

Mencap response to the Inquiry on Independent Living



Executive Summary

- Mencap believes that the right to independent living should form the basis of Government policy on disability in the UK, and include the right for all disabled people, including those with profound disabilities. However, we believe, it is important that independent living is considered as a result in its totality and not only in the context of personalisation and individual budgets.
- Mencap believes that the vision as set out in Valuing People Now and the Independent Living Strategy strike the right tone and have helped to drive on improvements to the lives of people with a learning disability. However, in certain areas we would have still liked to see more detail and a more ambitious approach being taken, with more resources committed to make it happen.
- There are still many barriers in the way of making the right to independent living a reality for all people with a learning disability. Access to independent living arrangements remains difficult for all people with a learning disability, and in particular those with more profound and multiple learning disabilities, employment opportunities are still rare and support arrangements vary in quality and sustainability. Mencap is now concerned that budget constraints both on the national and local level will negatively impact on the already limited opportunities of people with a learning disability to live a more independent life. Some recent policy decisions, for example, around housing or social care clearly run the risk of undoing some of the good work that has been going on.
- Mencap believes that there are a number of changes to policy, practice and legislation that the Government should consider. We believe that they are necessary to ensure that the right of disabled people to independent living will be honoured in the future.

Background information

- Mencap is the voice of learning disability. Everything we do is about valuing and supporting people with a learning disability, and their families and carers.
- We work with people with a learning disability across England, Northern Ireland and Wales. All our services support people to live life as they choose. Our work includes:
 - a) providing high-quality, flexible services in things like housing, employment, education and personal support that allow people to live as independently as possible in a place they choose
 - b) providing advice through our help-line and website
 - c) campaigning for the changes that people with a learning disability want.
- We work with people with a learning disability of all ages. All our services are tailored to the individual so we can provide support throughout their life.

Consultation response

Should the right to independent living continue to form the basis for the Government policy on disability in the UK?

- 1) Mencap has long argued for the right of people with a learning disability to live a more independent life. Our vision is a world where people with a learning disability, including those with profound and multiple learning disabilities, are valued equally, listened to and included. We want everyone to have the opportunity to achieve the things they want from life. It is for this reason that we campaign for people with a learning disability:
 - To be equal citizens with control over their lives
 - To have a childhood like any other child
 - To get the support they need to live independently
 - To be supported to get a job
 - To lead a fulfilling life
 - To get good healthcare
 - To have the money to do what they want to do
 - To have the opportunity to make friends
 - To form relationships and enjoy family life
- 2) Mencap strongly believes that the right to independent living should continue to form the basis for Government policy on disability in the UK. It is in this context, however, what we would like to see a greater acknowledgment of the importance of support and advocacy, as well as access to good housing, healthcare and employment, so as to ensure that independent living as a principle goes beyond direct payments and individual budgets. People with a learning disability should be enabled to exercise choice and make decisions for themselves, and fully participate in society.
- 3) Mencap also believes that the right to independent living and what this means on the ground is still not widely understood by many people, both in public services and by the general public. We therefore believe that there is still a lot more to do.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

- 4) Mencap believes that the Independent Living Strategy, as well as Valuing People and Valuing People Now, all present steps in the right direction and support the goal of independent living for people with a learning disability. Particularly, we believe that the attempt in Valuing People Now to concentrate on implementation started to change people's understanding of learning disability and has started to make some, even if slow, progress. Having people work on the programme within the Department for Health has for example helped to facilitate better joint working between different Government departments, leading to in some cases better policy decisions on the ground. An example of such an improved policy decision is the introduction of an additional bedroom allowance under LHA rules for those who have an overnight carer.

