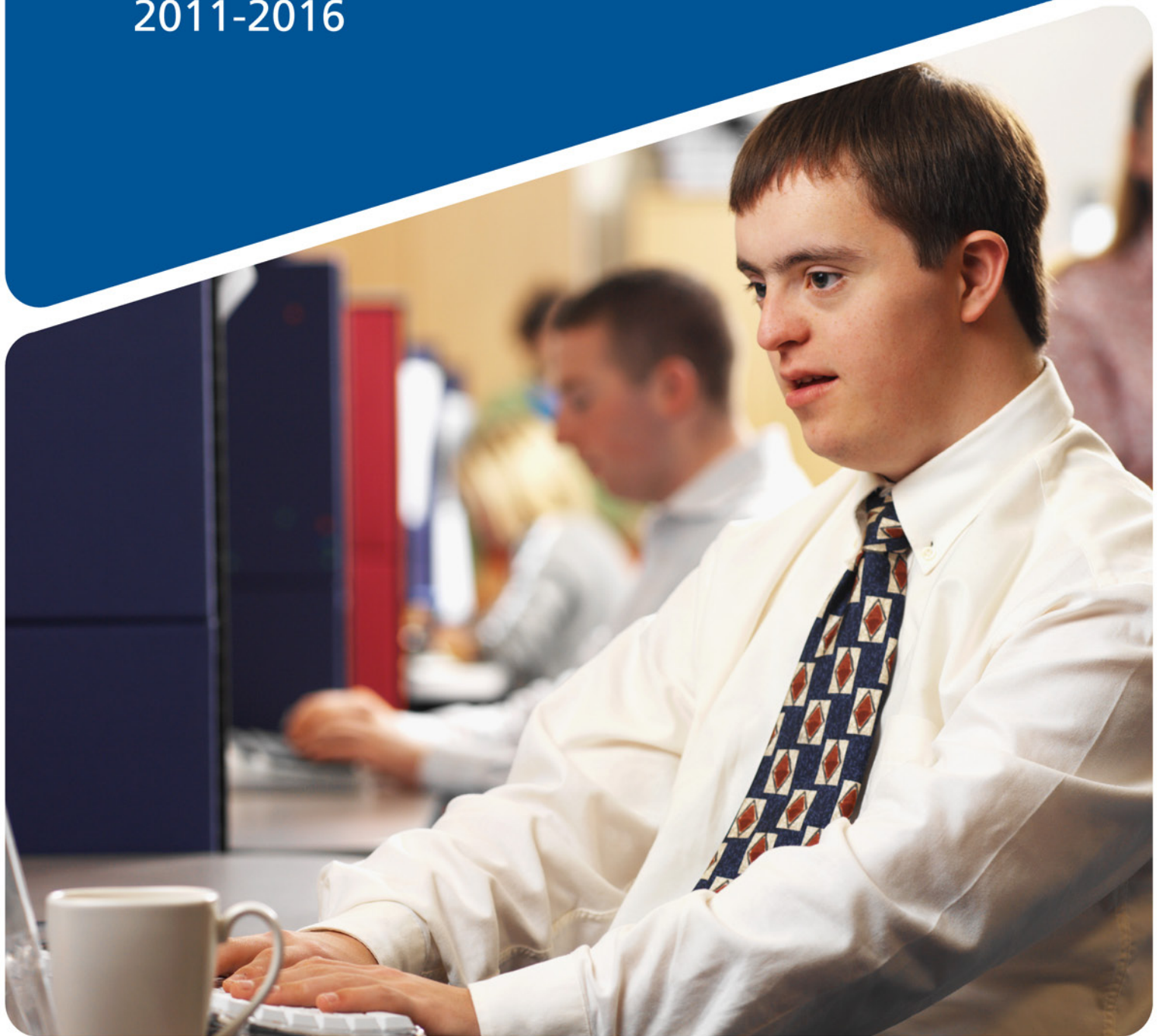




London Borough  
of Hounslow

# Joint Commissioning Strategy for People with Learning Disabilities and Autistic Spectrum Conditions

2011-2016



**NHS**

*Hounslow*

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## 1. Introduction

- 1.1 The next five years will be a period of major transition for health and social care. Local authorities are undergoing efficiency programmes and experiencing major transformations in the way they provide and commission services with the introduction of the Personalisation Agenda. This will offer residents greater choice and control over every aspect of their lives, from the place where they live, to the way they choose to access support and care. Personalisation includes access to education, employment, leisure and social opportunities, so that they are enabled to live full and rewarding lives. In Hounslow, the local authority takes the strategic lead for commissioning services for residents with a learning disability, although a joint approach to commissioning has been in place for some time.
- 1.2 Similarly, changes to the way the NHS commissions its health service and efficiency programmes, combined with the probable introduction of Personal Health Budgets, will place greater emphasis on the need for us to make mainstream, and universal services, more widely available and accessible to residents with learning disabilities and Autistic Spectrum Conditions (ASCs).
- 1.3 The combined budget of the London Borough of Hounslow and NHS on commissioned services, for residents with learning disabilities during 2010/11, was £25,472,980. This strategy will be implemented in the context of reduced public funding, major transformation of public services and the move to GP commissioning. Our strategic aims will need to be delivered within existing and reduced resources, so the focus is on reshaping and reconfiguring existing services to deliver the planned improvements.
- 1.4 It is important, during this period of change, that we work together to ensure we commission efficient and effective services that our residents with learning disabilities, Autistic Spectrum Conditions (ASCs) and their carers, will want to choose to access. In this Joint Commissioning Strategy we set out our strategic aims which have been shaped and informed by local residents and national policy, together with our assessment of the current and expected needs of our residents.
- 1.5 We will continue to prioritise engagement and involvement of our resident, and professional stakeholders, to inform our future commissioning intentions and service developments. This is a 'live' strategy, it will be reviewed frequently, to take account of the changing national policy agenda, and local developments informed by what we know about the changing needs and requirements of our residents.

- 1.6 We have set out our four key strategic aims which are underpinned by a number of objectives:
- To improve the choice and control residents with learning disabilities and ASCs have over the decisions that affect their lives;
  - To reduce health inequalities by increasing access to, and take up of, universal health and wellbeing provision for residents with learning disabilities and ASCs;
  - To increase access and availability of local housing options to enable residents with learning disabilities and ASCs, to live as independently as possible, in a place of their choosing;
  - To strengthen quality across the range of services for residents with learning disabilities or ASCs;
- 1.7 This strategy crosses over with a number of other local strategies, such as the Personalisation Strategy; the Joint Commissioning Strategy for Older People's Mental Health Joint Commissioning Strategy and our End of Life Joint Commissioning Strategy.
- 1.8 There are also a number of cross cutting themes within this strategy that shape the values by which we intend to commission services for people with learning disabilities or ASCs:
- Residents are able to exercise more choice and control over their lives, using individual budgets to purchase tailor made services that can respond to their needs;
  - Residents have the same opportunities to access universal, health and social care services as everyone else;
  - Residents are able, through the promotion of independence, to live full and rewarding lives, including employment, education and housing;
  - Residents are able to take positive risks that allow people to prosper, develop and live in the local community;
  - Services will provide value for money ensuring quality support with transparent pricing structures.
  - Residents going through transition will be supported to access adult social services in a seamless manner.
- 1.9 It is important to emphasise the emerging needs of people with ASCs, including children and young people. In this strategy, we begin to set out our intentions to increase the identification of residents with an ASC, and how best we might meet their needs. To support these aims and objectives, we have set up a dedicated project, to drive forward this work in the first year of our strategy. We will use what we learn to further develop our commissioning plans.
- 1.10 Our strategic aims will build on the achievements we have made over the period of the last strategy and these include:

- Development of an adult placement scheme 'Shared Lives';
  - Commissioning of Speak Out, a user led advocacy, consultation and engagement service;
  - Increased support to older and black and minority ethnic carers;
  - Commissioning of a specialist employment service;
  - Development of community safety initiatives, including piloting a safe haven scheme; introducing message in a bottle scheme for independent tenants and awareness raising with the police, fire brigade and ambulance service.
- 1.11 This strategy has been commissioned and approved by the Hounslow Learning Disability Partnership Board, who will oversee its implementation during 2011-2016. The Partnership Board is comprised of representatives from health and local authority service commissioners, providers, private and voluntary sector providers, carers and services users. Work on the strategy will be progressed each year through the annual commissioning intentions and an annual action plan.
- 1.12 This Joint Commissioning Strategy for People with Learning Disabilities and ASCs has also been approved by NHS Hounslow and London Borough of Hounslow.

## 2. Demographic Profile and Needs Assessment

This section provides a high level view of the range of needs our residents with learning disabilities and ASCs are likely to experience. Greater detail is provided in Appendix One.

### 2.1 Learning Disabilities

- A learning disability is caused by the way the brain develops. There are many different types, and most develop before a baby is born, during birth or because of a serious illness in early childhood.
- A learning disability is lifelong and usually has a significant impact on a person's life. People with a learning disability find it harder than others to learn, understand and communicate.
- People with profound and multiple learning disabilities (PMLD) need full-time help with every aspect of their lives - including eating, drinking, washing, dressing and toileting.
- Some people with learning disabilities exhibit challenging behaviours, including self injury and self neglect.
- Approximately twenty people in every thousand have a learning disability, of these 4.6 of these are likely to be known to local health and social services.<sup>1</sup>
- As of 1<sup>st</sup> February 2010 there were 580 people registered with Hounslow GPs with a learning disability.
- Children with a learning disability are often socially excluded and 8 out of 10 children with a learning disability are bullied. Half of all families with a disabled child live in poverty.<sup>6</sup>
- A higher proportion of people with learning disabilities are reaching older age, therefore, we need to ensure that we provide equitable services.
- In terms of ethnic monitoring, British remains the highest category of people with a learning disability, and Asians as the second highest.
- The majority of the people affected have a mild to moderate learning disability, but there are a number of young people coming through transition with profound and multiple learning disabilities and ASCs.
- People with learning disabilities experience health inequalities and are more likely to have poorer overall health.<sup>2</sup> They are 58 times more likely to die aged under 50 than other people. Four times as many people with a learning disability die of preventable causes, as people in the general population.
- Nationally, 75% of GPs have received no training to help them treat people with a learning disability.<sup>3</sup> In Hounslow, however, 80% have recently received training.

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<sup>1</sup> Emerson, Eric and Hatton, Chris (2008) Estimating Future Need for Adult Social Care for People with Learning Disabilities in England

<sup>2</sup> DH (2001) Valuing People: a new strategy for the 21<sup>st</sup> Century

<sup>3</sup> Facts about Learning Disability; Mencap: <http://www.mencap.org.uk/page.asp?id=1703>

- It is estimated that there is a 40% prevalence of mental health problems associated with learning disability. Furthermore, 3% of people with learning disabilities, compared to 1% of the general population suffer from schizophrenia, and there is also a greater risk of dementia.
- Hounslow has over 350 16-18 year olds who are not in education, employment or training (NEET), of these, 20% have a learning difficulty and/or learning disability.
- The proportion of adults with a learning disability in employment is little higher than the London average.<sup>4</sup>

## 2.2 Autistic Spectrum Conditions

- An Autistic Spectrum Condition (ASC) is a developmental condition affecting the way the brain processes information. It affects the way a person communicates and relates to others.
- People with an ASC often find it difficult to read signals; i.e. facial expressions, tone of voice and body language; that most of us take for granted. There are three common areas of difficulty that all people with an ASC have:
  - difficulty with social communication
  - difficulty with social interaction
  - difficulty with social imagination<sup>5</sup>
- While people with autism often have an accompanying learning disability, people with Aspergers Syndrome and High functioning Autism, generally do not have an additional learning disability, in fact, they are often of above average intelligence.<sup>6</sup>
- A recent study in South East London, estimated the prevalence of childhood autism at approximately 1% of the population.<sup>7</sup>
- If the prevalence rate of 1% found by SNAP was applied to the Hounslow population aged 5 to 16 years (June 2009 GP registered data) we would expect to see 354 cases.
- Over time, there will be increasing numbers of adults with an ASC within the borough of Hounslow. At present, a total of 146 young people below the age of 18 are identified.
- There are more people in Hounslow with an ASC than is currently known, both with and without a learning disability. This strategy will try to ensure that they are supported to access appropriate support from health and social care services.

## 2.3 Finance and Performance

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<sup>4</sup> LBH Joint Strategic Needs Assessment 2009

<sup>5</sup> Autism UK: [www.autism.uk](http://www.autism.uk)

<sup>6</sup> <http://www.asdcare.com/whatis.htm>

<sup>7</sup> (Baird et al, Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), The Lancet 2006; 368:210-215)

- 2.3.1 The summary of our needs assessment for people with learning disabilities, indicates a growing demand for care and support .There are higher numbers of younger people with complex and profound learning difficulties approaching transition, and, increasingly, more people with learning difficulties living longer and experiencing more complex additional problems eg dementia. It is likely that there will be more demand for services from residents with ASCs. The number of young people and adults we know about are increasing year on year.
- 2.3.2 This increase in demand will place inevitable pressures on NHS, social care and housing support. This pressure comes at a time when the focus is on obtaining ever greater efficiencies from our commissioned services. We are clear that there is no new money to invest, and in some cases, there will be budget reductions, so all of our service improvement plans must be achieved through reconfiguration of our existing resource. The impetus is also on us to develop joint commissioning solutions and increase our partnership working to develop our main strategic priorities. This will involve considerable partnership working with families, carers, universal and mainstream services, and other statutory and commissioned services.
- 2.3.3 In Appendix Four, we outline our estimated expenditure on learning disability services. The total budget for 2010/11 was £25,472,980 but this is likely to be an underestimate of the full costs. For example, we are not able to disaggregate spending on primary or emergency care, nor do we show costs for acute hospital care or prescribing. It will be important for us to develop a tool for estimating these costs, to provide a fuller picture, and inform future planning.
- 2.3.4 The overall expenditure does not include provision for ASCs. This would appear in children’s health, social care and education costs and, possibly, in adult mental health costs. We will endeavour to better understand these costs as part of the current Autism Special Interest Group.
- 2.3.5 Overall the expenditure breaks down by commissioning organisation as follows:

<b>London Borough of Hounslow</b>	<b>NHS Hounslow<sup>8</sup></b>
£19,824,802 <sup>9</sup>	£5,648,178

<sup>8</sup> These costs are those that are specifically attributed to learning disability – there will be other costs, such as universal health services, that are not shown here.

