

# JSNA: Limiting long-term illness and disability

## Introduction

This chapter includes an overview of trends in the overall rate of long-term limiting illness and disability and the levels of physical and sensory impairment within Bolton. There is no gold standard disability data source and no single definitive measure of disability. Estimates of disability prevalence vary between surveys according to the definitions of disability that are used and the motives of the collector. This chapter therefore provides a variety of information from different sources which may be relevant for future commissioning priorities.

The term 'Physical Impairment' refers to people who have one or more physical impairments. These impairments may be congenital or acquired at any age, be temporary, long-term, or fluctuating. People with physical impairments may often have unique and multi-dimensional requirements. They therefore require tailored services to address them all in a person-centred holistic fashion.

The term 'Sensory Impairment' encompasses visual impairment (including blind and partially sighted), hearing impairment (including those who are profoundly deaf, deafened and hard of hearing), and dual sensory impairment (deaf blindness). Sensory impairments may, like physical impairments, be congenital or acquired at any age. They are more prevalent with age as are additional sensory or other impairments. Most sensory impairments develop gradually and are often secondary to other disabilities.

Information on some of the specific long-term health conditions which could result in disability, such as cardiovascular disease, are included in other chapters. Similarly, information on learning disabilities, autism, and mental health are also included separately.

## Implications for commissioning

Increased focus across health and care services on early intervention and prevention to promote independence and inclusion.

Encourage the social care market to develop a range of services that respond to individual needs.

Improve information to allow people to make informed choices about their care and support. In particular, provide information to enable people to remain as independent as possible for as long as possible.

Improve local monitoring of outcomes and evaluation of relevant services.

Improved links and shared learning between specialist and universal services.

Ongoing review of housing needs of people with disabilities to ensure adequate future provision that allows people with physical disabilities to live as independently as possible.

Work with other services to enhance support for people with disabilities to go to work or to remain in work if they acquire a disability or sensory impairment. Where appropriate encourage increased opportunities for volunteering.

Ensure universal services are accessible to disabled people e.g. transport, leisure, health.

More efficient delivery of services to ensure services can continue to meet increased future demand.

The promotion of healthy lifestyles for people with physical disabilities.

Consider options to speed up the processing of DFG applications.

### Who's at risk and why?

Disability affects all age groups and all parts of the population, although some communities have a higher incidence of chronic conditions. Some impairments and illnesses are particularly associated with ageing, while some people have a lifetime disability. Other disabilities are acquired, by either accident or disease. Some people have multiple long-term conditions which may mean they have complex health and care needs.

There are two main models that have been developed to conceptualise disability - the medical and social models. The medical model focuses on the individual and regards disability as being caused by the impairments that prevent an individual from living a normal life. The Disability Discrimination Act definition of disability is based on the medical model. The social model turns the cause of disability around and proposes that the inability of those with impairments to undertake social activities is caused by "the erection of physical or attitudinal barriers by the non-disabled majority that constrain the lives of people with impairments".

Much of the data on disability prevalence that is collected in the UK is based on the medical model. The social model is, however, becoming increasingly important within social policy and therefore there may be a gap around information to quantify the effect of the environment on an individual's experience of disability, particularly at a local level.

Nationally, it is acknowledged that compared with non-disabled people, disabled people are<sup>1</sup>:

- More likely to live in poverty – the income of disabled people is, on average, less than half of that earned by non-disabled people;
- Less likely to have educational qualifications – disabled people are more likely to have no educational qualifications;
- More likely to be economically inactive – only one in two disabled people of working age are currently in employment, compared with four out of five non-disabled people;
- More likely to experience problems with hate crime or harassment – a quarter of all disabled people say that they have experienced hate crime or harassment, and this number rises to 47% of people with mental health conditions;
- More likely to experience problems with housing – nine out of ten families with disabled children have problems with their housing;
- More likely to experience problems with transport – the issue given most often by disabled people as their biggest challenge;
- More likely to experience problems with access to information and guidance relating to their condition and care;
- More likely to have difficulties in accessing health and care services.