- 5) However, it is important to remember that policy statements such as VPN or the Independent Living Strategy do not operate in isolation and interact with other wider policies on housing, employment and social care, and that more could be done to ensure that those take account of the needs of disabled people. There are many policies that could be improved and new legislation that we believe should be laid. In the context of VPN itself, for example, we have argued in the past, that we would like Learning Disability Partnership Boards to have a statutory footing, so that they would actually be able to fully hold to account local authorities over their policies on learning disability. Furthermore, we also believe that more should be done to outlaw disability hate crime, which plights the lives of so many people with a learning disability and has a severe impact on their ability to live independently as equals in the community. We also believe that more could be done to improve some of the policies around access to work and housing.
- 6) Mencap is concerned, however, that rather than moving to improving policies to support independent living for people with a learning disability, we are seeing a retreat from some of the commitments made on already existing policies. While the Government has given its commitment to Valuing People Now and the values within, the recent dismantling of the Valuing People Now programme staff in the Department of Health, the reduced amount of funding to the National Forum and the National Valuing People Families Forum, and the uncertain future of Learning Disability Partnership Boards raise concerns that we may be returning to an era of policy without a vision of implementation on the ground. For policy to work and achieve the outcomes it aims for, implementation must be at its heart. A case in point is the recent Raising Our Sights report¹, which resulted from work undertaken in the context of Valuing People Now and which makes detailed recommendations as to how the lives of people with profound and multiple learning disabilities and their independence could be improved. However, the Government response to the report was light on detail and made few commitments on how to improve the situation on the ground. As a result we are seeing little being done to ensure that the independence and lives of those with profound and multiple learning disabilities are being improved.
- 7) We are also starting to observe in some areas a mismatch between the values and ideas laid out in the Independent Living Strategy and in Valuing People Now and policy decisions taken by other departments. An example of that is the recent reduction of Support for Mortgage Interest, which has had the side-effect that a long-established Homes and Communities programme of home ownership for people with long-term disabilities (HOLD) is now unable to support new claimants as a result.
- 8) Furthermore, implementation on the ground is also still very patchy. We hear from many of our members that there is still a lack of choice of services despite the long-established idea of personalisation. As local authorities often see personalisation as a way of saving money, the chronic under-funding of services is actually making this worse. This means that people with a learning disability do often not receive the amount of care and support that they require to live an independent life.
- 9) Last but not least, in its last report from 2009, the Independent Living Scrutiny group highlighted the importance of Public Sector Agreements and national reporting structures in order to monitor and ultimately improve implementation of measures to improve independent

¹http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117961.pdf

living for people with a disability on the ground. Mencap is now concerned that the potential move away from centrally collected data will make monitoring of improvements for disabled people on the ground increasingly more difficult, particularly as being able to compare the achievements of different local authorities is vital to ensuring that progress is made in the future. While the new social services outcomes framework will ensure that some national data should be available in the future, it remains to be seen at this point, how transparent and useful this information will be.

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

- a) The decision to remove the mobility component of Disability Living Allowance for people living in residential care.
- 10) Mencap in line with many other disability organisations was gravely concerned with the proposal to remove the mobility component of Disability Living Allowance for those living in residential care. This would undermine the aim of increasing independence, participation and employment opportunities, three important pillars of independent living, for those living in residential care. We welcome the deferral of this proposal and would urge the Government to ensure that it is protected in the review as part of the move from DLA to PIP.

“My mobility car has changed my life. When my mum and other relatives now see me they can see how happy I am. I have freedom because of my care to do what other people can do. Before I was not happy; I would sit at home watching other people in the home going in and out as they liked. I could only dream about that kind of freedom. Please don't take my car away from me. ”