<sup>9</sup> The above LBH figure includes the transfer of funding from NHS to the Local Authority for residents of long stay hospitals resettled under the section 28a agreements

- 2.3.6 Further work regarding the transfer of NHS Learning Disability assets to LBH will continue to be negotiated and agreed in the coming year.
- 2.3.7 The bulk of our expenditure is on residential placements, and supported housing, at 38% and 22% of the budget respectively. We are keen to develop schemes to move more of our expenditure from residential, into supporting independent local living for our residents, including offering meaningful day opportunities.
- 2.3.8 As part of the London Borough of Hounslow and NHS efficiency programmes we are anticipating the need to review Learning Disability expenditure and compare spend against other care groups.

## **2.4 Performance**

- 2.4.1 Although there are no specific national targets for learning disability or ASCs, there are a number of initiatives which aim to drive up standards in access and care eg introduction of a local enhanced service for annual health checks. Other initiatives are:
- Employment of People with Long Term Conditions, as a measure of enhanced quality of life<sup>10</sup>.
  - The 2010 Learning Disability Health Self Assessment has resulted in a detailed action plan submitted to NHS London;
  - Implementation of the Big Health Day to promote and obtain feedback on access to health services;
  - Valuing People annual self assessment;
  - Campus closure target for long stay NHS patients by December 2010.
  - The Green Light Toolkit, working towards accessible mental health services for people with learning disabilities;
  - Development of an Autism work plan addressing ten priority areas.

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<sup>10</sup> The NHS Outcomes Framework 2011

### 3. Strategic Aim One: Improving Choice and Control

When we asked local residents with learning disabilities about their needs they told us:

- *Residents thought they made quite a lot of choices about their life and more than they used to;*
- *Residents do not always remember how new policies might benefit them and therefore, do not always come forward to access new initiatives;*
- *What residents do during the day is the most important thing to them;*
- *Mostly residents are happy with what they do during the day and feel day centres are very important;*
- *Outings are very important to residents and they feel they don't have enough;*
- *Residents do want jobs and but some didn't know how to find a job.*

#### 3.1 Strategic Aim

3.1.1 To improve the choice and control residents with learning disabilities and ASCs have over the decisions that affect their lives:

- Increasing take up of options for residents to decide upon and commission their own care and support, including Self Directed Support, personal budgets and individual service funds;
- Increasing choice and access to meaningful day opportunities, including mainstream and universal services;
- Engendering a culture where residents are encouraged and supported to take positive risks to develop personally;
- Improving transition from young persons' to adult and adult to older persons' services;
- Increasing access to information, advice and advocacy.

#### 3.2 Why is this one of our priorities?

3.2.1 **Self directed support and personal budgets:** It is widely acknowledged that residents with learning disabilities or an ASC, do not receive the same opportunities to make important decisions that affect their lives, as everyone else does. The remodelling of services, to provide a greater emphasis on meeting individual need, is viewed as essential to meeting the outcomes residents regard as important. It is envisaged that greater choice and control via the Personalisation Agenda<sup>11</sup> will facilitate this. During the life of this strategy there will be a major transition phase in the commissioning, and

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<sup>11</sup> <http://www.puttingpeoplefirst.org.uk/>

provision, of social care and support, as Personalisation is implemented, both locally and across the country.

- 3.2.2 Self Directed Support is the name given to the redesign of the social care system, adopted by Hounslow, giving users much greater control over services they use. The new system of personal budgets, gives residents who use social care, the opportunity to control the resources allocated for their support. Moving away from traditional service delivery to self-directed support, requires changes in the way the Borough commissions social care. Residents will, in effect, have the opportunity to become commissioners of their own services.
- 3.2.3 However, when we consulted with residents with learning disabilities, it became clear, that people did not always remember new policies and ways of accessing or commissioning their own services. It is necessary that we work with our residents to make these new options more accessible to them. The increased role of internal and external brokerage will be essential in ensuring that people with learning disabilities and ASC are able to exercise choice and control in their care and support.
- 3.2.4 A greater emphasis on partnership working across the traditional borders of adult social care will be required, to provide truly holistic approaches to meeting individual need. Partnerships with leisure, transport, planning, faith organisations and the voluntary and private sector, are integral to providing more individualised packages of support, and improved access to universal services.
- 3.2.5 Our partnership with carers, including parent carers, will also be central to the roll out of this agenda. We are developing more detailed plans in our Personalisation Doing Group, which will incorporate the needs of residents with learning disabilities and ASCs, and their carers.
- 3.2.6 **Choice and access to meaningful day opportunities:** Residents have told us their daytime activities are important to them, and they often access support to help them learn, work, maintain health and wellbeing and enjoy leisure and social activities. The majority of these services, known as Day Opportunity Services, are provided 9-5pm, Monday to Friday, but can also include evening and weekend support services. Appendix Five details current services.
- 3.2.7 Residents have told us they would like to access more day time trips and outings; this is likely to be in response to a reduced number of organised outings offered by the day centres. It was also apparent from the consultation that access to employment opportunities, whilst available from one local

provider, is an issue as residents would like increased opportunities for paid or voluntary work.

3.2.8 The Personalisation agenda offers new ways of providing day opportunities, moving away from traditional, more institutionalised and specialist services, to services that reflect the needs and choices of our residents. During the next five years, we will modernise our day service provision and facilitate greater access to more mainstream provision.

3.2.9 **Residents are encouraged to take positive risks:** For many people risk is an accepted part of life. However, people with learning disabilities are often discouraged from taking risks. This is either because of assumed limitations or fear that they or others might be harmed.

3.2.10 However, risk taking can offer positive benefits and result in a wider range of opportunities being available for the individual. We want to encourage our residents to travel widely, take part in regular leisure and sporting activities, go to college and work and have families. Ultimately, we want our residents to have aspirations much like their non learning disabled counterparts.

3.2.11 There are however, particular vulnerabilities with this resident group, and a balance has to be achieved, so that a duty of care is provided by statutory and independent service providers and employers. Involvement of residents, their families and practitioners is essential in weighing the risks against benefits of any major plan or decision.

3.2.12 Where people do not have the capacity to consent and no family or friends to help them in making important care and treatment decisions, a specialist advocate can be appointed on their behalf. The independent mental health capacity advocacy service for Hounslow is provided by Cambridge House on behalf of all Boroughs in North West London.

3.2.13 The Mental Capacity Act (MCA) is designed to protect people who can't make decisions for themselves or lack the mental capacity to do so. Under the MCA a person is presumed to make their own decisions "unless all practical steps to help him (or her) to make a decision have been taken without success".

3.2.14 **Improving transition:** The transition from school to adulthood is a time of celebration, change and challenges for all young people. They will be making decisions about their career, their continuing education, their social life and where they live. Having access to timely and comprehensive information, advice and guidance, can be enough to help them reach their goals. For young disabled people, and those with special educational needs, more support may be needed during this time, from a range of services, to enable them to reach their full potential.

- 3.2.15 It is essential that integrated and comprehensive services are available throughout the transition process. According to the Disability Discrimination Act 1995, the population of disabled children and young people, across the UK, stood at over 770,000, and the evidence suggests this number is rising. This rise is due to a number of factors, including increased survival of pre-term babies, more effective medical interventions for those children experiencing trauma or illnesses, and greater numbers of children being identified with ASCs.
- 3.2.16 A number of different agencies are responsible for providing services to young people with learning disabilities, throughout the transition period, from 14 years. To make this transition process smoother, it is clear that collaboration and co-ordination between agencies is essential for young people who will need to have their needs individually assessed.
- 3.2.17 There is an agreed protocol in place to facilitate the transition of young people moving into adult services and the adult world. There is also a transition tracking group which maintains a list of children, so that their individual transition needs are planned for.
- 3.2.18 Data kept by the tracking group, shows a larger number of young people with learning disabilities and ASCs aged 14 to 16, who are currently being monitored as part of their transition plan (see Appendix 1 for more details). Although the numbers are too small to detect any meaningful trends, it is clear that there are likely to be increased pressures on services as this younger group transition into adult services. However, this advance warning allows us to make plans to meet their needs for local housing, education, employment, health and social care provision.
- 3.2.19 As more people with learning disabilities reach older age, it is also necessary to give consideration to the transition from work age adult to older people's services. It is not always necessary to do this at the age of 65, which is the traditional transition point. Planning should be informed by the individual's needs. For some the transition will be better earlier, and for others it might be later. One of the major service transitions is between adult mental health and / or adult learning disability, and older people's mental health services. This is especially the case, due to the increased incidence of neurodegenerative disorders, such as dementia, among people with learning disabilities. Strategic Aim Two describes this issue in more detail.
- 3.2.20 More people with learning disabilities are reaching older age therefore we need to ensure that we provide equitable services to this group of older people by ensuring they can access provision that is right for them, at every stage, and transition planning is central to the success of this.

3.2.21 The Joint Commissioning Strategy for Older People's Mental Health<sup>12</sup> outlines proposals, to further develop pathways of care for residents with a learning disability and cognitive or functional mental health problems i.e. dementia and depression / anxiety.

3.2.22 **Increasing access to information, advice and advocacy:** It has always been important that residents, especially those with additional vulnerabilities, have access to information, advice and advocacy services. Some people are not clear about their rights as citizens, or have difficulty in fully understanding these rights. Others may find it hard to speak up for themselves. By ensuring better access to information, advice and advocacy we will enable people to take more responsibility and control for the decisions which affect their lives

3.2.23 Information, Advice and Advocacy can help service users to:

- make clear their own views and wishes;
- express and present their views effectively and faithfully;
- obtain independent advice and accurate information;
- negotiate and resolve conflict.

### 3.3 What will we do to achieve this aim?

3.3.1 **Self directed support and personal budgets:** Putting People First in Hounslow – Personalisation - is working to ensure that all residents in receipt of adult social care will be offered choice, control and ownership of their support plans.

3.3.2 Developing options for the personalisation of support and care is a key aim within this and the wider Personalisation agenda. It is important that we develop effective ways of communicating personalisation options to our residents with learning disabilities and ASC, to help them find out about new initiatives that affect their lives. There are also a number of other mechanisms that will need to be put into place in order to increase the use of personal budgets and individual service funds:

- Ensuring access to good advice, information and brokerage;
- Ensuring care management and brokerage are well versed in the options and additional considerations for residents with a learning disability e.g. physical access and travel issues; supporting universal staff to work effectively with residents, including managing difficult behaviours;
- Developing universal services, and specialist services, so that residents and carers are aware of what is available, and what has been

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<sup>12</sup> London Borough of Hounslow Joint Commissioning Strategy for Older People's Mental Health 2011-16

endorsed or accredited, by the Borough, to ensure that staff have been appropriately trained in enabling residents access;

- We will also need to detail costs for available services, including any considerations for payment on achieving outcomes; for example, an employment support service could be paid a fixed fee for initial assessment profiling and action planning, a payment for the outcome of supporting the resident into employment and a ongoing payment for workplace support;
- We will also need to consider options for bulk buying of benefits for our residents such as reduced rate leisure cards;
- We will need to pilot a range of options to test what works for our residents.
- We need to think about how we can support groups of residents to jointly purchase services, and facilitate friendship and support networks eg jointly purchasing outings or leisure activities.
- Consideration needs to be given to access and travel, and ensuring services are developed to support the needs of residents eg the travel buddy scheme.
- Training and support will need to be offered to carers so they can facilitate use of personalisation options.

3.3.3 We intend to remodel our commissioned and in-house Borough day services to provide a greater range of meaningful activities, based on the individual choices of our residents. This will include expanded opportunities for community and drop in services rather than building based services. In effect, the resident will become the commissioner of their own services. It is recognised that many residents, including those with learning disabilities, may require additional support to manage this process.

3.3.4 Think Local, Act Personal Next Steps for Transforming Adult Social Care is a proposed sector wide partnership agreement moving further towards personalisation and community based support. Think Local, Act Personal is the next stage of Putting People First. The priority for adult social care is to ensure efficient, effective and integrated partnerships and services that support individuals, families and the community and reduce the need for acute health and care support.

3.3.5 It is expected that changes to the NHS will result in the personalisation of healthcare provision. The successful piloting of Personal Health Budgets in other parts of the country suggests that this will be rolled out for all non emergency NHS provision. All care group Joint Commissioning strategies will revisit this area, as and when, the changes occur.

3.3.6 **Choice and access to meaningful day opportunities:** We are planning to reconfigure day opportunities provision for people with learning disabilities,

physical disabilities, and sensory impairments. Our objectives include the provision of services which are:

- Designed and funded around each person's needs, wishes, and aspirations;
- Offering better access to preventative and enabling/rehabilitative interventions;
- Making the most efficient and effective use of available resources;
- Measurable and able to report on success in terms of defined quality of life outcomes.