Also of relevance nationally are the following issues highlighted in the National Service Framework for People with Long-term Conditions (2005):

- There is a wide variety of long-term neurological conditions and people have very different experiences. Conditions may be present at birth (e.g. cerebral palsy) and some of these may be associated with varying degrees of learning disability. Other conditions appear in childhood (e.g. Duchenne’s muscular dystrophy) or develop during adulthood (e.g. Parkinson’s disease);
- Approximately 10 million people in the UK have a neurological condition and 20% of acute hospital admissions are due to this;
- Two people in every 100,000 experience a traumatic spinal injury every year;
- Approximately 350,000 people across the UK require support with daily life because of a neurological condition and 850,000 people are carers for people with neurological conditions.

Some Black and Minority Ethnic (BME) groups are at higher risk of developing eye conditions:

- African and African Caribbean ethnic groups are four times more likely to develop Glaucoma and are also at higher risk of developing age related macular degeneration under the age of 60;

<sup>1</sup> Prime Minister’s Strategy Unit (2005) *Improving the Life Chances of Disabled People*, Prime Minister’s Strategy Unit.

- People of South Asian ethnicity are at a higher risk of developing cataracts;
- African, African Caribbean, and Asian ethnic groups are at a higher risk of developing Diabetic eye disease.

## The level of need in the population

From the Census 2011, the percentage of Bolton residents whose day to day activities are limited because of a long-term health problem or disability was 19.8% (54,913 people); higher than the national average of 17.6% but lower than the North West average of 20.3%, and down from 20.3% in Bolton in 2001<sup>2</sup>. Overall, 10% of residents indicated their day to day activities are limited a lot and 9.8% a little. There is considerable variation across the borough; Halliwell Ward has the largest proportion of residents with a limiting long-term health problem or disability (24.8%) compared with Bromley Cross at 15.4%. More detailed information from the Census is yet to be released but is likely to confirm that disability increases with age.

The *Bolton Health & Wellbeing Survey 2010* estimated that 11.1% of the adult population have a disability that limits their daily activities a lot and provides some information on types of disability. Multiple disabilities/health problems are common:

<b>Disability</b>	<b>Proportion (%)</b>	<b>Number of adults in 2013</b>
<i>Other</i>	5.4	11,659
<i>Physical</i>	5.1	11,011
<i>Longstanding illness</i>	4.1	8,852
<i>Mental Health</i>	3.5	7,557
<i>Sensory</i>	2.0	4,318
<i>Learning/cognitive</i>	0.7	1,511
<i>Total with one or more disability</i>	11.1	23,965

Based on Health Survey for England national projections, Oxford Brookes University and the Institute of Public Care (PANSI), estimate the number of people aged 18 to 64 years in Bolton with moderate and serious physical disabilities as shown below. The total number of people with a physical disability increases with age and the proportion with a severe physical disability is highest among those aged 55-64 years (28%).

<sup>2</sup> As the question asked in the 2011 Census on limiting long-term illness and disability differed to that asked in 2001, it is not possible to directly compare activity limitations in 2011 with that in 2001, but the questions are sufficiently similar to draw indicative insights on change over time.

	<b>Moderate disability</b>	<b>Severe disability</b>	<b>Total</b>
<i>18 -24 years</i>	1,025	200	1,225
<i>25-34 years</i>	1,567	149	1,716
<i>35-44 years</i>	2,100	638	2,738
<i>45-54 years</i>	3,793	1,056	4,849
<i>55-64 years</i>	4,619	1,798	6,417
<i>Total</i>	13,103	3,840	16,943

Similar projections based on the 2001 Census estimate the number of people aged 65+ with a limiting long-term illness:

- 65-74 years = 12,453;
- 75-84 years = 8,382;
- 85+ years = 3,380;
- *Total = 24,215.*

The incidence of visual impairment in Bolton rises sharply after the age of 65, particularly at 75 plus. Of those aged 75 and over, approximately half have cataracts or refractive error (i.e. correctable sight loss) and if these are excluded those that remain will have visual impairments significant enough to be eligible to register as blind or partially sighted. Age related macular degeneration is the most common cause of registrable sight loss in older people. Around 20 people in Bolton have serious visual impairment in each of the younger age groups (18-24, 25-34, 35-44, 45-54, 55-64). In addition, 1,467 people aged 65-74 will have moderate or severe visual impairment and a further 2,455 aged 75 and over. Finally, 1,267 people in Bolton aged 75 and over will have a registrable eye condition.