Steven Colley, care home resident, Essex

- 11) Mencap believes that the Government has proposed the changes to the DLA mobility component based on the assumption of double funding. We know that this assumption is wrong, and that if the Government goes ahead with the proposal to remove the DLA mobility component for those living in residential care, this will have a significant and adverse impact on the everyday life of those affected. It will lead to either people being forced to remain indoors and as a result have a diminished quality of life that would not be in line with Article 19; or social services will have to make up the difference, which Mencap believes in times of great financial constraints will not be a real option for local authorities.
- 12) It is for the reasons above that we have and continue to call on the Government to continue pay the mobility component of DLA to those in residential care. Many disabled adults living in residential care have all their income taken to pay for their care, and are left with just £22 per week to live on. This is not intended to cover additional mobility costs, which we believe could be the result of removing the mobility component.
- 13) In addition, the resulting savings of £160 million are relatively small in contrast to the total of £81 billion in spending cuts the Government plans to make by 2014/ 15. However, the impact

on 80,000 disabled people to be affected will be huge, with many unable to afford to leave their home and denied the independence most people take for granted. This will be of particularly severe consequence to people with profound and multiple learning disabilities, who are the most likely of people with a learning disability to live in a residential care setting.

b) Changes to the Independent Living Fund

- 14) Since the announcements were made that the Independent Living Fund (ILF) would not be available to new applicants in December 2010, and the announcement that it is expected to fully close 2015, Mencap has heard of a number of parents and people with a learning disability worried about what this means.
- 15) In principle Mencap does not disagree with the decision to reform ILF, as we believe many councils use the discretionary funds to plug gaps in their funding, rather than addressing the problems in the current funding system. However we are concerned about the practical implementation of closing applications and in future to end the scheme, because the current social care system is inadequately funded. We are particularly concerned about local authorities who have seen a large cut in their funding being able to pick up the tab of closing this scheme. It is vital that local authorities protect services for the most vulnerable in our society.

Erica's story

Erica is 28 years old and has Profound and Multiple Learning Disabilities (PMLD) – severe learning disabilities; physical disabilities; epilepsy and complex health needs.

When Erica was a child – both her parents were working full-time and her parents employed and paid for child care in order to enable them to continue employment, in the same way as other parents. When Erica left school and moved into adult services, her family considered a number of options – including the possibility of Erica moving into residential care in order for her parents to continue to work and because they realised in terms of their ages they could not continue bearing the physical strain in terms of moving and handling and being awake during the night in the long term. As residential care was not their preferred option – they have put together a package of care with the local authority and health trust which enables Erica to live at home. This package includes both direct services and managing part of Erica's support through direct payments and Independent Living Fund (ILF).

The ILF makes a significant contribution to Erica's package in that the ILF enables Erica to have a level of independence despite her significant needs, which the other funding does not enable her to have. Erica receives funding which means that she employs personal assistants who support her during the late afternoon, early evening – whilst her parents are working. She also receives funding for 'floating hours' which can be used flexibly to give her greater independence. The 'floating hours' will pay for a personal assistant to attend a one-off evening or weekend activity; it enables her to spend time with her sister and allows her to have more creative breaks (ie. not residential respite). It for example helps pay for a PA to support her on holidays, enabling her to have some independence and providing a break for her parents.

For Erica the ILF is the only funding stream which can be used in a flexible way to fund more than 'basic care' and give Erica a level of independence as an adult. For her family it enables them to maintain responsibility for their daughter without feeling that it is a continual financial and emotional burden and enables them to lead an 'ordinary' life as they approach retirement age.

c) the 'Big Society'