3.3.7 In order that residents with a learning disability are provided with the support they need to secure and maintain employment, we will work with our local providers, to develop targeted and universal services that are accessible to this group, and meet the individual needs of people with a learning disability who want paid employment. This will require a greater focus on individual outcomes, evidenced based interventions and effective retention support.

3.3.8 **Residents are encouraged to take positive risks:** A cultural change in the way our workforce supports residents to live their lives is necessary if we are to support positive risk taking. Training to change the attitudes and expectations of staff and residents, and their carers, is being rolled out to providers. This will need to include those responsible for brokerage of packages of support and care.

3.3.9 **Improving transition:** In order to ensure consistent and timely plans are in place to support the smooth transition of young people into adult services, we will need to continue to develop joint working arrangements, and protocols between children and adult health, education and social care professional.

3.3.10 As commissioners we need to take stock of the emerging transition needs of these young people, especially those with complex needs, to ensure local provision can meet these, and therefore, reduce reliance on out of borough residential placements.

3.3.11 To achieve this aim we will need to review the needs of vulnerable young people 14 years plus, to develop our commissioning intentions for the life of this strategy (see Strategic Aim One for more details). We will also need to undertake further consultation to understand the needs and experience of residents, and their families, of the transition process, and where, if necessary, improvements can be made.

3.3.12 We will work with Joint Commissioners for Older People's Mental Health and providers, to ensure equitable access for all older people, including those with learning disabilities, and recognise that a flexible and often joint response is

required. We will make full use of referral and eligibility protocols, to enable older people with learning disabilities, access to the most appropriate care to meet their needs at the time.

**3.3.13 Information, Advice and Advocacy:** We will work with residents, and their carers, to ensure greater access, and take up, of advocacy services to support residents to make informed and positive decisions about their lives. We will continue to promote existing advocacy resources such as Speak Up groups run by Speak Out in Hounslow, the user led campaigns, engagement and advocacy service.

### **3.4 What do we want to see changed by 2016?**

- Genuine partnerships between statutory agencies and teams that facilitate real choice and control for residents with learning disabilities and ASCs;
- Contracts with providers that enable easy and accessible use of personalisation options;
- An increase in the use of personal budgets;
- A greater uptake of universal and mainstream services by residents;
- An enabling and learning culture where people with learning disabilities are empowered to take informed positive risks which lead to successful outcomes;
- Every young person with a learning disability or ASC, will have person centred transition plan, to reflect their changing needs as they reach adulthood;
- Transition plans and emerging needs of young people, are able to inform commissioning intentions for adult services, especially those, that reduce the reliance on specialist out of borough residential care;
- Increase in number of young people placed out of borough returning home when transitioning in to adult services;
- Every resident has greater access to day activities of their choice and appropriate to meet their needs;
- An increase in residents engaged and sustained in meaningful employment (eg work experience, volunteer work or paid employment).

Targets for each of these will be set as the strategy and associated actions develop.

## 4. Strategic Aim Two: Keeping Healthy and Staying Safe

When we asked local residents with learning disabilities about their needs they told us:

- *People felt they had to wait a long time for healthcare but that the care itself had improved;*
- *Lots of people were worried about going to the dentist in some cases so much that they didn't go.*

### 4.1 Strategic Aim

4.1.1 To reduce health inequalities, by increasing access to, and take up of, mainstream health and wellbeing provision for residents with learning disabilities and ASCs including:

- Targeted health promotion and screening;
- Developing pathways to meet the changing mental health needs of residents, including access to age appropriate services;
- Increasing identification of people with an ASC, and the support they receive
- Access to information about relationships sexual health and screening;
- Health and other needs of residents, within the criminal justice system, are appropriately assessed and inform decisions made about them;
- NHS Continuing Health Care;
- Keeping residents safe.

### 4.2 Why is this one of our priorities?

4.2.1 **Health inequalities:** It is universally agreed that there are links between having a learning disability and other medical conditions leading to poorer health.<sup>13</sup>

4.2.2 Communication difficulties are also prevalent amongst people with learning disabilities, including expression and comprehension. These problems contribute to barriers in accessing health care. There are also further compounding issues of consent and capacity.

4.2.3 Research supports the conclusion that people with learning disabilities experience greater variety of complexity and range of health problems than

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<sup>13</sup> DH (2001) Valuing People: a new strategy for the 21<sup>st</sup> Century

the rest of the population. This leads to a greater risk of poorer health. These conditions include<sup>14</sup> epilepsy; dementia; schizophrenia; osteoporosis; sight and hearing problems; weight problems; dental hygiene and mental health problems.

- 4.2.4 A number of high profile reports and inquiries have consistently highlighted that people with learning disabilities are effectively invisible to mainstream NHS, a position which has been fully accepted by the Department of Health (DH).<sup>15</sup>:
- 'Healthcare for All' urges all NHS bodies to ensure that reasonable adjustments are offered through all services they commission and/or provide.
  - In support of this, the DH announced the requirement of PCT's to set up a direct enhanced service (DES), to offer health checks to people with learning disabilities who are known to local services.
  - The DH operating framework for 2009/2010 vital signs, required PCT's to demonstrate, how they are meeting the recommendations, as outlined in Healthcare for All. In particular, access to general health services, and to state what reasonable adjustments are being made in service delivery.
- 4.2.5 Research suggests people with learning disabilities have poorer oral and dental health. Consultation with residents has also revealed a concern about accessing dental and oral health care. Residents expressed anxieties about going to the dentist and many, it seems, avoid the dentist altogether. Avoidance of routine dental screening can lead to an exacerbation of dental problems and over reliance on emergency dental care.
- 4.2.6 Access to emergency services for people with learning disabilities is critical, and there is a need to improve understanding, of the complex communication needs our residents have, when accessing universal health services. This includes appropriate use of the London Ambulance Service and understanding patient triage and waiting times in A&E. Staff also need to be supported to manage challenging or difficult behaviour.
- 4.2.7 The rights of people who have a learning disability to engage in everyday activities that the rest of society takes for granted can be severely curtailed. Their rights to sexual relationships are not widely accepted. However, sexual relationships can be an important part of life, regardless of disability, and it is important to ensure that sexual health promotion, screening and treatment, including reproductive health and family planning are made accessible to people with learning disabilities and ASCs. It is also important to provide advice and support about relationships including same sex relationships.

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<sup>14</sup> Mencap (2004): *Treat Me Right – Better healthcare for people with a learning disability*

<sup>15</sup> Healthcare for All, Sir Jonathon Michael Inquiry (2008); Disability Rights Commission; Death by Indifference, Mencap

- 4.2.8 **Developing Mental Health Pathways:** It is well recognised that people with learning disabilities are at greater risk of experiencing mental health problems. It is estimated that between 25 and 40% of the population, will experience some kind of mental health problem at some time, and for some, this will be a long term problem. Mental health problems can also manifest in acute phases and include challenging and self harming behaviour.
- 4.2.9 People with learning disabilities are also at an increased risk from dementia. Research suggests that prevalence is 21.6% compared to 5.7% of the general population.<sup>16</sup> People with Down's Syndrome are also at a high risk of developing dementia. Much like the general population the problem of early onset dementia is now becoming more widely recognised. However, services currently tend to be designed to meet the needs of older people aged over 65, therefore, younger adults find there is little provision to meet their specific needs, particularly day provision, and this is even more accentuated for people with learning disabilities.
- 4.2.10 Ensuring adequate assessment, treatment and ongoing care for residents with learning disabilities and mental health problems can be a challenge, as their needs can often require very specialist interventions, and these are often not provided in one place. In order to begin to address these issues, we have developed a clinical advisory group for adults with mental health problems and learning disabilities, to oversee the implementation of the Green Light Toolkit<sup>17</sup> which focuses on implementing the mental health and learning disability protocol for shared care, and undertakes reviews of complex cases as necessary.
- 4.2.11 There are a number of challenges for each of the specific age groups experiencing mental health problems described below.
- 4.2.12 For children and young people, mental health provision is a particular challenge, as the local Child and Adolescent Mental Health Service, is only able to work with children with mild and moderate learning disabilities, and the Borough based Challenging Behaviour Project are only commissioned to work with children with severe learning disabilities.<sup>18</sup> Therefore, there are significant gaps in the learning disability pathway. The capacity to provide for this group is also limited, which increases the risk of reliance on out of borough specialist outpatient and residential provision.
- 4.2.13 Acute adult mental health inpatient care is provided locally in Hounslow, however, historically, this has not always been accessible to, or appropriate for, residents with learning disabilities. This has resulted in an over reliance on

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<sup>16</sup> Mencap (2004): Treat Me Right – Better healthcare for people with a learning disability

<sup>17</sup> Green Light Toolkit Action Plan and Clinical Advisory Group Terms of Reference (for adults)

<sup>18</sup> Hounslow CAMHS Review 2010

very specialist, high cost inpatient provision, which often takes residents away from their family and community support networks.

- 4.2.14 For working age adults with learning disabilities and dementia there are several challenges. Firstly, many dementia services are designed to meet the needs of older people, aged over 65; and, secondly, these services are not specialist in managing severe learning disabilities. Therefore, well developed pathways, that support joint working between learning disability and speciality mental health teams are essential. The same is true for day provision and well considered support for carers.
- 4.2.15 For older people there is no definitive pathway for the transfer of people with learning disabilities to move into older people's services. Many people will remain under the care of the Community Learning Disability Team (CLDT). This may be an appropriate model of care where a person is already known to the CLDT and where their primary need is their learning disability. However, where a person is not known to the CLDT, and/or their primary needs become more age related (e.g. complex bereavement issues; dementia; age related physical decline; deterioration in functioning; social isolation/lack of support etc), it is thought that the older people's service may be best placed to support these individuals (with support/joint working from learning disability services where necessary).
- 4.2.16 In Hounslow, there are currently 63 older people with learning disabilities known to the Community Learning Disability Team.<sup>19</sup> There are also a number of younger adults with learning disabilities, who have experienced early onset dementia, however, the exact number of these residents is not known at time of publication.
- 4.2.17 Often children and adults with learning disabilities and mental health problems exhibit challenging behaviour, including self harming behaviour, severe self neglect and isolation leading to depression. These behaviours can cause strain within the family and caring support network. They can also make access to local services, without the appropriate expertise in managing this behaviour, problematic. Sometimes residents are excluded from local services, where there needs are high and complex, and this can lead to a reliance on high cost residential placements.
- 4.2.18 The complex needs of some people with learning disabilities and challenging behaviour can also make the task of providing an informed psychiatric or psychological assessment, and subsequent treatment, complicated. We have recently carried out a self assessment, to help us focus our energies on ensuring certain standards, in meeting the needs of residents with challenging

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<sup>19</sup> Learning disability self assessment 2010, CTPLD tracking list

behaviour.<sup>20</sup> We have developed an action plan that helps us work towards a robust set of arrangements for supporting people with these needs.

**4.2.19 Increasing identification and support for residents with ASC:** The identification and assessment of people with an ASC has been cited as a problem. The National Autism Strategy, Fulfilling and Rewarding Lives,<sup>21</sup> highlights the need for robust processes, in identification and assessment of needs for people with an ASC, and recognises the inequalities in existing provision and the need to raise awareness of ASC to better meet needs.

4.2.20 In Hounslow, ASC has tended to be identified and supported within mental health or learning disability services. However a number of people are thought not to be receiving appropriate services, as it is not clear whether these services are meeting the specific needs of people with ASC.

4.2.21 Hounslow has an autism special interest group, which has highlighted the need for identification and assessment of people with an ASC and lack of specific services available. Further work is required to establish how main stream services could be reconfigured to appropriately support people with ASC.

**4.2.22 Assessment of residents within the criminal justice system:** We need to ensure that health and other needs, as they relate to residents with learning disabilities, within the criminal justice system, are assessed, and that these are used to inform decision made about them. This also includes raising awareness of the specific needs of these residents with the police, the probation and court services and within Feltham Young Offenders Institute (FYOI).

4.2.23 The Bradley Report<sup>22</sup> emphasises the need for early identification and intervention for people in prison who have a learning disability. The report concludes that this will lead to better outcomes for individuals, by ensuring better informed charging, prosecution and sentencing decisions. In the longer term, the impact may be that more offenders can be treated in the community, ensuring that those individuals who must be in prison, can receive targeted, effective care while they are there.

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<sup>20</sup> Self Assessment of People with Learning Disabilities with Behaviours that Challenge in Hounslow (January 2011)

<sup>21</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

<sup>22</sup> Lord Bradley's Review of people with mental health problems or learning disabilities within the criminal justice system (2009): [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh.digitalassets/documents/digitalasset/dh\\_098699.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh.digitalassets/documents/digitalasset/dh_098699.pdf)

**4.2.24 NHS Continuing Healthcare:** NHS Continuing Health Care<sup>23</sup> criteria are used to assess whether a person should receive care funded fully by the NHS. It is awarded depending on whether a person's primary need is a health need. It can be provided in a range of settings, including an NHS hospital, a care home or someone's own home.

**4.2.25 Keeping residents safe:** We are committed to ensuring our resident's safety is everybody's responsibility, and that every adult has the right to:

- a) live a life free from fear;
- b) be treated with dignity;
- c) have their choices respected and not forced to do anything against their will;
- d) As we move towards people taking more control of their own services and who delivers them, there are challenges as to how we support residents to protect themselves from becoming victims of abuse.

**4.2.26** A report, 'Promoting safety and security of disabled people'<sup>24</sup> in April 2010 found that disabled people were more likely to experience threats and attacks on their safety than their non disabled counterparts.

