Birmingham City Council

NHS

Joint Strategic Needs Assessment

Adults & School Leavers with learning disabilities

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Contents

Figures

Tables

Executive Summary

Key Points

In this report ‘people with learning disability’ (LD) refers to adults and school leavers with a permanent reduced ability to learn new skills and live independently as a direct result of impaired intelligence and social functioning. LD also includes neurological and genetic conditions but it does not include adults who have acquired brain damage or those with only organic mental health problems such as dementia.

Refined local estimates, taking into account the ethnic profile, suggests that 2.47% of Birmingham adults were learning disabled in 2009. Predictions for Birmingham suggest an increase of Adults with learning disability from 18,451 (2009) to 20,776 (2030).

The increase in adults aged 65+ is estimated to rise from 2,817 (15%) in 2009 to 3,525 (17%) in 2030.

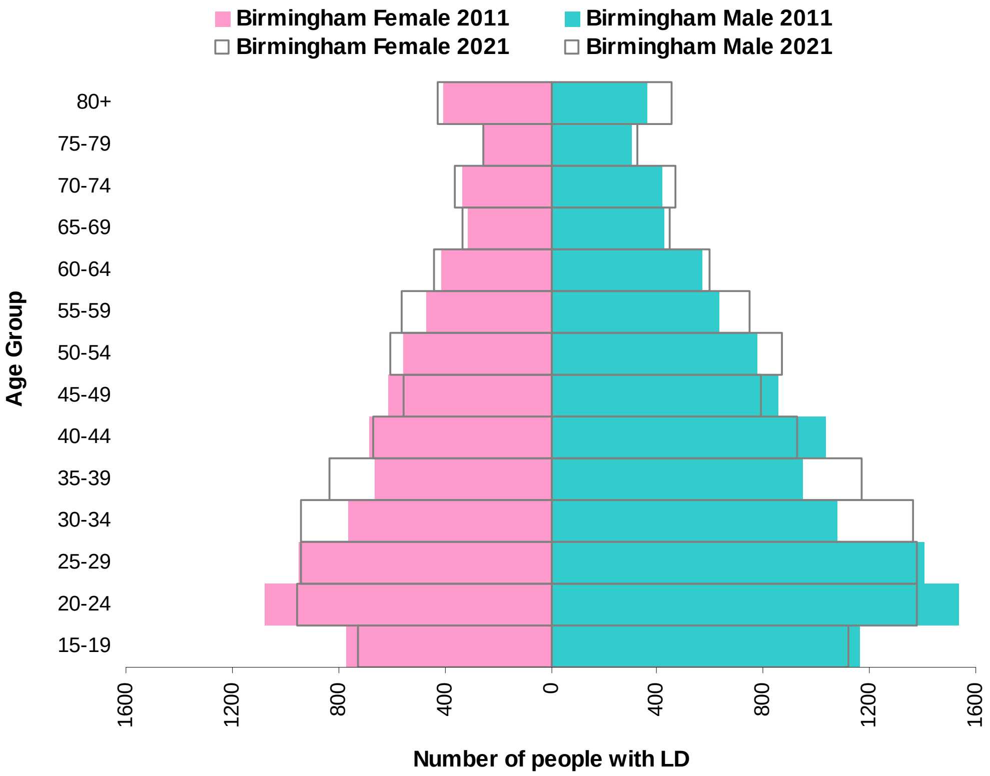

Figure 1 Projections of people with learning disabilities in Birmingham by age group and gender for 2011 and 2021 (Source: Emerson 2004, Office of National Statistics mid-year population estimates, PHIT)

However, in 2008/9, 3,044 learning disabled adults received services from Birmingham City Council[1]. This figure is only 0.40% of the estimated adult population.

This suggests that only an approximate 17% of adults with learning disability are known and supported by City Council services.

This may be due to the selection criteria, need, access issues or people choosing not to access services.

There is a body of evidence to suggest that any improvements to services for people with learning disability need to differentiate better between mild, moderate, severe and multiple learning disabilities. These sub-populations often have different life experiences and different living and caring arrangements. The analysis has also highlighted a number of specific challenges for the population with learning disability in Birmingham.

People with learning disabilities are 58 times more likely to die before the age of 50 than the general population.

It is known that people with a learning disability are predisposed to the development of a number of health limiting conditions (congenital heart conditions, Alzheimer, gastrointestinal problems and cancer). Many of these conditions can either be prevented, or the severity reduced by early screening and good access to primary and secondary care health provision. It is of special concern then that health related databases record so few learning disabled people.

It is important to care planning to note that the commonly quoted co-morbidities for this population are reflected in higher hospital admissions (e.g. diseases of the respiratory system, diseases of the ear and mastoid process and endocrine, nutritional and metabolic diseases). It is also important that this group appear to have a higher hospital admission rate (compared to the general population) for injury, poisoning and certain other consequences of external causes which may be an issue worth further study. This underpins the need for early detection and intervention for good health care.

Section 1.3 gives recommendations for commissioners.

The Shadow Health and Wellbeing Board will consider in Autumn 2011 a new framework for the JSNA, including monitoring of JSNA commission and outcomes. The monitoring of the implementation of this needs assessment will form a part of the new framework.

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[1] According to RAP returns for Birmingham City Council.

Estimating the numbers of people

At present there is no single and reliable data source describing the learning disabled population nationally or locally. This report draws from a variety of data sources, some of which are in turn aggregated figures, generated from raw administrative data. Some of the information is also the result of estimates relying on qualitative assumptions concerning the nature of the population with learning disability nationally and locally. Therefore, when possible, each figure presented will be qualified by its reliability in terms of precision and potential bias.