- 16) The Government's commitments on the Big Society provides a valuable opportunity for community, charitable and voluntary organisations to run and provide services on behalf and in partnership with the public sector, particularly local government. As a cross-government policy programme, opportunities that help to create a climate that empowers local people and communities is to be welcomed and could lead to many advantages and benefits to those who are committed to independent living for disabled people.
- 17) We await with interest the Government's forthcoming Public Service Reform White Paper - informed by the Modernising Commissioning Green Paper - and the opportunity this aims to create for a level playing field for charities, voluntary groups and social enterprises that wish to bid for public service contracts. If local citizens, communities, and independent providers have an opportunity to play a greater role in shaping services, this could lead to considerable benefits in the quality and range of services accessed by disabled people and their families and carers. However, we seek assurances processes are developed to ensure continuity of service is maintained in any public service that is provided by voluntary, community or business groups. If such processes are not in place there is a risk that disabled people could see a decline in the quality of services they can access, thereby undermining independent living.
- 18) If the voluntary and community sector is to provide services in the interests of its clients, it will be vital to develop strong relationships with local authority and other public sector partners that can support a balanced and equal approach to identifying the best ways forward. Effective partnership working between the public sector and the community, charity and voluntary sectors is vital if the interests of disabled people are to be enhanced.
- 19) At a local level across the country, recent budgetary pressures are leading to many local authorities reducing their level of grants to voluntary and community groups who provide services for disabled people. Services such as advocacy, citizens advice and community groups are amongst those facing significant reductions in their grants, thereby having a disproportionate impact on some of the most vulnerable people in society, who often most reliant on accessing them. Sometimes there is a disconnect between the government's commitment to the ideals of the Big Society and the impact of reductions in grants by local authorities.

d) Restrictions on local authority funding, social care budgets and benefits reassessments.

- 20) Mencap has been following with great concern the extent of the cuts to local authorities, and we are still in the process of trying to understand what these cuts mean for social care budgets for people with a learning disability. Our assessment so far has shown that cuts of social

services have become a reality for people with a learning disability on the ground, be it in the form of higher charges, fewer hours of support or the closure of vital services, such as shortbreak homes.

21) A recent report by the Learning Disability Coalition confirmed that our concerns are justified. Out of the local authorities, which responded to the survey that underpins the report:

- a. 84% rated the funding situation for learning disability services as difficult.
- b. 10% percent are already making cuts to services.
- c. 53% indicated that supported living services were likely to be affected by budget constraints.
- d. 45% thought that services for people with mild to moderate learning disabilities would be affected.
- e. 42% felt that support for people with challenging behaviour was likely to be affected.²

22) We are already seeing a growing gap between the people who need care and who are not getting it. Mencap fears that this will get worse as a result of the cuts. Mencap is aware that eligibility criteria in some areas are being moved from severe to critical only. This will have severe implications on many people's ability to enjoy an independent life. Whatever national policy is in place, unless action is statutorily required, local authorities will be pushed to circumvent it to contain costs, particularly at this time of financial constraints. Cuts to frontline services, are ultimately cuts to people's independence and will make the right to an independent life hard to achieve for all disabled people.

Case Study

Andrew is 32 and has a learning disability. He has been assessed as 'moderate' under the eligibility criteria set by his local council and receives care and support which has enabled Andrew to live a fairly independent life.

He currently attends a day service 4 days a week, where is takes part in various activities including learning how to live a sustainable life by growing vegetables on an allotment and learning how to use computers and the internet. He also receives 8 hours a week of living support in a one-bedroom flat.

The council are looking to tighten the eligibility criteria so that they only provide care and support to those assessed as substantial or critical. This would mean that Andrew would lose his care and support.

² Learning Disability Coalition (2010) 'Social Care in Crisis: from the perspective of local authorities in England

Andrew would not be able to attend the day service, which he has done for 14 years. It is likely that he will lose his current social networks, becoming more dependent on his family. He will also be preventing from doing the activities that he enjoyed at the service, including learning how to grow vegetables and how to use a computer.

Losing the support to live in his flat will mean that he will no longer be able to live in his own home. He needs support to organise his finances and support in identifying threats to his own safety.

His parents are extremely concerned about his future as they believe that he needs the support to live an independent life and believe that there would be no other option other than to take him into the family home. This presents further problems for the parents as they are divorced and do not own their homes, his mother has a health condition which sees her in hospital for long periods of time.

23) Furthermore, we are also seeing a number of changes to disabled people's entitlements, including the introduction of the Work Capability Assessment (WCA) and the employment and support allowance (ESA), as well as the current reform of Disability Living Allowance (DLA). We know from the roll-out of the WCA, that a high number of claimants are failing the WCA and not being found eligible for ESA. As a result, many of these claimants will be receiving Job Seeker's Allowance instead. Mencap is very concerned about this in relation to people with a learning disability who will miss out on the extra support available to those in the work-related activity group of ESA.

