

## Focus on...

# Adults with learning disabilities

January 2013

There are many different types of learning disability. Most develop before or during birth or because of a serious illness in early childhood.

A learning disability is life-long and usually has a significant impact on a person's life. A learning disability is a diagnosis, but it is not a disease, nor is it a physical or mental illness. A learning disability diagnosis has three criteria: Intellectual impairment; Social or adaptive dysfunction; and early onset, i.e. impairments are present from childhood.

People with an Intelligent Quotient (IQ) score of 70 or less are regarded as having a global learning disability. There are four classifications of global learning disabilities:

- mild (IQ 50-69)
- moderate (IQ 36-49)
- severe (IQ 21-34)
- profound (IQ 20 or lower).

However, the degree of intellectual impairment alone reveals very little about the needs of a person. Assessment of learning disabilities is usually done via a number of tests to measure social functioning in addition to intellectual function.

People with learning disabilities find it harder than others to learn, understand and communicate. This affects their health and wellbeing, with the impact increasing with the severity of the person's disability. People with learning disabilities are more likely to experience common social determinants of poor health including poverty, poor housing, unemployment, social isolation and discrimination.

## Key facts & figures

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**707** adults and **124** children with a global learning disabilities were registered with an Islington GP in 2010/11. This is one of the highest prevalence rates in London.

**475** people aged 18 and over with learning disabilities received a social care service in 2011/12.

**220** people were registered with their GP as having an autistic spectrum condition in 2010/11.

However national prevalence estimates indicate that 0.8% of the population will have an autistic spectrum condition. This would equate to approximately 1,700 people living in Islington and suggests that there is significant under-recording.

## Key issues for Islington

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- Prevalence of learning disabilities is greater at higher levels of deprivation. Islington is the 5th most deprived local authority area in London and 14th in England, with the 2nd highest child poverty levels in the country.
- Approximately four in 1,000 Islington adults have received a diagnosis of a global learning disability, this is one of the highest prevalence rates in London, but similar to national levels.
- In Islington the actual number of adults with learning disabilities is expected to increase by 8% [50 people] in 2012/13, which is significantly above the national average and will bring an estimated additional cost pressure of around £2,800,000.
- Demographic increases means core services such as day care and respite short breaks for family carers are under considerable pressure.
- Islington is a desirable, small and densely populated borough. Consequently the availability and cost of land is at a premium, the market is underdeveloped and local accommodation options for people with learning disabilities are limited. Islington has been one of the highest commissioners of out of borough residential and nursing home placements for people with learning disabilities.
- People with learning disabilities find it harder to access mainstream services including leisure, educational, training and employment services and this impacts negatively on health and social inclusion outcomes.
- There is a growing number of older carers, who have supported their children (who often have complex behavioural and physical needs) for many years with only limited support from public services. Now, as they age, the relatively inexpensive and informal care arrangements are breaking down, requiring the Council and NHS to step in.

