



## **The Housing Challenge for People with a Learning Disability - What we see going forward**

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### ***The need***

There is no definitive numbers of people with learning disabilities, and estimates vary widely and often focus on different criteria, demographics or sample size. One of the most authoritative estimates comes from University of Lancaster's Institute of Health Research 2004 study. This study, undertaken by Professor Emerson and Central England People First Research Team in 2004, estimates there are around 1.5 million in UK with learning disabilities, 350,000 with severe learning disabilities.

These figures are broadly supported by Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century (March 2001) which states:

*“In the case of people with severe and profound learning disabilities, we estimate there are about 210,000; around 65,000 children and young people, 120,000 adults of working age and 25,000 older people. In the case of people with mild/moderate learning disabilities, lower estimates suggest a prevalence rate of around 25 per 1,000 population – some 1.2 million people in England.”*

### **Increasing population**

Learning disability is also seen to be on the rise - Independence, well-being and choice (DoH green paper March 05) estimates that the number of people over the age of 20 with learning disabilities is expected to rise expected to rise by 14% by 2021 and Valuing People states “evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years”

While the prevalence of severe and profound learning disability is fairly uniformly distributed across the country and across socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are higher in deprived and urban areas.<sup>1</sup>

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## **Housing need**

Valuing People now claims “we know that too many people still have to live in the family home when they don’t want to, too much Council and NHS money is locked into ‘out of area’ placements and too many people still live in NHS beds. Many people have to share with people they don’t get on with.”

Emerson et al estimate 75% of people with and learning disability share a house with 4 or more people, 22% more than 10 people

While many people with learning disabilities were not expected to outlive their parents increasingly people are living well into their 50’s and 60’s and this is further compounding housing problems faced

“It is estimated that a third of people with LD living in the family home are living with a carer aged 70 or over. Many are sole carers with reduced support. ...There is some evidence to suggest that up to 25% of PWLD do not become known to statutory agencies until later in life, when the parent becomes too frail to continue caring for their adult son or daughter.” (The story so far ... Valuing People, a new strategy for LD for the 21<sup>st</sup> Century - 2005)

## ***The policy context***

### **Personalisation agenda**

The entire social care policy context appears at present to be driven by the personalisation agenda. Indeed the DoH website highlights the onus being placed on personalisation not just in social care but across public service delivery.

*“Personalisation, including a strategic shift towards early intervention and prevention, will be the cornerstone of public services. This means that every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings.*

*The work on direct payments and individual budgets, alongside that of In Control, are crucial to delivering greater personalisation, choice and improved quality. They are not separate initiatives or fleeting experiments, but fundamental components of a future social care system.”*

### **Valuing People Now**

Valuing People Now can be viewed as the learning disability specific response to the personalisation agenda and has focussed attention in the sector on four key priorities.

Valuing People identified 'housing' as one of four key priorities because it recognised that "*housing can be the key to achieving social inclusion*" (ibid:19). "*The aim should be*", the Department of Health states (ibid:69), "*to provide them with ordinary housing and support services, in the least restrictive environment possible, with opportunities to lead full and purposeful lives*".

In 2007, the Government published 'Valuing People Now' – an update and progress report to its original White Paper – and re-emphasised its commitment to the Valuing People agenda. It also re-confirmed that housing remains one of its four big priorities and highlighted the fact that, although progress has been achieved in many areas, most people with a learning disability still do not have their own home (Department of Health, 2007:47).

*"Most people with a learning disability still do not have their own home. Over half of adults continue to live with their families, many into middle age and even older. Some people and their families want this to be the case – many more do not. Many others live in residential care, adult placements or other forms of shared housing that they have not chosen. Only 15% of adults with a learning disability have a secure, long term tenancy or own their own home – compared to over 70% of the general adult population who own their own home and nearly 30% who rent."*

Valuing People also revealed that where people do have their own tenancies and require support provided by a third party, it is typical that their rights as tenants are overlooked on a day-to-day basis because of their need for that support (ibid:47).

## ***The changing nature of funding***

As the move towards personalisation appears to gather speed so the nature of funding for both housing and social care can be seen to be changing:

### **Individualised budgets/direct payments**

Increasing emphasis is being placed on the assessing people's needs in a variety of ways from traditional care planning, through person centred approaches and towards self-assessment. It is also increasingly the case that the result of this assessment process is the award of an individualised budget or direct payment in lieu of direct service provision.

As local authorities continue to struggle with an overall increase in the demand for care and support provision, they have moved to tighten the eligibility criteria and to introduce an element of means testing through fairer access to care.

The result of these two factors is that more people with a learning disability are purchasing their own services, directly or through an advocate or broker and are

using a range of personal benefits and income to “top up” their state entitlement to social care.

## **Local Housing Allowance**

The local housing allowance has replaced housing benefit for all new tenancies since April this year and it is possible to view Local Housing allowance in the same light as individualised budgets or direct payments, and as part of the overall move towards personalisation.

The local housing allowance is an attempt to establish your state entitlement for your housing costs and is built around geographic market conditions and size of property required to meet need. Some people have lost out in the new system and it has been successfully challenged in the court for not providing enough housing allowance. However, there has been a positive start for some people with higher levels of disability who, if they need to, can access a higher rate of allowance. The underlying principal is that the entitlement should meet basic needs and then the individual should be free to “top up” if they choose.

## ***What does all this mean?***

Supporters of the personalisation agenda would argue that all this means an increased choice for people with a learning disability, their families and carers, and this may well be the case if both the policy context and level of funding stay in balance, the fear would be that the policy context may outgrow the funding capacity.

For providers operating within the social care sector (and within this I include the provision of the supported accommodation) a number of things seem to be clear:

- There are growing aspirations and expectations from the people we support and their families and carers. This is fuelled by both observing the options and solutions that others have obtained and the notion of paying directly for a service.
- The overlapping of a number of different policy and funding streams, together with the above raising of expectations is adding to complexity of service delivery.
- All parties, individuals, families, commissioners and providers are accessing increased choice in who supports and how and this is driving “churn” in service provision.

In short it would appear that the days of one provider, being paid to support a person by one funder over an extended period and part of that person’s life are over.

## ***GLH's response***

The approach GLH has taken over the past 10 years has been one of a specialist provider of supported housing for people with learning disabilities, and as such we have always been faced with the challenge of managing this “niche” between traditional housing provision (RSL, LA's & private landlords) and care and support provision. This still feels right going forward. We are there to reach the individuals that other organisations cannot reach.