24) Mencap is concerned that this will have a negative impact particularly on people with milder learning disabilities, who may also find that they will in future not be entitled to DLA either. While we therefore would undoubtedly argue that some of the recently suggested changes, such as the idea of simplifying the benefit system as outlined in the Universal Credit model, are a step in the right direction, we are very concerned that the detail as it has emerged may lead to greater numbers of people with a learning disability losing out and having their right to a successful independent life with employment opportunities restricted.

Case study

S has a learning disability and is 21 years old. He left full-time education in June 2009. At this time he made an application for ESA and attended a work capability assessment. He scored '0' points against all the descriptors looking at mental, cognitive and intellectual function. Having started on a programme with Mencap's employment service, Mencap is helping S to appeal the decision.

Mencap's employment service has been working with S to complete a work experience placement of 6 weeks. This was in a charity shop. S's role involved him helping to serve customers and to put stock out on the shelves. He had one to one support from his job trainer to learn his role, understand his routine tasks and develop a good working relationship with other staff members. The Mencap employment service staff working with S commented on a number of descriptors that "stood out" where they claimed they felt S should have scored, but did not get any points at all, such as 'learning or comprehension in the completion of tasks'.

'coping with change', and 'coping with social situations'. Staff therefore felt that the new assessment was not appropriate for assessing people with a learning disability.

- e) Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people.

"We seem to be being squeezed from all sides with cuts happening locally and now DLA. I'm not sure the government is seeing the bigger picture."

Respondent to Mencap's Disability Living Allowance survey

- 25) The Coalition Government is rapidly moving forward an intensive devolution programme, with the idea of 'Localism' at its heart. The programme is accompanied by the driver to reduce the regulatory burden on local authorities and trust decision-making to local people. As a result, more financial decisions are being taken locally.
- 26) While Mencap believes that local authorities are in many ways best placed to deliver services on the ground, we also know that in times of financial constraints services other than statutory ones suffer greatly. A good example of this is Supporting People. Supporting People was unringfenced prior to the new Government coming into power. While nationally Supporting People money was relatively protected in the last Budget, locally, decisions taken in some areas are most likely to have a severely negative impact on the ability of people with a learning disability to live an independent life. Cornwall, for example, is cutting its Supporting People budget by 40%, even though its Supporting People allocation has actually been increased. In contrast to Cornwall, Hounslow or East Sussex are protecting their Supporting People budget.
- 27) Greater devolution also more generally brings with it the risk of an increased postcode lottery. While there are clearly differences between the provision of social services, for example, in one area compared to another at the moment, greater local decision-making, and fewer statutory duties on local authorities, which is what the Government seems to aim for, are only likely to increase that difference, unless steps are taken to ensure that in terms of entitlement, people are treated the same in all local authorities. Mencap therefore believes that localisation must therefore be accompanied by measures that ensure that people with a learning disability do not lose out as result of this. We would therefore like to see amongst other things national eligibility criteria in social services introduced as well as more done to explore how portability of services could be improved. Localisation should not mean that disabled people can get a service in one area, but not in another; this would severely limit their choice as to where they can live and therefore their ability to live more independently like everyone else.
- f) Cuts to housing benefit and Support for Mortgage Interest, changes to social housing legislation
- 28) Mencap also has a concern that the changes and uncertainties with regards to Housing Benefit regulations, as well as the changes to Support for Mortgage Interest and social housing more

generally, could potentially have a detrimental effect on the ability of people with a learning disability finding a suitable home, which is key to an independent life.