## Key programmes and services

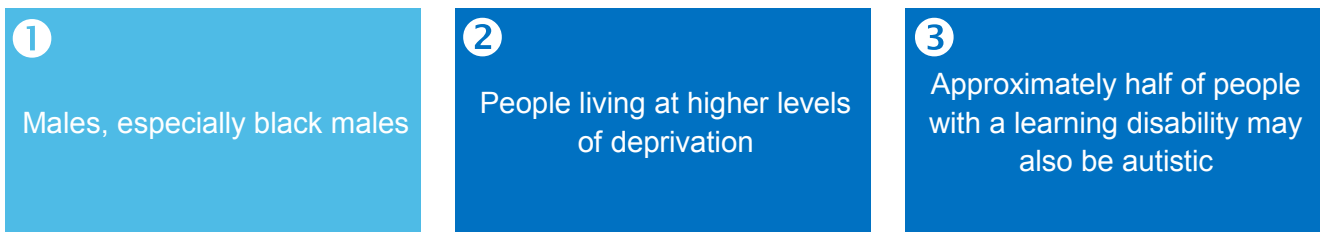
- Adults with global learning disabilities are supported by the Islington Learning Disabilities Partnership (ILDP) ILDP in an integrated health and social care team. It supports people with learning disabilities via a range of services including social work; extra care housing; outreach services; day services; short breaks; and specialist healthcare (including psychiatry, pharmacy, psychology, speech and language therapy, occupational therapy, physiotherapy and nursing services).
- Islington funds a wide range of accommodation services to people with learning disabilities including: outreach housing support to people living in generic housing for people with low learning disabilities needs; extra care supported accommodation schemes for people moderate to severe learning disabilities; residential and nursing care; and assessment and treatment placements.
- Islington Council directly provides: Residential services for adults with profound learning disabilities needs at Wray Court and Orchard Close; Daylight, a day centre for 80 adults with moderate to profound learning disabilities; and a short breaks respite service for family carers at King Henry's Walk.
- Islington commissions a Health Advocacy Service to help people with learning disabilities look after their health and support access to mainstream healthcare.
- Islington also provides a group of leisure and social inclusion services offering activity programmes in the borough which promote independence.
- Islington is committed to ensuring people with learning disabilities and their family carers have a voice and input directly into the design, commissioning and performance of services. To support this activity Islington employees a group of people with learning disabilities called the Power and Control group. The group is supported by the Elfrida Society. C404 another local charity is commissioned to support family carers of people with learning disabilities. Islington also commissions a user and family carer monitoring service which assesses the quality of local services.
- Planning for the accommodation and support needs of young people in transition from children's to adult services is a major activity for Islington. To date Islington has commissioned a 'Move on' flat for three people with moderate to severe learning disabilities needs attached to an extra support accommodation scheme for people with learning disabilities. Islington intends to committed to commissioning more local quality transition services.

## Key population groups

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- The average prevalence of learning disabilities is higher in men (0.46%) compared to women (0.31%) across all age groups, with a particularly marked gender difference in those aged less than 20 years.
- The prevalence of learning disabilities does not differ significantly by ethnic group in women, but is higher in black men (0.67%) compared to all men in Islington (0.46%). However, the number of white men with learning disabilities is higher.
- National estimates indicate that the prevalence of people with autism who also have learning disabilities is 52%. This equates to 432 people in Islington with a learning disability who may also have an autistic spectrum condition.

### At risk groups



## Key issues for adults with learning disabilities

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Adults with learning disabilities continue to be amongst some of the most vulnerable and socially excluded people in society.

They have the same rights as the general population to live healthy, productive and independent lives with appropriate and responsive treatment and support to develop to their maximum potential, but in fact experience much health social and economic outcomes. This is due to people with learning disabilities experiencing a greater range of health problems compared to the general population, compounded by difficulties in accessing universal services.

In line with the disability provisions of the Equality Act 2010 and Mental Health Capacity Act 2005, general and NHS health care services need to put in place reasonable adjustments to ensure that people with learning disabilities have equality of access, treatment and outcomes.

## THE ISLINGTON PICTURE

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The number of people with learning disabilities aged 18 and over who received a social care service in 2011-12 was 475. In addition to these (social care funded adults):

- 13 number of adults with learning disabilities paid the full cost of their care themselves
- 9 people with learning disabilities received Continuing Healthcare funded by the NHS
- 15 were in Assessment and Treatment centres
- 137 were in Supported Accommodation funded by the Supporting People programme.

As of September 2012, less than 20% of the adults with learning disabilities in a residential placement were placed within Islington. A further 20% were placed in other London boroughs, and over 60% were out of London.

### What other health conditions do adults with learning disabilities have?

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People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population, with overall mortality among adults with severe and profound learning disabilities about three times that of the general population. The most marked increase in mortality is due to congenital malformation and diseases of the nervous system and sense organs.