The numbers of people acquiring moderate and serious hearing impairments also rises steeply with age. The number of people of working age with profound hearing impairment (where lip reading or British Sign Language may be the preferred or first language) is small. The numbers of people experiencing moderate hearing loss (usually remediable with a hearing aid) or serious hearing loss which may make communication difficult without learning lip reading skills or BSL are higher particularly in the older age groups.

	<b>Moderate or severe hearing impairment</b>	<b>Profound hearing impairment</b>
<i>18-24 years</i>	38	0
<i>24-34 years</i>	181	0

35-44 years	540	0
45-54 years	2,186	18
55-64 years	3,543	39
65-74 years	4,997	159
75-84 years	8,831	89
85+ years	4,669	237
<b>Total</b>	<b>24,985</b>	<b>542</b>

The *Bolton Health & Wellbeing Survey 2010* indicated that only 14% of disabled adults under 65 years of age are working and 29% of all disabled people are struggling financially. Also, over half (52%) are unable to heat their homes as well as they would like. Disabled people in Bolton are more likely to smoke, have a poor diet, and undertake no physical activity, although they are less likely to drink alcohol excessively. They are also more likely to be obese and to have low levels of wellbeing.

In May 2012 there were 15,050 people claiming Employment and Support Allowance/incapacity benefits in Bolton; 8.5% of the working age population. This compared with 8.2% in the North West and 6.3% nationally. The incapacity rate has reduced significantly since 2010 (9.4% in May 2010) but this is likely to be linked to administrative changes. The most prevalent conditions for ESA/incapacity claimants in Bolton are mental and behavioural disorders and disorders of the musculoskeletal system and connective tissue.

Disability Living Allowance (DLA) is intended to meet costs for personal care, attendance and some travel costs. There were 18,520 people (10,150 of working age and 6,630 of pension age) claiming DLA in Bolton in May 2012, almost 8.7% of the adult population aged 18 and over. The number of DLA claimants in Bolton has grown steadily over the last five years (6% since May 2008), higher than the 5.7% growth across the North West but lower than the 10.5% growth nationally. The most prevalent conditions for DLA claimants in Bolton are arthritis (18.6% of claimants), learning difficulties (9.7%), psychosis (7.9%), disease of the muscles, bones or joints (6.4%), and back pain/other (5%).

## Current services in relation to need

Bolton's 2009-14 Long-term Condition Strategy acknowledges there are significant numbers of people who have not been identified as having a long-term condition (either because they

have not contacted the health service or they are unaware of their condition) and are therefore not receiving any treatment. People with long-term conditions tend to be more intensive users of health and care services and these conditions are a major contributor to health inequalities in the borough. The strategy aims to improve prevention and management of long-term conditions through early identification, promotion of self-care, and effective treatment.

Given that there are limited resources and the potential level of need is very large, a key aspect of disability policy is deciding who is disabled and entitled to support. The Department of Health has developed the Fair Access to Care Services Guidelines (FACs) that are used by local authorities to decide who they can provide services to. These guidelines are intended to ensure fairer and more consistent eligibility decisions across the country for adult social care. There are four categories of risk to independence and wellbeing (critical, substantial, moderate, or low). The local authority decides which bands it provides support to. Councils are advised to consider their own resources, local expectations, and costs when setting their eligibility criteria. Currently, local authorities are not compelled to provide services if they do not have sufficient resources although they do still have duties to clients if removal of services would result in an 'unacceptable quality of life or severe physical risk'.

In Bolton, social care is currently provided to those with critical and substantial risk under the FACs guidelines. The Council stopped meeting moderate needs in 2010/11 due to budget pressures.

In addition to the universal services provided by the Council, NHS and voluntary and community sector, the following more specialist services are provided in Bolton for people with physical disabilities:

- Adult Disability teams (Health and Social Care);
- Residential and Nursing Care;
- Adult Placement Scheme;
- Community Support Outreach Service;
- Short-term Home Support (re-ablement) service;
- Home Care;
- Sensory Centre and Service;
- Direct Payments;
- Safeguarding;
- Jubilee Information Point;
- Bolton Carers Support;
- Disability Equipment Service;
- Blue Badge Scheme;
- Disabled Parking;
- Careline Community Alarms Service;

- Home Adaptations;
- Telecare;
- Extra Care;
- Respite Care;
- Active Ageing;
- Bolton Care and Repair;
- Community Meals.