- 29) Over the last few years, a number of organisations have been working on developing new models of independent supported living. The Great Tenant Project by Golden Lane Housing is one such model. Rather than relying on the traditional route into housing for people with a learning disability via a residential care home or social housing, it works closely with private landlords to develop a partnership that means that someone with a learning disability can rent a home like anyone else. The changes to the Local Housing Allowance, moving from the LHA being set at the 50th percentile to the 30th percentile, as well as the caps on LHA, particularly in London, will make finding landlords willing to rent to people with a learning disability more difficult.

"Since April this year, it has become increasingly difficult to secure private rented sector accommodation for those with a learning disability. As market rents continue to rise due to stagnant mortgage lending increasing demand for rental property, these cuts to LHA have further widened the gap between LHA levels and rental values. In affluent areas such as Surrey, London and Kent, it is now virtually impossible to find property without there being some form of top-up payments from the individual or their family needed - something that the majority of families are unable to provide. With the rise in the age limit for shared-rate LHA from 25 years to 35 years, this is only going to exacerbate the problem to the point where vulnerable people wishing to live independently in the private rented sector may be forced to live away from their family, friends and other valuable members of their support network."

Katie Sherjan, Development Manager, Golden Lane Housing

- 30) Another model, that was developed over the last 15 years to increase the pool of housing available for people with disabilities, particularly those with learning disabilities, was the Home Ownership for People with Long-term disabilities. The model, which was developed to provide people with long-term disabilities, particularly those with learning disabilities, with a stable home, was based on payment via the Support for Mortgage Interest (SMI) route. It has enabled around 1,000 people over the last 15 years to find a home. At the end of last year, the interest rate in SMI was reduced dramatically. As a result, the few lenders that had been willing to lend to people in this position retreated from the market, effectively shutting down this route for people with a learning disability, and putting some people already owning a home in the position of being unable to pay for their mortgage.

Case study

N is 26 years old and has Williams Syndrome and a severe learning disability. She currently lives with her parents in Dorset. N has been in education all throughout her life but is now coming to the end of her last year. Both the parents and N feel that now is the right time for N to get her own home.

A friend of the family, who also has a daughter with a learning disability, was able out of own savings to turn land she owned in Somerset into nine 2 and 3 bedroom houses for a supported living scheme. The houses will be sold to a Housing Association, which will then directly sell on 75% of the mortgage to the individuals buying the house as part of a shared-ownership arrangement. N and a friend of hers from school are planning to part-buy one of the 3-bedroom houses with a mortgage of £56,250 each through this arrangement.

The changes to SMI now threaten to destroy N's possibility of a safe and stable individual living environment. N is likely to have a mortgage rate set at around 5-6%, which would put monthly repayments at between £234 and £281. The changes now mean that she will only get £176 paid through SMI. This will leave her and her friend to cover between £15 and £25 per week each out of other benefits.

- 31) In addition to the changes the Local Housing Allowance already touched on in paragraph 23 above, Mencap is also concerned that the extension of the single room rate from 25 to 35 from April 2012 could have severe implications for particularly those with milder learning disabilities and their ability to find their own accommodation, particularly for those between the ages of 25 to 35, who currently already rent a flat of their own. They may also find it more difficult to find someone to share a flat with. While sharing is a concept that many people with a learning disability do and enjoy, particularly those with milder learning disabilities may not be known to social services and therefore lack the support to help them find other suitable individuals to share with. The suggested new Housing Benefit rules (Clause 68, Welfare Reform Bill), are also likely to cause complications particularly for disabled people who already.
- 32) Perhaps one of the biggest threats, or opportunities, to independent living for people with a learning disability is the forthcoming review of the 'exempt accommodation' rules. Currently around 170,000 disabled people rely on this system to pay for their home; 40,000 of these are people with a learning disability. While the review is welcome, as current regulations are out of date and have caused many problems locally for those needing a home as well as providers of such homes, Mencap would be concerned if the new system would lead to restricting provision even further. We will therefore watch closely what the suggestions are and make recommendations to ensure that independent accommodation for people with a learning disability becomes the norm, not the exception. Changes that would lead to restricting the availability of accommodation provided via this route, rather than help expand it, would work against the independent living agenda, and make it even more difficult particularly for those with more complex needs to access a home in the community.
- 33) Summarising the above, finding accommodation for someone with a learning disability to live a more independent life is still very difficult. Many parents and individuals have to fight for

