in his 'supported living' environment.</p> <p>B is beginning to slowly rebuild his life, learn about the nature of social relationships and how to get on with others, develop his own self-confidence, improve his personal care and most of all to keep safe.</p> <p>Cost £1800 per week</p>
<p>A has severe learning disabilities and B has moderate learning disabilities. However, they both need support to manage their daily lives.</p> <p>A had his specific needs recognised in the early days of transition. He is living a successful and happy life. B received too little support and went through a period of crisis. Fortunately, he is now receiving sufficient support to rebuilt his life; but at great expense to his local authority.</p> <p>Cutting costs in transition provides poor outcomes both for the young person, in terms of their experience, and for the funding authority in terms of expenditure.</p>	