People with severe and profound learning disabilities are more likely to die from respiratory infections, diseases of the genitourinary system and digestive system, cerebrovascular disease, mental disorders and accidental causes compared to the general population.

Recorded prevalence of ischaemic heart disease, stroke and diabetes are lower among people with known learning disabilities compared to the overall practice population, suggesting that these conditions are being missed. Diagnostic overshadowing, where symptoms of physical ill health are mistakenly attributed to either a mental health or behavioural problem, was a significant obstacle to people with learning difficulties getting their physical health concerns taken seriously in primary care.

The prevalence of psychiatric disorders is significantly higher among adults whose learning disabilities are identified by GPs, compared to general population rates. Reported prevalence rates for anxiety and depression are at least as high as the general population and higher amongst people with Down's syndrome.

Compared to the general population, people with learning disabilities are 17 times more likely to have epilepsy, 6 times more likely to have a psychotic disorder, and twice as likely to have diabetes.

The proportion of adults with learning disabilities who have been assessed for depression is significantly higher compared to the wider Islington adult population.

People with learning disabilities are more likely to be obese compared to the general population. Obesity is particularly high in women with learning disabilities, with 36% of women being assessed as clinically obese.

Women with learning disabilities are also 50% more likely have asthma.

## Prevention and management of interventions

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Oversight of Islington's prevention and intervention programme is provided by the Islington Learning Disabilities Partnership Board. This is jointly chaired by the Corporate Director of Housing and Adult Social Services and a service user with learning disabilities. The Partnership Board comprises of a number of working groups:

- Health
- Housing
- Personalisation
- Employment Training
- Family Carers
- Power and Control (Service user group)

A wide range of initiatives are required around prevention and early diagnosis and intervention to meet the range and complexity of health and social care needs of people with learning disabilities. These include:

- Islington Learning Disabilities Partnership provides a comprehensive one stop multi-disciplinary health and social care service for adults with global learning disabilities which is easily accessible.
- Making reasonable adjustments to ensure that people with learning disabilities are able to access and receive the same high standards of healthcare as anyone else. For example, allowing longer appointments times for people with learning disabilities, and ensuring that patient documentation is in an easy read/accessible format.
- 31 of the 37 Islington GP practices are signed up to the learning disabilities Directly Enhanced Service (DES) contract. The contract commissions a GP learning disabilities training programme and incentivises learning disabilities Health Checks and Health Action Planning. Islington also intends to recruit a GP learning disabilities champion to progress this work further.
- A Social Services learning disabilities register is being developed and cross referenced with GP learning disabilities registers so that the borough is aware of and can support all people with learning disabilities.
- People with learning disabilities may not always be able to explain what their needs are and how they should be met when being admitted to hospital. Hospital passports have been developed to provide a portable key information record for people with learning disabilities and hospital staff.
- The Whittington Hospital has employed a learning disabilities Liaison Nurse to ensure the needs of patients with learning disabilities are met. The post has been very successful.
- North London Hospitals have formed a group to share sharing good learning disabilities care and practice.

## WHAT DO LOCAL PEOPLE THINK ABOUT THE ISSUE?

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People with learning disabilities and their family carers have a strong voice in Islington and are routinely involved in the prioritisation, design, commissioning and performance management of our services. People with learning disabilities and their family carers want the following:

- To be safe and access services that are free from institutional abuse and provide quality care.
- To have the option of living in Islington, close to family and professional networks. They don't want to have to move away because there is not enough local health and social care accommodation provision.
- To live as independently as possible in the community rather than in institutional type settings. People with learning disabilities want more local extra care supported accommodation provision that gives them the dignity of renting their own flat whilst receiving all the support they need.
- To access services which are personalised and address their individual bespoke needs.
- To be able to access quality local training and activity services.
- To be able to work and participate in mainstream society.

## WHAT WORKS?

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People with learning disabilities are at increased risk of having other long term conditions including heart disease, diabetes and clinical obesity. Much of this increased risk is attributed to lifestyle factors, including physical inactivity and an unhealthy diet.