- In 2009/10 there were 80 safeguarding incidents reported and investigated within the Borough.<sup>25</sup> This number is similar to previous years.
- There is no one single approach to addressing the broader issue of disability harassment and hate crime. The Home Office in April 2008 issued good practice guidance called 'Learning Disability Hate Crime'<sup>26</sup> the guidance recommends a multi agency, multi faceted approach is required to address this issue.
- The Keeping Safe, Working Together initiative is a programme that draws together a number of wide ranging 'practical' measures that aims to:
  - raise awareness amongst residents, carer's and care providers about the wider issues of community safety, including hate crime;
  - take a practical approach to 'community safety' that seeks to empower service users and carers;
  - aims to better 'connect' service users, carers and care providers with mainstream/statutory services e.g. Police, Fire Service, Ambulance Service etc.

### **4.3 What will we do to achieve this aim?**

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<sup>23</sup> Continuing Health Care is complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need.

<sup>24</sup> Promoting Safety and Security of Disabled People (2010), Equality and Human Rights Commission

<sup>25</sup> LBH Annual Safeguarding Report 2009/10

<sup>26</sup> Learning Disability Hate Crime: Good Practice Guidance for Crime & Disorder Reduction(2008), Home Office

- 4.3.1 **Reducing health inequalities:** We acknowledge that health inequalities are experienced by people with learning disabilities. By building upon the existing work, we aim to improve the equity and equality of local health care provision, against a backdrop of individual rights and decision-making, which are underpinned by the person centred planning process.
- 4.3.2 We will continue to provide annual health checks for people with learning disabilities, and ensure they include wider issues, such as, oral and sexual health. These will be followed up with an individual action plan.
- 4.3.3 We will ensure the annual check of accessibility and appropriateness of health service is continued, and explore ways to extend this to other types of provision.
- 4.3.4 It is important that we target the health needs of children and young people with learning disabilities, and support their parents and carers, in maintaining a healthy lifestyle and good physical and mental health. We also need to work in partnership with Childrens Service and Lifelong Learning to make sure our local children's education, health and social care services are able to promote good physical and mental health.
- 4.3.5 Targeted health promotion is required to raise the profile, and importance, of maintaining good physical and mental health among our residents with learning disabilities. This might be provided via day opportunities, or as part of the care management and brokerage provision. Health promotion should also be targeted at carers, so they too, can support the person they care for in looking after their health and wellbeing.
- 4.3.6 We will work with dental health commissioning to explore solutions for making services more accessible, including targeted oral health screening for our residents.
- 4.3.7 We need to address, not just sexual health issues for residents with learning disabilities, but recognise that sexual relationships, including same sex relationships, are an important issue that requires support. Sexual health providers will need to ensure their services are accessible, and that their staff are able to respond sensitively, and appropriately, to these issues. We also commission a sexuality support service that provides a range of training to providers, and one to one support to residents.
- 4.3.8 We need to work with residents and their carers, to increase their understanding of appropriate use of emergency and urgent care, including ambulance call outs. We also need to ensure the emergency care workforce is able to support residents with learning disabilities, in navigating and negotiating the emergency healthcare system, for example management of

waiting for treatment in accident and emergency departments. There is also potential for London Ambulance Service and A&E to proactively assess residents with learning disabilities, so that they are aware of their specific needs in an emergency. Residents most at risk could be referred for assessment during their annual health review. This would reduce risk for all parties and would complement the 'Message in a Bottle' scheme.

- 4.3.9 **Developing mental health pathways:** We will continue to improve mental health and learning disability services through the Green Light clinical advisory group, which will progress the Green Light Toolkit action plan, and oversee implementation and continuous improvements, to the adult mental health and learning disability shared care protocol.<sup>27</sup>
- 4.3.10 We will work with providers to ensure mental health services are accessible to all age groups.
- 4.3.11 It is important that our workforce is aware of the high incidence of mental health problems associated with learning disabilities and ASCs, so that they are able to sign post and refer, as necessary, to the appropriate services.
- 4.3.12 We will work with children's services, to address the gap in provision for those children, young people and their families, who require specialist assessment, treatment and ongoing care, by developing pathways of care that enable local support rather than a reliance on residential care.
- 4.3.13 In order for us to provide local, acute mental health inpatient care, we need to develop local services, so that we can offer assessment and treatment, locally, rather than relying on very specialist providers.
- 4.3.14 We will develop our workforce to become skilled in managing challenging behaviours i.e. in some universal health and care services, and ensure there are specialist professionals, who can take specific referrals when behaviour is a primary concern for the resident and their family / carers. Continued development of the Hounslow Community Learning Disability Challenging Needs Service is critical if we are to meet this objective and to reduce out of borough residential placements.
- 4.3.15 For younger adults and older people, we will need to work with providers to ensure we have well developed pathways for those with learning disabilities and dementia. This is not just about enabling access to specialist assessment and treatment, it will also entail providing suitable, and wherever possible, age appropriate day provision and follow up care. This work will be overseen by

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<sup>27</sup> The Clinical Advisory Group is also tasked with developing a protocol for residents with a learning disability accessing West Middlesex University Hospital.

the Older People's Mental Health Forum as part of the reconfiguration of the Cognitive Impairment Pathway.

- 4.3.16 We also need to provide support for carers, to ensure their mental health needs are assessed and addressed to enable them to continue with their caring responsibilities.
- 4.3.17 We will work with partners to deliver the standards for People with Learning Disabilities and Behaviours that Challenge.
- 4.3.18 **Increasing identification and support to residents with ASCs:** We need to consider ways to increase the identification of residents with an ASC, and to ensure appropriate support services are in place, to meet their needs, and reduce the risk of isolation and social exclusion. This will be addressed as part of a project running during 2011 aimed at better understanding the local needs of people with an ASC, and how we, as commissioners, can meet these needs.
- 4.3.19 **Assessment of residents within the criminal justice system:** We are rolling out awareness training with magistrates, probation officers, and court liaison workers to increase the understanding and increase the chances of intervening early for residents within the criminal justice system.
- 4.3.20 **NHS Continuing Healthcare:** The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, sets out the factors that are considered, to decide whether someone meets the criteria for NHS Continuing Healthcare. NHS Hounslow is reviewing NHS funded learning Disability Placements, to ensure that resources continue to meet identified needs, and resettlement plans are agreed for all clients. We are focussed on reducing high cost and out of borough residential placements wherever possible.
- 4.3.21 **Keeping residents safe:** We will work with residents, their carers and families so that they are aware of how to raise concerns, and know that appropriate action will be taken to investigate and deal with any allegations.
- 4.3.22 We will work to ensure that substantiated cases of abuse are appropriately managed, and that lessons learnt are fed back in to policy and service development.
- 4.3.23 The Keeping Safe and Healthy sub group of the Learning Disability Partnership Board, has identified the need to be pro-active in the area of wider 'community safety'. To this end, it has developed an initiative called 'Keeping Safe, Working Together', in order to, address the harassment and hate crime issues that affect people with learning disabilities.

#### **4.4 What do we want to see changed by 2016?**

- Universal health services providing full and equal access to quality healthcare;
- 100% of all residents with a learning disability in receipt of an annual health check and action plan;
- An increase in targeted health promotion for residents and their carers, including children and young people;
- Fewer oral health and dental problems among our residents and less reliance on emergency dental care;
- A well established pathway for children and young people with learning disabilities and ASCs, who also have a mental health problem; and a reduction in out of borough assessment, treatment and residential care;
- A well established pathway for, and protocols for sharing care of residents with learning disabilities and mental health problems;
- A cognitive impairment pathway that provides age appropriate assessment, treatment and follow up care for residents with learning disabilities including protocols for shared care;
- Better diagnoses and identification of people who may have an ASC and appropriate care/support plan in place.

Targets for each of these will be set as the strategy and associated actions develop.

## **5. Strategic Aim Three: Improving Choice and Access to the Places People Live**

**When we asked local residents with learning disabilities about their needs they told us:**

- *People didn't always know who to talk to about housing choices, or if they were unhappy with the place they lived in, but felt having someone to talk to was the best way to receive information and consider options;*
- *People want a place where they can test out living independently but with support on hand;*

### **5.1 Strategic Aim**

5.1.1 To increase access and availability of local housing options to enable residents with learning disabilities and ASCs to live as independently as possible in a place of their choosing:

- To increase access to information and advice on housing opportunities and practical support to obtain housing;
- To promote and support independent living;
- To increase availability of a range of supported living options to enable residents to remain living locally;
- To develop housing solutions for those with complex health and/or behaviour needs to reduce reliance on high cost residential care.

### **5.2 Why is this one of our priorities?**

5.2.1 Adults with learning disabilities and ASCs have the same rights as their fellow residents, to access housing in the borough, which enables them to live full and independent lives, wherever possible. Where additional support needs are required that housing options are developed to meet these needs.

5.2.2 Housing support can range from providing assistive technology in the family or resident's home, making day to day living easier and safer, through to support with maintaining a tenancy and providing supported housing, which offers residents with additional needs day to day support.

5.2.3 When a resident's needs are very complex or specialist, it will be necessary to seek a specialist residential solution, and at present, this can mean a placement out of the borough. However, we intend to reduce the requirement for this over the life of this strategy, so that monies invested into high cost

residential placements, might be reinvested into local, long term and sustainable provision.

- 5.2.4 We do, however, recognise that, for some, independent living will not be an option, and we will ensure that these support needs are met.
- 5.2.5 It is also important that we make sure provision meets the needs of young people with learning disabilities as they become adults, and reach the point in their lives where, they too, will wish to exercise choice over the place that they live. At present, we have a higher than expected number of young people placed away from home in residential accommodation. As these young people transition to adult services, it is critical that we have made sustainable provision locally. Consultation with parents and carers, has also increased our awareness of their desire to be supported in exploring, and viewing, local housing options, to help them, and the young person they care for, make considered plans well in advance of transition. They are keen to access local independent living options so that their family can remain close.
- 5.2.6 We need to be mindful of resident's changing housing needs when they transition from working age adult services to older people's services, usually at 65 years of age unless otherwise indicated.
- 5.2.7 Residents need also to be able to access appropriate advice and, where necessary, advocacy, regarding benefit entitlements; tenancy agreements; complaints procedures; and support with moving home as needed.
- 5.2.8 As the Personalisation agenda develops it is envisaged that residents will be more in control of the choice of place that they live. There is also the possibility that groups of residents with similar needs could jointly commission supported housing options.
- 5.2.9 The current housing profile for people with learning disabilities shows that:
- We currently estimate that 195 live in the family home, and of these, 142 live with carers over the age of 60, and 21 people live with carers over the age of 75.
  - There are approximately 185 people with moderate to severe learning disabilities living in their own tenancies in Hounslow. A further 73 live in supported accommodation, and 43 live in residential accommodation within Hounslow.
  - There are currently 149 people placed outside of the borough in a variety of services ranging from specialist hospital settings to residential services.
- 5.2.10 During 2009/10 NHS Hounslow funded 58 out of borough residential placements. The London Borough of Hounslow funded a further 91 placements. Many people that are placed out of the borough have complex

and challenging needs that cannot be met by existing local services. This is particularly the case for children and young people, who may need to access suitable education opportunities or because local services are not sufficiently developed.

5.2.11 There are occasionally other reasons for an out of borough placement such as when a resident's family moves and he or she wishes to remain close to the family's new address.

5.2.12 Much progress has been made in developing appropriate housing options since the last Learning Disability Commissioning Strategy:

- In 2010 a Shared Lives Scheme (Adult Placement Scheme) was developed in partnership with the London Borough of Richmond, to provide five long term placements and additional short term respite placements across Hounslow.
- Over the last few years two residential services have been remodelled to become supported housing, providing greater choice and control for people residing in those settings.
- There has also been limited success with supporting people in to independent tenancies, both within the private and social housing sectors, over the last few years with nine supported in to independent tenancies.
- Work is progressing with Housing services and the local library service to provide accessible information about the choice based letting system and other housing options available.

5.2.13 However, there are still substantial challenges and barriers in enabling access to appropriate housing, and providing housing related support to sustain independent and supported living.

### **5.3 What will we do to achieve this aim?**

5.3.1 We will work with housing and advocacy partners to ensure our residents are able to seek and access advice and information to address their housing concerns including:

- Advice regarding benefit entitlements;
- Housing options;
- Support with complaining and resolving housing issues;
- Support with moving home;
- Tenancy sustainment .

5.3.2 We will work with residents, their carers, care managers and housing providers, where necessary, to ensure that support packages are in place to enable independent living, whilst preventing social isolation including:

- Access to a range of assistive technology;
- Enabling people to travel independently i.e. promoting the use of the travel buddy services and peer support;
- Transition planning to enable greater choice in a place to live.
- Connecting people with their local communities and assisting them to access the full range of community services and facilities

5.3.3 We will continue to develop the adult placement scheme 'Shared Lives', offering five long term and 10 respite placements.

5.3.4 We will use current information about our learning disability and ASC populations to plan, and develop, suitable housing solutions, to enable residents to live locally, and reduce reliance on expensive out of borough residential placements:

- This will include obtaining resident views, experiences and feedback by asking about their housing support needs, and ascertaining how well these are being met, through the annual review process. This information will be collated and used to inform strategy development.
- We will need to carry out a specific review of the housing needs of residents with complex health and behaviour needs, including children who will be transitioning into adult care during the life of this strategy. This will determine how we can support the return home for those who are currently in residential care, and how we enable those who live locally, to do so, for as long as possible.
- In order to ensure a full assessment of current and future need, we will also review the needs of those with less complex health needs, including children, who nevertheless are at risk of being placed in residential care, for a range of reasons e.g. lack of local provision, to develop local housing solutions and the necessary local support.
- We will assess the needs of residents living with older carers who may have health and social care needs of their own.