many years to be listened to, and to have their right to an independent life fulfilled. With housing and support going hand in hand for people with a learning disability, it is a multi-agency approach that needs to be taken to make it work; and often there are delays and problems. The changes and cuts to Housing Benefit as outlined above, in combination with cuts to social services locally, provide for a bleak outlook for the right to an independent life. Constant changes in policy and funding, with further restrictions on funding on the way also make it very difficult for providers to develop housing options.

What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

- 34) Funding is vital to making services work and Mencap in line with many other learning disability organisations have argued for a long time that adult social care in the UK is chronically underfunded. As touched upon in paragraphs 20-24 above, the situation is likely to get worse. We clearly have welcomed the decision to put £1 billion extra into adult social care, however, this is unlikely to meet demand in light of the increased number of people with a learning disability needing services (3-5% increase by year)³, the increasing numbers of people with profound and multiple learning disabilities (1.8% increase per year)⁴ and the rising number of elderly people.
- 35) Without adequate funding being available for social care services, support, and housing provision, pressures on finances will mean that good ideas and progressive thinking will lose out. While some savings can clearly be made via efficiency savings and while new assistive technologies may be able to replace a few hours of support for some people, supporting for example new people coming through the system costs money. Without this funding being available, it is unlikely that someone wanting to leave the family home to live more independently will be given the support to do so easily in these times of financial constraints. Mencap is already aware of the reluctance by some councils to fund more costly independent living arrangements.

³ Emerson, E. and Hatton, C (2008) Estimating Future Need for Adult Social Care Services for People with a Learning Disabilities in England, Lancaster: Centre for Disability Research

⁴ Emerson, E. (2009) Estimating Future Numbers of Adults with Profound and Multiple Learning Disabilities in England, Lancaster: Centre for Disability Research

Victoria's story

Victoria is 38 years old. She was born with Tuberous Sclerosis. Tumours can affect all the body organs, and in Victoria this means that she has physical and learning disabilities. She also has behaviour which can challenge services and people; either passive or withdrawn or self harms, screams and lashes out.

Twenty years ago her parents set Victoria up in a home of her own, together with one of her friends, as they felt that residential care provision was not the right thing for her and that she deserved a more independent life. This was one of the first schemes to give independence, choice and control to two very disabled women. Opposition was high, particularly from medical professionals.

Victoria has now lived for the past 18 years in her own tenancy in the London borough of Islington. She has 24 hour support, a circle of friends and a person centred plan and very much lives the life of her choice. However, her mother Jean has had to consistently fight to keep this in place.

Because of the cost to meet Victoria's needs, her support package is always under scrutiny and there have been a number of attempts to reduce it, which would make her life as it is unsustainable and seriously challenge her independent life style. Islington have now, made the decision that they will never again fund individuals with complex needs to live independently because the costs are too high, restricting other people in this situation to lead an independent life.

What steps, if any, should the coalition Government, the Scottish Government and other public agencies take to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK? If you consider changes to policies, practices or legislation in the UK to be necessary, please explain why.

36) Mencap regularly contributes to consultations on White Papers, Bills and policy changes, in which detailed recommendations on particular areas of work can be found. Outlined below, based on these more detailed recommendations elsewhere, are some of the steps that we think the Government should take to ensure that the right to independent living moves on from being a right in theory to a right in reality.

Broad recommendations

- i. Teachers, social workers, health professionals and parents to raise aspirations among people with a learning disability. Finding employment and leading an independent life should be what young people with a learning disability aspire to.
- ii. The social model of disability to form the basis of all policies, thinking and practice around disability. This should support the mainstreaming of the right to an independent life for disabled people.