Historically care professionals have tended to focus on a person's learning disabilities at the expense of their physical health needs. To address this trend GPs are commissioned to provide Health Checks and Health Action Plans for people with learning disabilities as part of the Directly Enhanced Service GP contract. Health checks help detect unmet health needs and support positive health action planning.

Nutritional and Practical Guidelines for Children and Adults with Learning Disabilities (2007) recommends the following:

- GPs should be involved in promoting the nutritional health of children, young people and adults with learning disabilities throughout their lives.
- GPs should proactively offer people with learning disabilities an annual health check. This should look at a range of indicators related to nutritional health such as body weight, weight change, bowel health, oral health, specific medical conditions, difficulties around eating and drinking, and medication reviews.
- Everyone with a learning disability should be encouraged to be involved in developing their own health action plan, with support from a health facilitator, and to include in it information about their nutritional health.
- NHS Diabetes issued guidance on Commissioning for people with learning disabilities who have Diabetes (2011) and recommended the following:
  - Patient's to hold their own care management plan, with realistic goals.
  - All information to be available in easy to read formats to allow access to read and review information where possible, and picture and other formats based on the individual's communication requirements.
  - Allowance to be made for additional time to explain and review new information to ensure there is understanding, and additional appointments are made, if necessary, to repeat and confirm the information given to ensure confidence and understanding.

## FUTURE NEED

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The number of adults with learning disabilities who received a social care service from Islington in 2010-11 was 436. This increased by approximately 9% in 2011-12 and is projected to increase by a further 8% in 2012/13. On average 50 new people with learning disabilities become eligible for a service from ILDP every year. The increase is due to:

- Growing numbers of children and young people with complex and multiple disabilities now survive into adulthood.
- Increases in the life expectancy of people with learning disabilities – with many more people living into older age – as a result of improvements in health care.
- Increases in the complexity of health problems associated with people living longer (e.g. early onset of dementia in people with Down's Syndrome) .
- A sharp rise in the reported numbers of school age children with autistic spectrum disorders (partly due to improved diagnostics), some of whom will have learning disabilities.

Major challenges lie ahead in managing the disproportionate impact of welfare benefit and housing benefit changes to disabled people and their carers especially on their ability to live independently within the borough.

People are living longer but are developing long-term conditions earlier in life. There are also a growing number of frail older family carers. Planning is necessary to meet the needs of an increasing number of people with profound and multiple disabilities and manage the resulting pressure on resources.

## TARGETS & OUTCOMES

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Key Priorities as identified in the Islington Joint Commissioning Strategy 2012-17 were:

- Strengthening Service User and Family Carer involvement
- Improving Young People's transition into adulthood
- Developing local accommodation and support services
- Developing social inclusion, day and employment opportunities
- Supporting family carers
- Improving access to mainstream health services
- Promoting more choice and control Market management: optimising efficiency and effectiveness.



## NATIONAL & LOCAL STRATEGIES

Valuing People, first published in 2001 enshrined four key principles - civil rights, independence, choice and inclusion. Updated in 2009, it has become the framework through which services across England have been developed, and it has been updated regularly with the introduction of a comprehensive annual self-assessment and delivery plan. Current national priorities are to:

- Ensure strong leadership through learning disabilities partnership boards
- Secure access to - and improvements in - health care
- Increase the range of housing options for people with learning disabilities
- Ensure the personalisation agenda is embedded
- Increase the number of people in employment
- Improve the joint working between services for children and services for adults

### NATIONAL STRATEGIES

#### **Valuing People (DH 2001)**

A New Strategy for Learning Disability for the 21st Century and as revised in:

#### **Valuing People Now (DH 2009)**

Sets out the national vision for inclusion of people with learning disabilities. It also responds to the main recommendations in Healthcare for All, the independent inquiry into access to healthcare for people with learning disabilities.