5.3.4 We will use this information to work with partners in the Borough and Housing partners to develop a housing strategy to meet these needs.

5.3.5 We will also work with other boroughs as necessary to develop joint housing solutions where the economic case is indicated.

5.3.6 There is considerable work to be done with providers in moving from traditional residential care, to provision that enables greater independence

through supported living. This is likely to involve moving from block contracting to individualised arrangements.

5.3.7 In order to facilitate opportunities for people to live locally, greater emphasis will need to be placed on workforce development. This will include the assessment of skills within existing services, to meet the needs of people with complex and challenging needs, particularly those planning and providing support in housing developments.

5.3.8 We have commissioned a post within the Community Learning Disability Team, which is dedicated to promoting the use of assistive technology to support people to be able to live as independently as possible.

5.3.9 The Housing Doing Sub Group of the Learning Disability Partnership Board has a multi disciplinary membership, and is actively working towards improving accessibility and housing choices for people with learning disabilities. The group has developed an action plan to address these strategic issues and to ensure residents get the support they need.

#### **5.4 What do we want to see changed by 2016?**

- All residents with learning disabilities and ASCs will be able to feedback annually on their housing needs;
- Residents are aware of their rights and entitlements in regards to housing;
- Residents are able to access advocacy to support their housing needs;
- Residents have a range of housing options available to them either, in borough, or as close to Hounslow as possible;
- Greater partnership work between residents, housing officers, care management and developers in ensuring new developments are of good quality and meet the needs of people with a learning disability or ASC.
- Plans and developments are in place to enable residents with complex health and or behavioural needs, to live locally, with less reliance on out of borough residential placements;
- A workforce that is able to support residents to live locally and as independently as possible;
- An increase in the number of residents living independently.

Targets for each of these will be set as the strategy and associated actions develop.



## 6. Strategic Aim Four: Improving Quality and Value for Money

**When we asked local residents with learning disabilities about their needs they told us:**

- *Carers wish to be engaged and involved in assessments; care planning and important decisions about the life of the person for whom they provide care.*
- *Residents wanted to be involved in decisions that affect them and be treated with dignity and respect.*
- *Carers wanted to feel confident that the person they care for receive good services that help them to be as independent as possible.*

### 6.1 Strategic Aim

6.1.1 To strengthen quality across the range of services accessed by residents with learning disabilities or Autistic Spectrum Conditions by developing:

- A skilled and knowledgeable workforce;
- Holistic and comprehensive support for carers including respite;
- User led services;
- End of life care;
- Continuous improvement of partnerships;
- Monitoring and review of quality standards.

### 6.2 Why is this one of our priorities?

6.2.1 **A skilled and knowledgeable workforce:** Our workforce is an important asset, and has the potential to vastly increase access for residents with a learning disability, to universal and mainstream services, as well as, continued and appropriate use of more specialist and or targeted services. It is important that our workforce understands the needs of residents with learning disabilities and ASCs, so that they can support meeting these needs. It is well recognised that staff confidence can vastly increase the positive experience of residents accessing services. There are a range of key issues - in particular:

- Communication needs;
- Understanding of access procedures i.e. payment for services; waiting times; travel to and from;
- Managing difficult or challenging behaviours and / or distressed individuals;

- Identification of learning disabilities and other problems, such as physical or mental health concerns and ability to sign post or refer to specialist services;
  - Identification of safeguarding concerns and ability to sign post or refer to specialist services.
  - Understanding and commitment to the personalisation agenda
- 6.2.2 We have introduced the patient passport for people with learning disabilities, and undertaken a series of training programmes with key staff within hospitals and support services. The passport gives an overview of a services users health and support needs and wishes and ensure the safe facilitation and smooth pathway in and out of any hospital admission.
- 6.2.3 **Support for carers:** Carers perform a vital role in our communities, caring for loved ones and friends because they are ill, have a disability or are older. Carers need information and access to appropriate services to meet their own individual needs and to help them to continue in their caring role.
- 6.2.4 A carer for an adult with learning disabilities must deal with more than just cognitive difficulties. Often there are associated medical issues that make caring more difficult, depending on the specific disability. For example, when a child with Down's syndrome transitions into adulthood, they face a much higher risk of illnesses and conditions like thyroid disease, hearing loss, dementia and more.
- 6.2.5 Many residents live at home with their older family carers. In these instances caring responsibilities can often work both ways, with the resident looking after elderly parents.
- 6.2.6 A carer's assessment will determine, what sort of impact the role as a carer is having on their physical, mental and emotional well-being. A carer's assessment will also address educational, employment and social aspirations. The assessment is a way to provide connections between the carer, the adult for whom care is being provided, and the services required. If a carer does not qualify for services, the assessment is still valuable in that it can signpost to organisations that can provide help and support.
- 6.2.7 We recognise the value of, and need for, respite, as a service for carers of people with a learning disability or ASC, which can support people to maintain their caring role. There is a need to develop a range of flexible respite options, looking beyond building based only options, to include use of Shared Lives schemes, day opportunities and other universal services available.

6.2.8 **User led services that provide equal access:** In developing this strategy, we have engaged residents to identify their needs and priorities to inform our commissioning strategy over the next five years. We have also commissioned Speak Out In Hounslow, to run a continuous programme of involvement and engagement. In addition, it will be necessary to undertake a number of consultations to inform the many aims and objectives set out in this strategy.

6.2.9 It is no longer acceptable for organisations to view people with learning disabilities as passive recipients of services; they must be seen as active partners. Listening to, and, involving children, young people and adults with learning disabilities, features in legislation, policy and practice guidance across health, education and social care services.

6.2.10 Valuing People (Department of Health 2001)<sup>28</sup> proposes that, where possible, people with learning disabilities should have equal access mainstream services. It is not always appropriate to divert people with learning disabilities into very specialist learning disability provision, neither is it cost effective. Residents with these needs should have equal access to universal and mainstream services, and it is incumbent on commissioners, to make sure service providers are able to meet the needs of people with learning disabilities wherever safe and practicable to do so.

6.2.11 Support and services should ensure they meet the needs of individuals, including seldom heard groups, such as;

- People from minority ethnic backgrounds;
- People with complex support needs;
- People on the autistic spectrum;
- People in prison;
- People that are Lesbian, Gay, Bisexual or Transgender (LGBT).

6.2.12 People from black and minority ethnic communities who have a learning disability or an ASC, are also less likely to access public services, and are potentially at risk of double discrimination.

6.2.13 In Hounslow, there are a high number of Asian families with disabled children and young people, these families access needs have to be considered if we are to increase take up of essential services.

6.2.14 **End of life care:** It is important to recognise that residents with a learning disability will need to access end of life care. At this point, many residents will also have additional physical or mental health needs. It is therefore important to enable access to high quality end of life care planning.

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<sup>28</sup> Valuing People DoH: <http://www.valuingpeoplenow.dh.gov.uk/>

6.2.15 We need to ensure good commissioning governance is in place, to monitor progress of this strategy, and continuous development of our commissioning intentions.

6.2.16 Mencap commissioned a report in 2008 titled 'People with Learning Disabilities'. The report highlighted the lack of essential data on learning disability and the subsequent effect this would have on planning for the future.

### **6.3 What will we do to achieve this aim?**

6.3.1 **A skilled and knowledgeable workforce:** We will develop a workforce strategy to enable services across the Borough, to open up access to residents with a learning disability, and ensures they and their carers' needs are met. We will need to ensure the strategy targets training for different groups of staff to cover the specific issues raised:

- Personalisation including access to universal services and reasonable adjustments;
- Engendering a culture of encouraging residents' personal risk taking;
- Supporting and managing challenging behaviour;
- Safeguarding and vulnerable adult protection.

6.3.2 It is envisaged that the workforce will include universal staff such as:

- Leisure and library services
- Health services
- Faith and culture groups
- Housing
- Travel providers
- Police and Fire brigade
- Ambulance staff
- It will also develop targeted or specialist staff such as:
- Social care and care managers
- Specialist Mental Health Providers
- HMP Feltham Young Offenders Institute

6.3.3 **Support for Carers:** We will work with residents and their carers to ensure greater access and take up of information, advice and advocacy services, to support residents to make informed and positive decisions about their lives.

6.3.4 Carers are our biggest resource, and we want to ensure they are respected as expert care partners, and will have access to the integrated and personalised services they need, to support them in their caring role.

- 6.3.5 Carers of residents with a learning disability or a ASC will be entitled to have their needs assessed. Carers will be supported to stay mentally and physically well and treated with dignity.
- 6.3.6 In order to better support Carers we will be undertaking a review of respite provision during 2011, this will ensure a transparent and equitable process for the use of respite provision. We are working towards modernising traditional bed based respite into respite options that reflect residents' choice, for example day time activities; weekend breaks or holidays.
- 6.3.7 We will continue to ensure young carers are able to access support and peer support, including emotional wellbeing and mental health. We will work with children's services to raise the profile of young carers support needs among the children's and adults' workforce, including schools and adult services.
- 6.3.8 **User led services that provide equal access:** We will continue to develop our engagement and involvement strategy with residents and their carers, including a specific focus on:
- Young people and their families and carers, preparing for and undergoing the transition to adult services;
  - Older residents and their carers on their experience of the transition process to adult services;
  - Consultation on housing needs;
  - Consultation with residents and families with complex health and behaviour needs, to establish ways to increase local support and reduce high cost of out of borough care;
  - Consultation with people with an ASC to establish what their main support needs are;
  - Support residents with learning disabilities and ASC to establish how best we can ensure universal services can be developed to meet their needs.
- 6.3.9 Speak Out in Hounslow, have been commissioned to provide consultations and carry out peer reviews of services provided. This has, and will continue to enable, a more joined up approach to service improvement and user engagement.
- 6.3.10 The access needs of residents, children, young people and their families from Asian and other minority ethnic groups, need to be reviewed across the spectrum of universal to specialist and targeted provision.
- 6.3.11 As older residents reach end of life, it is important that we ensure they, and their carers, are able to access the same advice and support planning, as

other residents, and that consideration is given to dignity in death, choice in place of death, lasting power attorney and supporting carers during and beyond end of life care, with bereavement and ongoing support, care and housing needs. We will work with our end of life care providers, to ensure residents with a learning disability have equal access to high quality end of life care, that focuses on dignity and consideration for individual needs.

**6.3.12 Continuous improvement of partnerships:** The Hounslow Learning Disability Partnership Board, is made up of key stakeholders, who can bring about change and include people with learning disabilities, their carers, London Borough of Hounslow, Hounslow and Richmond Health Care Alliance, NHS Hounslow and Service Providers. The Board was set up in response to the Valuing People, and oversees the programme of implementing the recommendations of this paper.

6.3.13 There are a number of sub groups focussed on improving the lives of people with learning disabilities that report to the partnership board, each have specific work plans that look at how services work, and are tasked with making practical changes and improving outcomes focused on the following areas:

- Housing
- Personalisation
- Keeping Safe & Healthy
- What we do during the day, evenings and weekends

6.3.14 A newsletter 'You say, We say' is published on a quarterly basis, providing updates on the work of the sub groups and partnership board. There is wide circulation of the newsletter including to providers and users, carers and families. We will review this to seek greater representation of resident's views on learning disabilities services and support.

6.3.15 We are aware of the need for clear information regarding the needs of people with learning disabilities, in order to, appropriately commission and design services that will meet demand and need.

6.3.16 NHS Hounslow carries out an annual health check on health services for people with learning disabilities, and views this as an important indicator of what is working well, what is not, and where there are gaps in health services. We will explore ways to adapt the annual health check of healthcare provision so that other services are checked for access and appropriateness for residents with a learning disability or ASC. This would be of particular use for universal services, as the Personalisation agenda is developed and opens up access to universal provision.

6.3.17 We are committed to developing a system where information on outcomes derived from individual support plans is collated and assessed, to inform commissioning activity, and annual commissioning intentions. This will allow us to develop and commission services that meet the expressed, as well as, the assessed need of residents and their carers.

6.3.18 Throughout the life of this strategy, we will continue to develop local pathways of care, and we will work with providers to develop greater flexibility in the provision they offer, to meet the demands of our residents, and increase access to universal and mainstream resources. As commissioners, our priority will be to continue to drive up quality and improve choice, especially local choice and ensuring the efficiencies are achieved by maximising the most from our local resources.

#### **6.4 What do we want to see changed by 2016?**

- A well trained workforce that has the experience necessary to provide access and support to residents with a learning disability or ASC;
- Genuine engagement with residents and their carers to inform commissioning and review of, and satisfaction with, services;
- Greater confidence that residents with a learning disability or ASC have equal access to quality services and experiences comparable to the wider population;
- Evidenced reasonable adjustments have been made to ensure compliance with legislative requirements;
- Residents are treated with dignity and respect and their views are taken in to consideration in the improvement and development of services;
- End of life and palliative care providers are accessible to residents with a learning disability;
- Improved and more informed commissioning intentions and plans using information collated from health action plans; person centred transition plans and person centred support plans. These outcomes will be collated and feed in to annual commissioning intentions.

Targets for each of these will be set as the strategy and associated actions develop.