In 2011/12 a total of 3,520 people with physical disabilities – 595 aged 18-64 and 3,025 aged 65+ years were receiving ongoing support from Adult Social Care in Bolton. In addition, 671 people aged 18-64 years and 3,155 aged 65+ years received short-term support from Adult Social Care in the form of equipment, short-term re-ablement or intermediate care. Notable features of the social care services provided in Bolton are:

- In 2011/12 96% of people with physical disabilities aged 18-64 were supported in the community (compared with an average of 94% across the North West);
- In 2011/12 80% of people with physical disabilities aged 65+ were supported in the community (compared with an average of 81% across the North West);
- The rate of admissions to residential or nursing care for adults aged 18-64 was 11.2 per 100,000 population in 2011/12, lower than the North West (16.8) and England (19.1) average;
- 315 people aged 18-64 with a physical disability received self-directed support/direct payment in 2011/12. This continues to rise and ensures disabled people have choice and control over the care received.

There were 368 enquiries regarding a Disabled Facilities Grant in 2012/13, with 166 completed. The average waiting time for completion ranges from 90 days to 428 days depending on the type of grant required.

The *Bolton Health & Wellbeing Survey 2010* indicated that people with disabilities are generally high users of health services but are less likely to have visited the dentist in the last year.

## Projected service use and outcomes

Whilst it is accepted that levels of mortality have declined over the last century the trends in levels of disability expectancy are not clear and this remains a disputed research area. There are three possible scenarios for the relationship between life expectancy and disability free life expectancy:

- Proportion of life in disabled state remains constant (disability free life expectancy increases at same rate as life expectancy);
- Proportion of life in disabled state increases (people are living longer but spend a greater proportion of their lives with a disability – expansion of morbidity);

- Proportion of life in a disabled state declines (people are living longer but spend a lower proportion of their lives with a disability – compression of morbidity).

Over the last twenty years evidence can be found for all three scenarios. Results vary according to the type and severity of disability that is measured, the period of time under study and the country in which the analysis is undertaken.

In Bolton, the 2011 Census indicates that the proportion of the population with a long-term health problem or disability is about the same as it was at the 2001 Census, although the actual number of people has increased due to population increase, and in particular due to an ageing population.

Based on national projections, there is expected to be a 3.4% increase in the number of people aged 18-64 with a moderate physical disability in Bolton by 2020 and a 3.8% increase in those with a severe physical disability. These rates of increase are lower than the national average but higher than the average across the North West. The increase is mainly a result of the increasing population aged 55-64 years.

PANSI also estimates there is expected to be only a slight change in the number of people aged 18-64 with a serious visual impairment and the number with a profound hearing impairment by 2020. There is, however, expected to be a 4.6% increase in the number of people aged 18-64 with a moderate or severe hearing impairment, again mostly as a result of the increasing population aged 55-64 years. This increase is lower than the national average (7.2%) but higher than the North West (3.6%).

Much more significant increases are expected in the number of people aged 65+ with disabilities in Bolton by 2020, as a result of the increase in the older population. POPPI estimates there will be a 16.9% increase in the number of older people with a limiting long-term illness by 2020. Although numbers are small there is expected to be a 19.5% increase in the number of people over 65 expected to have a moderate or severe visual impairment and a 25% increase in the number of people over 75 years with a registrable eye condition by 2020. There is also expected to be a 20.2% increase in the number of older people with a moderate or severe hearing impairment and an 18.1% increase in the number of older people with a profound hearing impairment. The rate of increase in the number of people with visual impairments in Bolton is higher than the North West and England averages.

Welfare reform will impact on disabled people of working age and carers through the reassessment for Disability Living Allowance and the move to Personal Independence Payments, and through the shift to Universal Credit and the tie in of Carers Allowance. Disabled people will also be impacted by other welfare changes such as the bedroom tax and Council Tax Credit. Some disabled people will be impacted by multiple changes to their benefits. As changes are currently being implemented it is unclear to what extent the

reduction in income for disabled people will impact on their ability to live independently and requirement for support from health and care services.