- iii. A change in the Government rhetoric around people on benefits. The language currently used in the press paints a picture of scroungers rather than one of people in need.
- iv. Improved cross-Government thinking within and between departments. Many policies are inter-related, yet departments and internal working groups often still work in silos.
- v. The Government should ensure that within all the policies that they are taking forward the impact on people with profound and multiple learning disabilities is assessed and addressed. This would ensure that unintended consequences and indirect discrimination are minimised.

Specific recommendations

- vi. A robust monitoring system of the Work Capability Assessment by impairment group, to ensure that we fully understand the implications of the changes on people with a learning disability.
- vii. A full-scale review of the additional costs of disability before reforming the Disability Living Allowance. Not doing so risks getting this reform wrong.
- viii. The DLA/ PIP mobility component to remain for those in residential care homes. As outlined above, this provides a vital lifeline to many people in residential accommodation.
- ix. Maintain the level of benefits for disabled people under the Universal Credit model. It is vital that people with a learning disability, many of whom already live on the poverty line, do not lose out on benefits as a result of the changes to the benefit system.
- x. Allowances to continue to be made and further improved within the Housing Benefit system for people with a learning disability, including those with milder learning disabilities.
- xi. An exempt accommodation system that works for people with a learning disability, particularly those with more specialist needs. This is vital to ensure that independent living for those with higher support needs can also be accomplished.
- xii. A Support for Mortgage Interest System that ensures that the Home Ownership for People with Long-term Disabilities model can continue. This will ensure that another avenue of housing for people who often struggle to find a suitable home is continued.
- xiii. Improved co-operation between social services and housing departments locally as well as better forward planning; Community Care Assessments to include housing on all occasions. This will ensure that Local Authorities are more fully aware of housing and support needs locally and can act responsibly.
- xiv. Better co-operation also between the police and Local Authorities on hate crime and safeguarding. This will ensure that they will have shared responsibility and incidences don't get lost in bureaucracy.

- xv. Police to take disability hate crime as seriously as racist hate crime. Disability hate crime cases currently are often prioritised or even recorded as hate crime.
- xvi. A properly funded social care system which meets the needs for all individuals who require care and support in order to live independent lives.
- xvii. A nationally set eligibility criteria system to eliminate the post code lottery within the social care system
- xviii. Addressing the failures of the practice of personalisation, for example ensuring there is that there is a real choice of services, and that individuals have full access to free information and support to be fully included throughout the process.
- xix. Changing Places toilets to be included in legislation and policy, as it is a practical way of widening the independent life of many disabled people.

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review? Are the current arrangements for involvement of disabled people in policy development and decision-making working?

- 37) Mencap welcomes the fact that the Government is now regularly publishing consultations in easy-read, as this clearly makes a difference to people with a learning disability. However, there is still room for improvement. More must be done to ensure that easy-read formats are published at the same time as the main consultation, which often is not the case, and sufficient time allowed for people to respond. We would also urge more focused involvement and consultancy work of people with a learning disability via focus groups or similar.
- 38) Furthermore, we would urge the Government to engage a wider group of people with a learning disability than is currently the case to ensure that the voices of as wide as possible a group are being heard. There is a feeling among the learning disability community that consultations often only take account of the view of a few select who have access to the consultation processes and the capability to express their views, sometimes to the detriment of the silent majority, which are not being heard.
- 39) On a more local level, we regularly hear from our members that they feel that consultations are not well promoted and that there is often a lack of awareness of consultations taking place. Given that many decisions particularly on service provision are made at a local level, it is vital that local authorities take their responsibility towards consulting people with a learning disability seriously.

Respondent's details

Full name: David Congdon
 Organisation: Mencap
 Your Role: Head of Campaigns & Policy

Address: 123 Golden Lane
London EC1Y 0RT

Email Address: david.congdon@mencap.org.uk

Phone Contact: 020 7696 6952

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