## **7. Taking the Strategy Forward**

- 7.1.1 The work to achieve our aims, as set out in this joint commissioning strategy for people with learning disabilities and autistic spectrum conditions has begun. Consultation with residents, their carers and professionals, combined with what we know about local needs, and what national policy and good practice is telling us, has provided us with four very clear strategic aims and a number of objectives for each of these.
- 7.1.2 Our focus for 2011-16 will be on the following major strands of this strategy:
- Supporting residents to live rewarding and fulfilling lives with the same choices and opportunities as their non learning disabled counterparts
  - Ensuring the health needs of our residents are met
  - Ensuring our residents feel safe and supported in the community
  - Ensuring our residents are able to live in the place that they chose and independently when this is their choice
- 7.1.3 Each year we will review achievements, outstanding areas of work, and set out our priorities for that year in a new action plan. This process will be led by the London Borough of Hounslow and NHS Hounslow Joint Commissioning team, and its successor, and undertaken in partnership with a range of stakeholders.
- 7.1.4 Overall review will be provided by the Learning Disability Partnership Board and sub groups. These groups will oversee progress and improvements in outcomes over the next five years. There will be a formal annual review of this strategy and annual commissioning intentions will be published.
- 7.1.5 The commissioning organisations will ensure the priorities outlined in this strategy are enshrined in contractual arrangements with providers, to make certain high quality care and outcomes for older people with learning disabilities problems are delivered.

## Appendix One – Needs Assessment

### What is a Learning Disability?

A learning disability is caused by the way the brain develops. There are many different types and most develop before a baby is born, during birth or because of a serious illness in early childhood. A learning disability is lifelong and usually has a significant impact on a person's life.

Learning disability is not mental illness or dyslexia. People with a learning disability find it harder than others to learn, understand and communicate. People with profound and multiple learning disabilities (PMLD) need full-time help with every aspect of their lives - including eating, drinking, washing, dressing and toileting. There are 1.5 million people with a learning disability in the UK. Like all of us, they are individuals who want different things in life and need different levels of support.<sup>29</sup>

### Learning Disability Profile

Research carried out indicates that approximately twenty people in every thousand have a learning disability, of these 4.6 of these are likely to be known to local health and social services. But these numbers vary with age.<sup>30</sup> The Improving Health and Lives Learning Disabilities Observatory has published, using a sample of selected authorities a revised analysis of the prevalence of people with a learning disability and the tables below demonstrates the numbers of estimated people likely to be known to adult social care or health services and the likely total number of people with learning disabilities in any given area.

Area	Population	Number probably known to services	Likely True Number
England	51,808,846	236,235	1,043,449
London	7,754,000	36,434	157,932

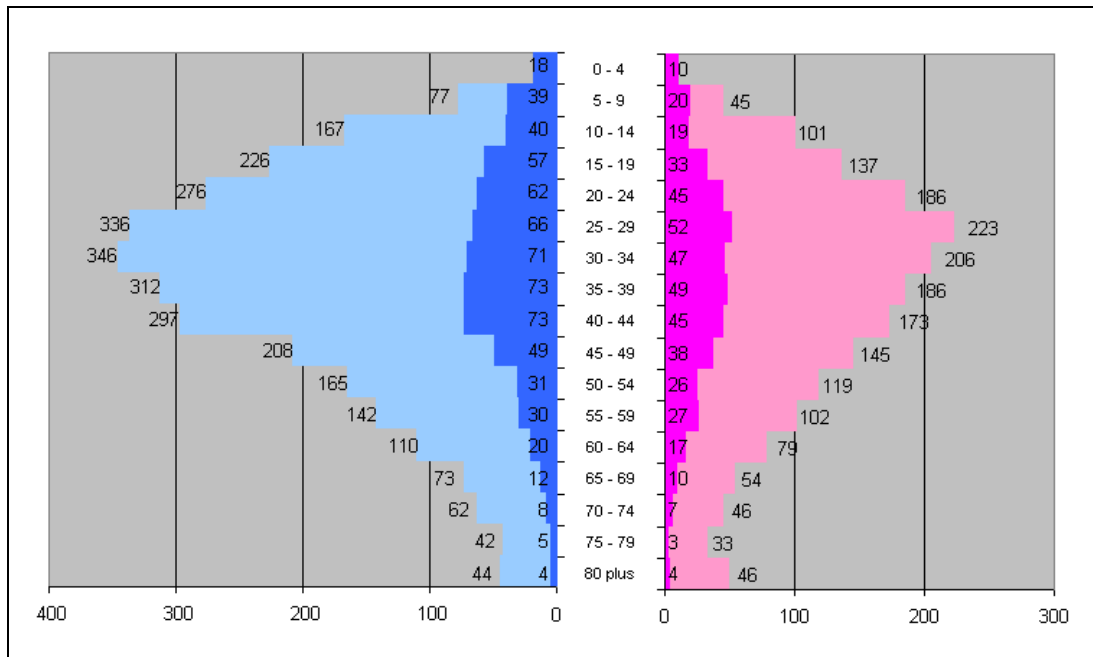
Source: *Improving Health and Lives: National Learning Disability Observatory 2010*

The Improving Health and Lives Learning Disabilities Observatory provides a gender and age breakdown of the estimated numbers of people with a learning disability both known to services and total number of people including those not known to services. Using local knowledge this breakdown appears to fit the profile of Hounslow although detailed analysis has not been completed.

<sup>29</sup> <http://www.mencap.org.uk/page.asp?id=1684>

<sup>30</sup> Emerson, Eric and Hatton, Chris (2008) Estimating Future Need for Adult Social Care for People with Learning Disabilities in England

## Learning Disability by Gender and Population Likely to be known to Services:



Source: *Improving Health and Lives: National Learning Disability Observatory 2010*

Key:	
Likely total number of males	Males likely to be known to services
Likely total number of females	Females likely to be known to services

The chart demonstrates that there is a great deal of potential unmet need; a significant amount is likely to be for residents with mild to moderate learning disabilities.

### Learning Disabilities in Hounslow

There are currently (as of 1<sup>st</sup> February 2010), 580 people registered with Hounslow GPs that have a learning disability. Of these, 450 people are domiciled within the London Borough of Hounslow and 130 people are registered with Hounslow GPs but are domiciled in the neighbouring areas. These people are supported and funded by services commissioned (residential and supported housing, nursing care, home care, equipment and adaptations, care management, respite day care etc) by the Borough and NHS Hounslow. The majority of people, especially younger, are enabled to live at home or in supported/independent housing and receive a range of community support services and funding to enable them to do so.

A number of elderly people with learning disabilities continue to be accommodated in residential care. People with learning disabilities are living longer which requires the planning and commissioning of suitable health and social care support needs and services and a need for collaborative working with older persons services.

There are various ethnic groups represented in the number of people with learning disabilities but white British remain the highest category, with Asian as the second highest.

The majority of the people with a learning disability have a mild to moderate learning disability but there are a number of young people coming through transition with profound and multiple learning disabilities and ASCs. Therefore, the profile is changing and the need to commission social and health care support and services for more complex needs is highlighted

**Number of adults with a learning disability who are known to services:**

Number		%
Age 18 to 64	501	91.09
Age 65+	49	8.91
Male	313	56.91
Female	237	43.09
Total 18+ male and female	550	100%

**Ethnic breakdown of adults with a learning disability (and percentages)**

Ethnicity	LD Clients	Percentage
01) White – British	350	63.64%
02) White – Irish	9	1.64%
03) White - Any other White background	14	2.55%
04) Mixed - White and Black Caribbean	2	0.36%
06) Mixed - White and Asian	2	0.36%
07) Mixed - Any other mixed background	9	1.64%
08) Asian or Asian British - Indian	73	13.27%
09) Asian or Asian British - Pakistani	22	4.00%
10) Asian or Asian British - Bangladeshi	4	0.73%
11) Asian or Asian British - Any other Asian background	15	2.73%
12) Black or Black British - Caribbean	8	1.45%
13) Black or Black British - African	13	2.36%

14) Black or Black British - Any other Black background	3	0.55%
15) Chinese	1	0.18%
16) Any other ethnic group	23	4.18%
17) Not stated	2	0.36%
TOTAL:	550	100.00%

## Learning Disability and Physical Health

It is universally agreed that there are links between having a learning disability and other medical conditions leading to poorer health<sup>31</sup>.

- Higher morbidity and mortality rates
- Higher rates of epilepsy, cerebral palsy and hypothyroidism being reported
- There is a higher prevalence of cardio vascular and muscular skeletal problems in certain syndromes specific to learning disability
- Respiratory diseases are the leading cause of death for people with learning disabilities and this is higher compared to the non disabled population
- Coronary heart disease (CHD) is the second highest cause of death with CHD rates rising due to the longevity of this group and the associated lifestyle changes of living in the community (e.g. smoking & diet)
- Cancer is the third highest cause of death with the patterns of cancers being different than those of the general population (e.g. lung and prostate cancer are low, with higher rates of stomach, gall bladder and leukaemia in this population)
- Higher levels of impaired vision and hearing than the non disabled population, yet are unlikely to be assessed for vision and hearing impairments and receive the appropriate aids and treatments
- Although most people with learning disabilities will have problems communicating their health needs, they receive fewer regular health checks and have a significantly lower uptake of screening services than the rest of the population, with health screening revealing high levels of unmet health needs
- Higher incidence of epilepsy with 22%, compared to 1% in the general population
- Osteoporosis younger than the general population and have increased fractures
- 40% of people with learning disability will have hearing problems
- Poor dental hygiene and dental care is also a concern it is estimated that 36.5% of adults with learning disabilities and 80% of adults with Down's Syndrome have unhealthy teeth and gums
- More likely than the general population to be over or underweight
- 58 times more likely to die aged under 50 than other people. And four times as many people with a learning disability die of preventable causes as people in the general population.

<sup>31</sup> Mencap (2004): *Treat Me Right – Better healthcare for people with a learning disability*

- 75% of GPs have received no training to help them treat people with a learning disability.<sup>32</sup>

### **Learning Disability and Mental Health**

There is a close relationship between learning disability and mental health with a greater risk of experiencing mental health problems and associated issues such as deliberate self harm, depression, challenging behaviour and greater reliance on community and residential resources. As more people with learning disability increasingly reach later life it too has become a consideration for older people's mental health services.

The Foundation for People with Learning Disabilities publication "Count Us In" estimated a 40% prevalence of mental health problems associated with learning disability. Applying these prevalence rates for Learning disability and associated mental health disorder to the June 2009 GP registered population data for 5-17 year olds gives us the following figures.<sup>33</sup>

### **Applying Learning Disability Prevalence Data to Hounslow Population:**

Age Group and Estimated Prevalence of Learning Disability	Estimated Learning Disability Population amongst Hounslow Children aged 5 – 17 years	Expected Hounslow Mental Health Caseload amongst Learning Disability Population, based on 40% estimated prevalence
Ages 5 to 9 (0.96%)	147	59
Ages 10 to 14 (2.26%)	327	131
Ages 15 to 17 (2.67%)	229	92
Total	703	282

For those with severe learning disabilities it is often very difficult to obtain a psychiatric diagnosis and these young people tend to require very specialist assessment in a specialist outpatient or inpatient setting.

As well as functional mental health problems such as depression and anxiety, older people with learning disability are also at greater risk from neurodegenerative disorders such as dementia. In Hounslow there are 63 older people with learning disabilities known to services. There are also a number of younger adults with learning disabilities who experience early onset dementia, however, the number of these residents is not known at time of publication.

<sup>32</sup> Facts about Learning Disability; Mencap: <http://www.mencap.org.uk/page.asp?id=1703>

<sup>33</sup> Taken from CAMHS Needs Assessment 2010

It is estimated that 25 - 40% of adults with a learning disability have additional mental health needs. Furthermore, 3% of people with learning disabilities, compared to 1% of the general population suffer from schizophrenia.

### **Learning Disability and Carers**

A Carer is someone who gives help and support to a relative, child, spouse, partner, sibling, parent, neighbour or friend who, due to disability, illness or frailty, is unable to manage living in their own home without help. Carers are unpaid, may be of any age and they may live with, or apart from, the cared for person.

In the 2001 Census 20,000 people reported they were providing informal care, however, only 700 are known to London Borough of Hounslow on the Carers register.

It is often the case that if the carer was not able to continue to provide care the older person would experience a greater reliance on health and social care professionals. A study by the University of Leeds for Carers UK reported that the average carer is saving the nation over £15,260 a year.

As more people with learning disabilities live longer it is increasingly the case that they too then become carers of their older parents or carers who have become frail or unwell. This is known as mutual caring, where responsibility for each other goes both ways. It is thought that 29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 1 in 4 of these cases have local authorities planned alternative housing.<sup>6</sup>

It is important to recognise that informal care can be a full time job for many and can be a source of stress and worry for the wellbeing of the cared for. Carers can be prone to feeling low in mood, tired and uncertain. Sometimes these feelings can lead to a diagnosable mental health problems but very often they result in periods when they simply need emotional and practical support with their caring responsibilities. It is important that the emotional and mental health needs of all carers are supported and breaks from caring are provided to help them maintain good mental health.

Seven out of 10 families caring for someone with profound and multiple learning disabilities have reached or come close to 'breaking point' because of a lack of short break services.<sup>34</sup> Carers are our greatest asset in helping older people to maintain independent lives. We need to make sure they are able to have their needs assess, especially their emotional and mental health needs and to give them the support they need to maintain their caring role.

### **Children and Young People with a Learning Disability**

Children with a learning disability are often socially excluded and eight out of 10 children with a learning disability are bullied. Half of all families with a disabled child live in poverty.<sup>6</sup>

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<sup>34</sup> Facts about Learning Disability; Mencap: <http://www.mencap.org.uk/page.asp?id=1703>

## **Learning Disability and Older Age**

More people with learning disabilities are reaching older age therefore we need to ensure that we provide equitable services to this group of older people by ensuring they can access provision that is right for them at every stage.