## Evidence of what works

### Putting People First

The Putting People First (PPF) concordat (2007) triggered a three-year programme for transforming social care. Superseded by the Care White Paper published in April 2010, local authorities are now required to offer all eligible users a personal budget by 2013.

### Improving the Life Chances of Disabled People

“By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society”. Major reform within health and social care will shape the way services will be delivered in the future, giving renewed priority to:

- Good prevention services and early-targeted intervention;
- Reducing health, social, and community inequalities;
- Improving access to community services, integrated and personalised care;
- All local authority areas should have at least one ULO based on a Centre of Independent Living.

### UK Vision Strategy (RNIB)

Aims to enhance the inclusion, participation, and independence of blind and partially sighted people.

### Commissioning Framework for Health and Wellbeing

Identifies the future priorities for effective joint commissioning as:

- A move towards services that are personal, sensitive to individual need and that maintain independence and dignity;
- A strategic reorientation towards promoting health and wellbeing, investing now to reduce future ill health costs;
- A stronger focus on commissioning the services and interventions that will achieve better health and reduced health inequalities across health services and local government.

### National Service Framework (NSF) for Long-term Conditions

Aims to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible. It puts the people who have these conditions, along with their family and carers, at the centre of care by setting evidence-based quality requirements (QRs) from diagnosis to end-of life care. Although the NSF is focused on people with long-term neurological conditions, the principles enshrined in the framework apply to all people with a physical disability.

## Our Health, Our Care, Our Say

White Paper, the Government's Vision for Health and Social care services is underpinned by achieving four main goals:

1. Better prevention and early intervention for improved health, independence and wellbeing;
2. More choice and a stronger voice for local individuals and communities;
3. Tackling inequalities and access to services;
4. More support for people with long term needs.

## The Independent Living Strategy (ILS)

Published in March 2008, the Strategy sets out actions aimed at improving the choice and control disabled people have over the services they need to live their daily lives. The aims of the strategy are:

- Disabled people (including older disabled people) who need support to go about their daily lives will have greater choice and control over how support is provided;
- Disabled people (including older disabled people) will have greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

Further key sources for information on effective interventions and evidence-based policy are highlighted on Bolton's Health Matters and can be viewed [by clicking here](#).

## Community views and priorities

A consultation event carried out by BADGE on behalf of the Office for Disability Issues in 2012 highlighted the importance of supporting disabled people to access employment and learning, including individual support to find a job, work with employers and improved transport options.

Specific issues raised via Bolton's Disability Partnership indicate some problems with the accessibility of services such as dentists and the availability of services such as the hydrotherapy pool at Bolton One.

The Adult Social Care Survey 2011/12 indicated that almost three fifths (57.4%) of people with physical disabilities were extremely or very satisfied with their care and support. The survey highlighted that some disabled people need more social participation and support to be able to do things they value and enjoy.

There is a need for more focused consultation with people with physical disabilities and their carers about health and wellbeing priorities in Bolton, including an appreciation of existing and potential community assets. Issues impacting on disabled people highlighted in other areas that may be relevant in Bolton include:

- Social isolation
- Lack of disability awareness in the health service and lack of involvement in own treatment;
- Long waits for home adaptations;
- Long waits for appropriate social housing and living in unsuitable homes;
- Difficulties with using buses and poor street environment for wheelchair and scooter users
- Difficulties with employment and volunteering;
- Fear of crime and feeling unsafe in some areas
- Complex benefit forms and a lack of information about entitlements.

### Equality impact assessments

No recent local equality impact assessments have been carried out that we are aware of. If you are aware of any such work locally please let us know at [Bolton Health Matters](#)

### Unmet needs and service gaps

Improved support to access employment based on individual needs.

More focus on the development of social networks for people with physical disabilities to prevent social exclusion.

Long waits for Disabled Facilities Grants to be completed.

Ongoing need to improve housing provision for people with disabilities.

Ensuring all services are accessible to people with disabilities.

### Recommendations for further needs assessment work

Monitor the impacts of welfare reform locally.

Evaluation of the impact of preventative services delivered for adults with disabilities and whether specific interventions prevent further loss of independence.

Much of the data on the numbers of people with physical disabilities in Bolton is based on national data and may not be a reflection of local needs. Improve collection of data on specific needs to inform commissioning.

There is limited data on health service activity related to people with physical disabilities.

### **Key contacts**

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