#### **Autism Strategy (March 2010)**

Sets out a number of key actions and recommendations in five key areas to improve service delivery to adults with autism

#### **The Equality Act (EA, 2010)**

Streamlines and strengthens anti-discrimination legislation across the board.

#### **The Public Sector Equality Duty**

Under the EA is a requirement on public authorities to consider how their policies and measures affect disabled people

#### **World Class Commissioning: Improving the health and wellbeing of people with learning disabilities (DH, 2009)**

A practical guide to support commissioners to meet the needs of this group, and ensure they are fulfilling their duty to promote equality.

#### **Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (DH, 2007)**

This report aims to support commissioners in developing local services for people whose behaviour presents a significant challenge.

### LOCAL STRATEGIES

#### **Joint Commissioning Strategy 2012 – 2017**

Sets out how Islington Council and Islington Clinical Commissioning Group will jointly develop services for vulnerable and disabled adults over the next five years

#### **Islington Profile Public Health Intelligence: Learning Disability (March 2012)**

This provides an overview of the Islington population with learning disabilities. It summarises the frequency of learning disability and compares health indicators for people with learning disabilities to the general population.



## WHAT IS BEING DONE LOCALLY TO ADDRESS THE ISSUE?

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Work that is being undertaken to address gaps in service provision and delivery includes:

- Islington has embarked on an ambitious programme to commission extra care supported accommodation services in borough to avoid the necessity for out of borough placements far from family and social networks. A supported housing scheme opens in April 2013 providing 10 one bed flats for adults with autism and high needs and another service in 2014 will provide one, two and three bed flats to 17 people with learning disabilities and high needs.
- Further funding has been secured to invest in a new local 'Move on ' transition service to support approximately 12 people with moderate learning disabilities needs to develop the skills and confidence to move into more independent housing options.
- New accommodation developments will make full use of assistive technology to ensure that people are able to live as independently as possible whilst being safe.
- Islington is exploring the development of local accredited post 19 educational opportunities for young people 18-25.
- Islington is developing new specialist local day care provision for adults with severe autism.
- Islington is supporting people with learning disabilities to take control by promoting personal budgets; whilst providing a reliable safety net of services, so people can get help if they get into difficulty.
- Islington is working with Job Centre Plus and other employment providers to ensure service users have correct information about benefit changes and are empowered to make decisions and choices for their needs and situation.

## FURTHER INFORMATION

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- If you want to refer yourself or someone else to Islington Learning Disabilities Partnership, please phone 020 7527 6600.

Further information on this topic can also be found at the following locations:

### **Islington's adults joint commissioning strategy 2012-2017**

<http://www.islington.nhs.uk/about-us/strategies/joint-commissioning-strategy.htm>

- **Islington Profile. Public Health Intelligence: Learning Disability (March 2012), Islington Council and NHS North Central London**

<http://www.improvinghealthandlives.org.uk/profiles/index.php?pdf=E09000019>

- **Health checks for people with learning disability: a systematic review of evidence. Improving Health and Lives (Learning Disability Observatory, 2010).**

[www.improvinghealthandlives.org.uk/uploads/doc/vid\\_7646\\_IHAL2010-04HealthChecksSystemticReview.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf)

- **Eating well: children and adults with learning disability, nutritional and practical guidelines (Caroline Walker Trust, 2007).**

[www.cwt.org.uk/pdfs/EWLDGuidelines.pdf](http://www.cwt.org.uk/pdfs/EWLDGuidelines.pdf)

- **Commissioning for people with learning disability who have diabetes (DH, 2011)**

[www.diabetes.nhs.uk/document.php?o=27](http://www.diabetes.nhs.uk/document.php?o=27)

## About the Evidence Hub

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The Evidence Hub is a partnership between the local NHS and the Islington Council that brings together information held across different organisations into one accessible place. It provides access to evidence, intelligence and data on the current and anticipated needs of the Islington population and is designed to be used by a broad range of audiences including practitioners, researchers, commissioners, policy makers, Councillors, students and the general public.

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