## **Learning Disability and Employment**

Hounslow has over 350 16-18 year olds who are not in education, employment or training (NEET). Of these, 20% have a learning difficulty and/or learning disability.

8% of people with a learning disability are in paid employment<sup>35</sup>, this is 2% lower than the national average and 4% lower than the London average<sup>36</sup>. Increased employment opportunities for people with learning disabilities will remain a target for the Learning Disabilities Partnership Board.

## **Autistic Spectrum Conditions (ASCs)**

An Autistic Spectrum Condition is a developmental condition affecting the way the brain processes information. It affects the way a person communicates and relates to others.

People with Autism & Aspergers Syndrome find it difficult to read signals; i.e. facial expressions, tone of voice and body language; that most of us take for granted. People with autism often have an accompanying learning disability.

People with Aspergers Syndrome and High functioning Autism generally do not have an additional learning disability; in fact they are often of above average intelligence. People with High Functioning Autism have similar traits to those with Aspergers Syndrome, although people with Aspergers Syndrome generally have an awareness of their disability and that they are 'different' from others, coupled with a desire to 'be like everyone else' i.e. have friends, relationships, employment - this awareness and desire can often cause problems for the individual.

People with Aspergers Syndrome and High Functioning Autism share many of the same characteristics of Autism, but each person is an individual and their Autism and Aspergers Syndrome will affect them in an individual way.<sup>37</sup>

**ASC Profile:** The Community Learning Disability Team and commissioned services within Hounslow (including residential services, day services, and supported living) were asked for numbers of clients with a confirmed or suspected (due to traits) Autistic Spectrum Condition. Questionnaires were sent to 11 services, of which 8 responded. These 8 services identified 67 clients.

The data only focused on people with a learning disability (LD) and does not include people with ASCs or a suspected ASC:

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<sup>35</sup> <http://www.hmg.gov.uk/linkuplinkin/regional-data/london.aspx>

<sup>36</sup> Valuing Employment Now 2009

<sup>37</sup> <http://www.asdcare.com/whatis.htm>

- without a LD
- within the local MH system
- within forensic services
- or those that are unknown to services

There are more people in Hounslow with an ASC than is currently known, both with and without a LD. It is highly likely that some of these people may be unable to access appropriate support from health and social services.

The Special Education Need database (provided by commissioning) was examined. The database includes the number of children and adults up to the age of 21 years with a diagnosis of an ASC. These individuals are highly likely to need support from the borough of Hounslow.

From the Special Education Need database, the numbers of students with a formal ASC diagnosis was noted to range between academic year groups. Additionally, this data focused only on primary diagnosis, therefore excluded pupils who may have an ASC that is secondary to needs such as a LD or physical disability. Furthermore, there are likely to be individuals with an undetected ASC who may currently be functioning well within the education system but could experience difficulties as they reach adulthood.

Over time, there will be increasing numbers of adults with an ASC within the borough of Hounslow. A total 123 young people below the age of 18 (funded by Hounslow LEA) were identified from the Special Education Need database. The numbers of students reaching adulthood within a calendar year ranged between 2 to 18, with an average of 9 per year. Given that the educational database focuses only on primary need, it is expected that there are greater numbers of individuals with an ASC in Hounslow's educational establishments.

### **ASC - application of National Prevalence Data to Hounslow 5-16 Population**

A recent study in South East London, estimated the prevalence of childhood autism at 38.9 per 10,000 and that of other ASDs at 77.2 per 10,000, making the total prevalence of all ASDs 116.1 per 10,000 or approximately 1%.<sup>38</sup> If the prevalence rate of 1% found by SNAP was applied to the Hounslow population aged 5 to 16 years (ref: June 2009 GP registered data) we would expect to see 354 cases.

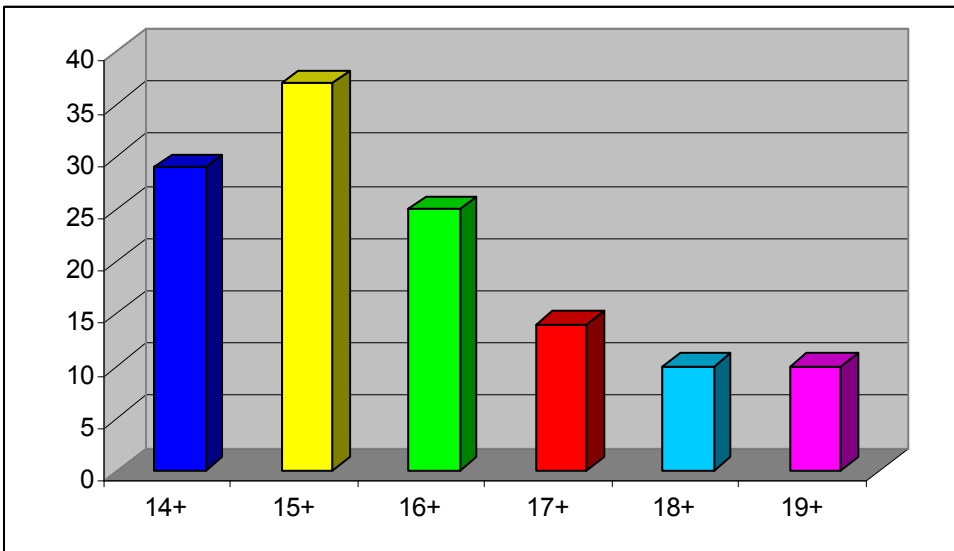
The Child Development Team caseload for children with Autism was 132 in December 2009.

### **Transition of Young People with a Learning Disability or ASC into Adult Services**

The table below provides an estimate of the likely numbers of people with a learning disability who will require support and/or care when they reach 18 years of age.

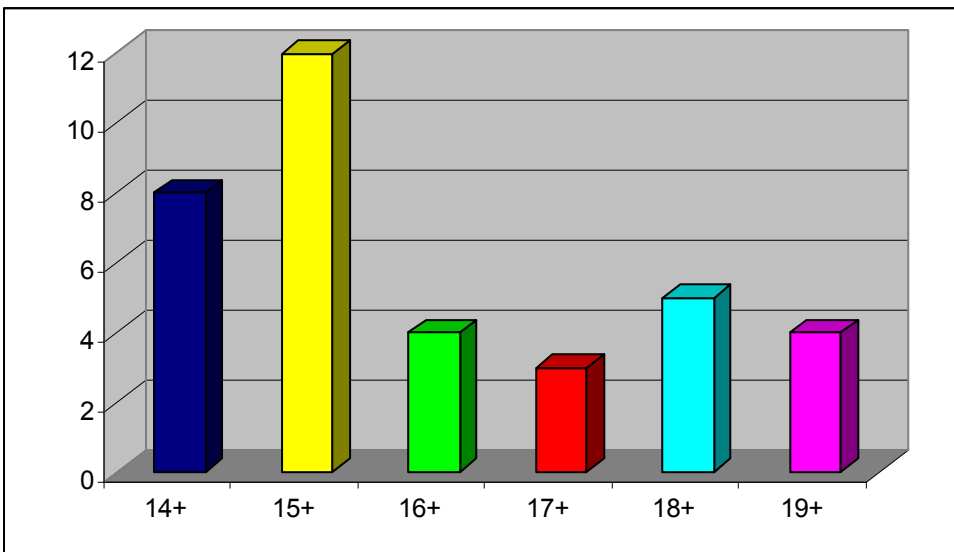
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<sup>38</sup> (Baird et al, Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), The Lancet 2006; 368:210-215)



**Young People with a Learning Disability, Source: LBH Tracking Group list Sept 2010**

The tracking group also holds a list of children identified with an ASC. Unfortunately, it is difficult to ascertain how many of these people will require any input from adult social care or health services.



**Young People with an ASC, Source: LBH Tracking Group list Sept 2010**

Both tables demonstrate the increasing numbers of children who are likely to go through transition and require help, advice and sometimes support to meet their needs. Although numbers are too small to detect any meaningful trends, it is clear that there are likely to be increased pressures as those young people who are currently 14 and 15 years of age transition into adult services.

### **Safeguarding of Residents with Learning Disabilities and ASC**

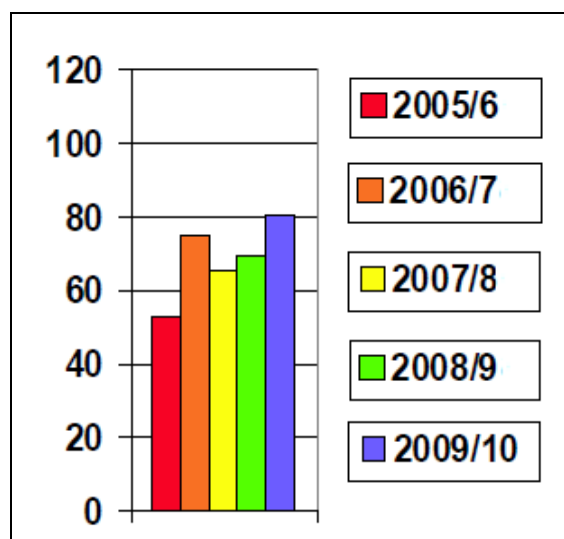
A report, 'Promoting safety and security of disabled people'<sup>39</sup> in April 2010 found that

<sup>39</sup> Promoting Safety and Security of Disabled People (2010), Equality and Human Rights Commission

disabled people were more likely to experience threats and attacks on their safety than their non disabled counterparts:

- 22% of disabled respondents in 2002 suffered harassment in public due to their impairment (an increase of 20%)
- 8% of disabled people suffered attacks compared to 4% of non disabled people
- Disabled people are four times more likely to be victims of crime compared to non disabled people
- 47% of disabled people have either experienced or witnessed physical abuse of a disabled companion
- 71% of people with mental health issues have been a victim of crime in the past two years (22% physical assault, 41% bullying, 27% sexual harassment) with only 19% of people feeling safe
- 90% of people with learning disabilities have experienced harassment and bullying, with 32% stating that bullying was taking place daily or weekly

The table below provides an overview of the number of reported and investigated safeguarding concerns where the client has a learning disability, received on an annual basis since 2005 through to 2010.



Source: LBH Safeguarding Adults Annual Report 2009-10

Whilst the number of reports involving residents with a learning disability continues to be very high, the Safeguarding Adults Team has carried out a detailed analysis of the possible reasons for this high level of reporting. The reasons include:

- It is a common factor across many London Boroughs.
- A high proportion of adults with a learning disability are known to services or are involved in services (e.g. Day activities, Specialist Health Care, Supported Living, Outreach Services) and as a result there is more opportunity for staff

to pick up indications of possible adult abuse. This is supported by the disproportionately high number of abuse reports from Day Services and from Service Providers.

- A large proportion of the alleged abuse is happening in the person's own home.
- A good level of awareness of adult abuse amongst staff working with people with learning disabilities. This is supported by the fact that, in general, there is a good take up of adult abuse awareness training amongst those staff who work with people with learning disabilities.
- In recent years people with learning disabilities have an increasing presence in the wider community but at the same time are often inherently vulnerable.

## Appendix Two – Outline National Policy

### **Key Policies for People with Learning Disabilities and/or Autistic Spectrum Disorders.**

This list is not exhaustive and there are many national and local studies, policies and guidance that have been drawn upon to influence the strategy. Below is a brief summary of the key national policies in relation to people with learning disabilities and people with an autistic spectrum condition.

**Valuing People - A New Strategy for Learning Disability for the 21st Century (2001)** Is the government's plan for making the lives of people with learning disabilities and their families better. It was the first White Paper for people with learning disabilities for 30 years, covering from cradle to grave, and is based on individuals having:

- Their rights as citizens.
- Inclusion in local communities.
- Choice in daily life.
- Real chances to be independent.

Valuing People sets out clear requirements for the implementation of person centred planning, the modernisation of day services and accommodation, with improvements to health service delivery and mainstream health care provision.

**Valuing People Now: A new three-year strategy for people with learning disabilities (2009)** Sets out the cross-government strategy for three years and in particular:

- Addresses what people have said about the support people with learning disabilities and their families need.
- Reflects the changing priorities across government which impacts directly on people with learning disabilities.
- Sets out the government's response to the ten main recommendations in *Healthcare for All*, the report of the Independent Inquiry into access to healthcare for people with learning disabilities.
- Provides a further response to the Joint Committee in Human Rights report, *A Life Like Any Other* (2008).

The strategy does not place many new burdens on services or frontline staff. Rather it is about emphasising what best practice looks like, and identifying the key levers to enable this best practice to become universal.

**Valuing Employment Now (2009)** - This policy is underpinned by some key principles which describe a fundamental shift in the Government's approach to employment for people with learning disabilities, including:

- If real disability equality is to be achieved, work should no longer be seen as optional for most people with moderate and severe learning disabilities. The default must be that everyone will have the chance to get a job.
- 'Work' in this context is defined as real jobs in the open labour market that are paid the prevailing wage. It does not mean volunteering or work experience unless this is part of a genuine pathway to real work.
- The aspiration is for as many people with learning disabilities as possible to work at least 16 hours a week, because this is the point at which most will be financially better off and achieve greater inclusion. It is however, acknowledged that people who have spent years in day services may need to build up to this.

**The National Strategy for Autism: Fulfilling and Rewarding Lives (2010)** This strategy follows the publication of *The Autism Act (2009)* The policy sets a direction for long-term change identifying specific areas of action. It draws on findings from the National Audit Office (NAO) report: *Supporting people with autism through adulthood (2009)* and is underpinned by the fundamental principles of equality and human rights. The governments' vision is that: 'all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them.'

Some of the main difficulties that people with autism face are:

- Social and economical exclusion.
- Services that are not available consistently: different adults with autism in the same area will have very different experiences.
- Risk of severe health and mental health problems, homelessness, and descent into crime or addiction for those without support.
- Although many adults with autism make successful and important contributions to their communities, the economy and their families, too many are dependent on benefits.

The strategy requires:

- The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults.
- The identification of adults with such conditions.
- The assessment of the needs of adults with such conditions for relevant services.
- Planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults.
- Other planning in relation to the provision of relevant services to adults with autistic spectrum conditions.
- Actions that this organisation will need to take will include: increasing awareness and understanding of autism among frontline professionals.
- Contribute to developing a clear, consistent pathway for diagnosis in every area which is followed by the offer of a personalised needs assessment.

- Improving access for adults with autism to the services and support they need to live independently within the community.
- Working with local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

**Healthcare for all: report of the Independent inquiry into access to healthcare for people with learning disabilities (2008)** The Inquiry found evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment, despite the fact that both the Disability Discrimination Act (1998 & 2005) and Mental Capacity Act (2007), set out a clear legal framework for the delivery of equal treatment. The evidence provided by witnesses involved in the Inquiry highlighted that:

- People with learning disabilities find it much harder than other people to get assessment and treatment for general health problems that have nothing directly to do with their disability.
- Parents and carers of adults and children with learning disabilities, often find their opinions and assessments ignored by healthcare professionals, and struggle to be accepted as effective partners in care by those involved in providing general healthcare.
- Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disabilities.
- The health needs, communication problems, and cognitive impairment characteristics of learning disability in particular are poorly understood.
- Partnership working and communication, between different agencies providing care between services for different age groups, and across NHS primary care, secondary and tertiary boundaries, is poor in relation to services for adults with learning disabilities.

The Inquiry stated that the main reasons they reached these disturbing conclusions were because:

- People with learning disabilities are not visible or identifiable to health services, hence the quality of care is impossible to assess.
- Lack of awareness of the health needs of people with learning disabilities is striking in primary care, and this is particularly important since primary care is the single point of access to health promotion and ill health prevention.
- Training and education about learning disability provided to undergraduate and postgraduate clinical staff in primary care, and in hospital services across the NHS, is very limited.

**Six lives: the provision of public services to people with learning disabilities (2009).** Six lives was the result of complaints made by Mencap on behalf of the families of six people with learning disabilities, who died between 2003 and 2005 while in NHS and local authority care. The complaints were made following Mencap's report *Death by indifference* (March 2007), which led to the setting up of

the Independent Inquiry into Access to Healthcare for People with Learning Disabilities.

The reports into each death illustrated significant and distressing failures in services across both health and social care, whereby people with learning disabilities experienced prolonged suffering and inappropriate care. The reports stated that on many occasions, basic policy standards and guidance were not observed, adjustments were not made, and services were not co-ordinated. There was a lack of leadership and in some situations it appeared that no one had a real grasp of what was happening. Among the key problems identified were a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights, resulting in an unacceptable standard of care and treatment that was experienced in the cases of the six people who died. The areas for concern were:

- Communication
- Partnership working and co-ordination
- Relationships with families and carers
- Failure to follow routine procedures
- Quality of management
- Advocacy

The report did not find a shortage of policy and good practice guidance on the planning and provision of health and social care services for people with learning disabilities. The recommendations of the Health Service Ombudsman and Local Government Ombudsman were:

- All NHS and social care organisations in England, to urgently review the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas.
- Those responsible for the regulations of health and social care services should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks, and performance monitoring regimes, provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements, in relation to the provisions of services to people with learning disabilities.
- That the Department of Health should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report.

**Equal Treatment: Closing the Gap (2006)** This document presented a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems. The Disability Rights Commission (2006) found that:

- People with a learning disability have poorer health than other people.

- More people with learning disabilities are overweight, have poor access to breast screening, have not had their health needs identified and treated, and do not have a GP.
- Current practice is not in line with the Disability Equality Duty placed on the NHS.
- Recommended establishing a strategic lead in each PCT / SHA area to lead on addressing health inequalities of people with a learning disability.

## **Appendix Three – Summary of Stakeholder Consultation**

The strategy has been informed by a series of consultation events, meetings and information forums run throughout the year, such as

- The Big Health Check Up Day and Getting Ready Meetings
- Keeping Safe, Working Together
- Carers Forum
- Learning Disabilities Partnership Board
- SIG Autism Group
- Day opportunities Review
- Housing Doing Group
- Personalisation Group

Speak Out Hounslow was commissioned to consult about what people with learning disabilities would like to see included within the strategy.

A total of 21 service users were consulted across the following services

- Two Bridges
- Acorn Centre
- Acton Lodge
- St Raphael's

### **Summary of what we found out**

- Most people said that what they do during the day is the most important thing to them.
- Mostly people are happy with what they do during the day and feel day centres are very important.
- Outings are very important to people and they feel they don't have enough.
- People felt they had to wait a long time for healthcare but that the care itself had improved.
- Lots of people were worried about going to the dentist in some cases so much that they didn't go.
- People can't remember their transition from children's to adult's services.
- People do want jobs and some think Leaders can help them to find jobs but some didn't know how to find a job.
- Most people thought staff at their services could help them to Speak Up about the services.
- People didn't know about advocacy including one person who is currently using Afia's services.
- People don't always know how to get help if they are not happy where they live.
- People thought they made quite a lot of choices about their life and more than they used to.

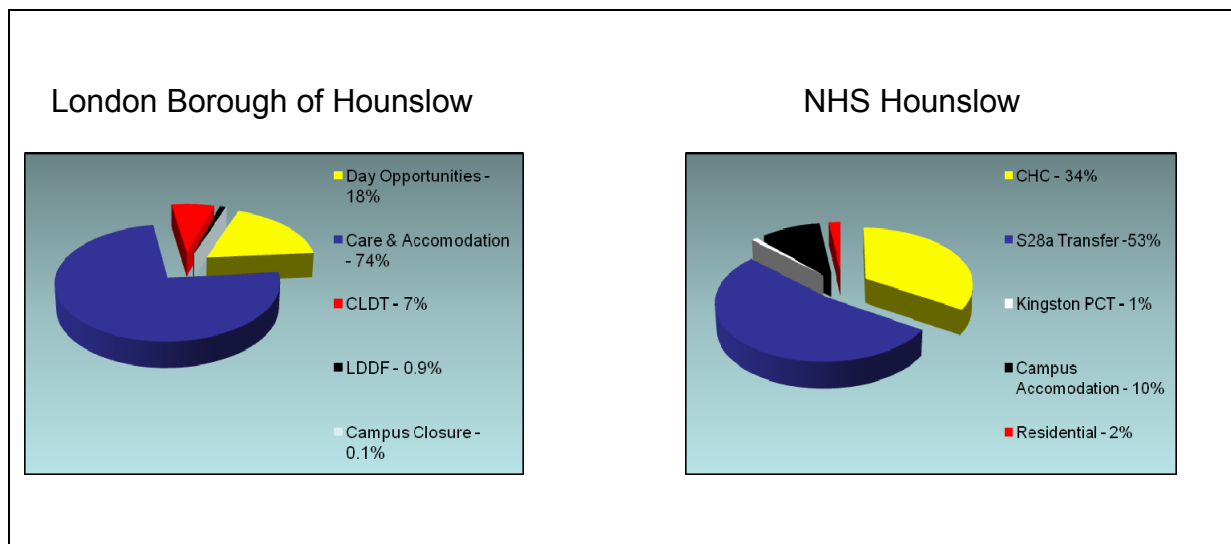
## Recommendations

- If you are asking people what they want it has to be a very clear choice between one thing and another. People can't imagine what they would do instead of day centres. We need to give them a clear idea of the alternatives in language they understand.
- We need to find ways to support people to go on more outings as day centres are finding this harder and harder to do. This could be by encouraging groups of people to pool personal budgets to purchase shared support for an outing or looking at provision of outings outside of day centres.
- A Consultation of people currently transitioning to adults' services is important as people currently using adult's services cannot remember their transition at all.
- As a reasonable adjustment it would be good if healthcare services could give adults with learning disabilities an approximate time that they will be seen when they are using drop in services such as Accident and Emergency and Heart of Hounslow drop in. This could be done by using a ticket scheme so that people could leave and come back and not lose their place in the queue.
- Speak Out could do a peer review of A and E and dentists to find out more about the problems.
- People need more information about support for finding a job. Most people only knew about Leaders as an option for support finding a job.
- One person complained that he was never told about when his Care Manager was leaving or when he had been allocated a new one. Communication between Care Management and Service Users needs to be improved. Perhaps when people are first assessed they could be asked about their preferred method of contact.
- We need to help people find a way to remember information they have been given as nobody knew what Personal Budgets were even though this has been covered several times at Speaking Up Groups. This could include looking at versions of information other than written information (audio, video). There is also a problem with people understanding the idea but not knowing the terminology used.
- People need to know what to do if they are thinking of moving house. Perhaps housing should be a standing part of people's annual review just to check how they are feeling about it and to pick up people who are having a problem.

## Appendix Four – Finance Schedule 2009-10

The overall budget for services for adults with learning disabilities across health and social care is £24,538,731

The charts below provide a breakdown of the funds for both the London Borough of Hounslow and NHS Hounslow.



The table below indicates a breakdown of expenditure from the local authority and health service for learning disabilities.

	LBH	NHS	%	
Residential	£9,606,429	£205,061	39	38.83%
Supported Housing	£5,641,871		22	22.33%
Day Opportunities	£2,406,810		9	9.53%
NHS Campus		£1,025,308	4	4.06%
Continuing Health Care		£3,486,048	14	13.80%
Advocacy				
Community Learning Disability Team	£935,981	£931,761	7	7.39%
Learning Disability Development Fund	£120,340		1	0.48%
Campus Closure Grant	£13,371		0	0.05%
Supporting People Fund	£934,249		4	3.72%
Other				
<b>Total</b>	<b>£19,824,802</b>	<b>£5,648,178</b>	<b>100</b>	

## Appendix Five – Learning Disability and Autistic Spectrum Disorder Services

### Day Opportunities

<i>Service Name</i>	<i>Service Type</i>	<i>Provider Name</i>	<i>Caseload</i>	<i>Bed Nos.</i>
The Triangle	Day Service	LBH	28	n/a
The Acorn Centre	Day Service	LBH	30	n/a
Acton Lodge	Day Service	LBH	65 (15 PD, 3 MH)	n/a
Two Bridges	Day Service	LBH	53	n/a
Isleworth Resource Centre	Day Service	Voyage/Milbury	25	n/a
Harle House	Day Service	Hounslow Mencap West	38 (aged over 50)	n/a
Leaders, Employment Resource Centre	Employment Service	LBH	10	n/a
Remploy	Employment Service	Remploy	5	n/a

### Supported Accommodation

<i>Service Name</i>	<i>Service Type</i>	<i>Provider Name</i>	<i>Caseload</i>	<i>Bed Nos.</i>
Star Road	Supported Housing	Support for Living	8	8
Finney Lane	Supported Housing	Support for Living	7	8

Van Goth Close	Supported Housing	Support for Living	4	4
Grange Close	Supported Housing	Support for Living	5	6
Victoria Road	Supported Housing	Support for Living	5	5
Bath Road	Supported Housing	Support for Living	3	3
South Street	Supported Housing	Support for Living	8	8
Independent Living Scheme - FTF	Supported Housing	Frances Taylor Foundation	9	9
Independent Living Scheme – Owl/Dimensions	Supported Housing	Owl/Dimensions	18	18
Thornbury Road	Supported Housing	Mencap	5	6
Martindale Road	Supported Housing	Life Opportunities Trust	5	7

### Shared Lives Scheme (formally Adult Placement Scheme)

<b>Service Name</b>	<b>Service Type</b>	<b>Provider Name</b>	<b>Caseload</b>	<b>Bed Nos.</b>
Adult Placement Scheme	Shared Lives	London Borough of Richmond Upon Thames/London Borough of Hounslow	5	

## Residential

<b>Service Name</b>	<b>Service Type</b>	<b>Provider Name</b>	<b>Caseload</b>	<b>Bed Nos.</b>
Mulberries	Registered care home	Dimensions	4	7
Spring Grove	Registered care home	Voyage/Milbury	8	13
St Raphael's	Registered care home	Frances Taylor Foundation	19	21
Grove Care	Registered care Home	Grove Care	Spot Purchase	35
Clover	Registered care Home	Clover	Spot Purchase	3
Vicarage Farm Road	Registered care Home	Owl/Dimensions	4	4
Hounslow Road	Registered care Home	Owl/Dimensions	3	4
Scott Trimmer way	Registered care Home	Owl/Dimensions	4	4
White House	Registered care Home	Craigmoor	1	4

## Respite

<b>Service Name</b>	<b>Service Type</b>	<b>Provider Name</b>	<b>Caseload</b>	<b>Bed Nos.</b>
Star Road	Registered	Support for Living	n/a	8

## Other

<b>Service Name</b>	<b>Service Type</b>	<b>Provider Name</b>	<b>Caseload</b>	<b>Bed Nos.</b>
EMAPP	Carers	Ealing Mencap	n/a	n/a

	Service			
Older Carers Project	Carers Service	Ealing Mencap	25	n/a
Advocacy Service	Advocacy	Speak Out	n/a	
Speak Out	Service User Groups	Speak Out	n/a	n/a
Outreach Service	Floating Support	Support for Living	18	18
Owl Floating Support Service	Floating Support	Owl/Dimensions	34	34

# **Joint Commissioning Strategy for People with Learning Disabilities and Autistic Spectrum Conditions**

2011-2016