The Joint Commissioning Strategy for Services for People with Learning Disabilities, (2006) report estimated for 2006 there were 29,135 people with learning disability, of whom 4,020 would have severe or profound learning disability and 25,115 would have mild or moderate learning disabilities[2].

Department of Health (DH) estimates[3] for Birmingham which take into account its ethnicity profile suggest that 2.47% of Birmingham adults are learning disabled in 2009. The same source indicates an increase of Adults with learning disability from 18,451 (2009) to 20,776 (2030), as well as an increase in adults aged 65+, from 2,817 (15%) in 2009 to 3,525 (17%) in 2030.

Against these estimates, one dataset for 2008/9 from Birmingham City Council[4] showed that 3,115 learning disabled adults received services, which is only 0.40% of the overall adult population of Birmingham. It would appear then that as little as 17% of adults with learning disability (3,115 registered adults out of 18,451 estimated adults) were approved and catered for services, due to either selection criteria, stated needs or barriers to access.

Another 867 people with learning disability have accessed at some time the Disability Employment Service unit for help with training, recruitment or employment. Their records have been matched against BIU records using date of birth (DOB), gender and ethnicity (ONS 16 categories) and a possible overlap of 98 people has been identified.

On this basis, potentially only 3,884 service users with learning disability may be known to Adult and Community Care services in Birmingham. Within the city's population an estimated 3,500 people were receiving Disability Living Allowance (DLA) due to a LD condition[5] in the FY 2008/09. Finally, General Practice (GP) records from the learning disability QOF (Quality and Outcomes Framework) register indicates that in FY 2008/09 there were 3,684 individuals diagnosed as having a kind of learning disability

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[2] Joint Commissioning Strategy for Services for People with Learning Disabilities, (2006), p. 16.
[3] PANSI (Projecting Adult Needs and Service Information System). http://www.pansi.org.uk
[4] Collation of records from CareFirst and other Service databases, Business Information Unit, Birmingham City Council.
[5] DWP 5% sample estimate rounded to the nearest one hundred.

These sets of figures are in reasonably close agreement. However, lack of access to Department of work and Pension (DWP) records, and QOF individual records does not enable us to estimate the overlaps between agencies' records and the extent individuals with low to critical conditions may be missing services from any concerned agency.

In Birmingham 2.86% of the school population was identified as having primary special education needs (SEN) associated with learning disabilities in 2008. Examination of current SEN records provide estimates prevalence rates between 1 and 2% at least.

This suggests that a large number of adults with learning disability are not 'visible' in primary health care measurements (they may of course still be receiving care and attention) or known to social care.

National indicator information about the housing and employment experience of disabled people in Birmingham shows that fewer adults live in settled accommodation (46.5 % in Birmingham versus 57.5% in the West Midlands or 65.2% in England) (NI 145, 2008/9) or find employment (1.5 % in Birmingham versus 2.9% in the West Midlands or 7.5% in England) (NI 146, 2008/9) than other parts of the West Midlands or England[6].

Safeguarding referrals for people with learning disability where increasing in both absolute and relative terms (280 or 57% of all referrals in 2007/8, increasing respectively to 509 and 82% in 2008/9). Of all safeguarding referrals for people with learning disability, 30.3% were related to physical abuse, and 20% were due to emotional, mental or psychological abuse.

Hospital admission records[7] show that 70% of the patients identified as having learning disability are under 25 years of age and present with a number of conditions; Epilepsy, Down's syndrome and Autism being the most common. The majority of patients with learning disability are of white origin (60%) followed by Asian or Asian British (17.8%). Not surprisingly there are significantly higher admissions for mental and behavioural disorders, congenital malformations, deformations and chromosomal abnormalities and diseases of the nervous system as these are directly related to learning disability.

There is also a strong indication about the higher than average requirement for hospital admissions for symptoms, signs and abnormal clinical and laboratory findings for the patients with learning disability. There are significantly lower rates of admissions for diseases of the circulatory system and neoplasms compared to the general population[8].

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[6] PAT Website.

[7] HES Database (2007-8). However, HES records does not always explicitly record patients with learning disability as such. Therefore the data is probably not giving a full picture of the health problems of people with learning disability

[8] See chapter **Error! Reference source not found.** on health.

In 2008/9 there were 25 adult patients with learning disability awaiting transfer from hospital and on average it took 59.4 days for this to happen (ranging from 2 to 248 days). In contrast for the 146 physically disabled adult patients awaiting transfer from hospital on average it took 30.3 days for this to happen (1 to 221 days). Between April 2009 and Jan 2010 there were 25 adult patients with learning disability awaiting transfer from hospital and on average it took 78.2 days for this to happen (ranging from 4 to 328 days). In contrast the 131 physically disabled adult patients awaiting transfer from hospital on average took 28.2 days for this to happen (2 to 200 days)[9].

In 2008/9 the reasons for delay were largely because of the time waiting for an assessment and getting public funding agreed. The first 10 months of 2009/10 indicate that in addition to these reasons there are additional pressures on residential and nursing places becoming available.

Recommended priorities for Commissioners

Because data is often limited, we have relied on triangulating available data with i) policy and legislation including statutory guidance, ii) horizon scanning for best practice in service commissioning and configuration and iii) the views of users, carers and their loved ones. Identifying suggested priorities for commissioners is therefore the result of this triangulation process, undertaken with practitioners, clinicians, users and carers as well as commissioners.

The available data suggests strongly that there may be many People with learning disability that are not visible to services, some of whom may not meet criteria for services, and a proportion of whom may meet criteria for service at present or at some point in the future. There is also a rising number of people with learning disability aged 60 or over that are likely to require services at some stage. The lack of readily available activity data must be a concern for on-going service monitoring.

This leads us to our first recommendation:

Commissioners should create a framework for the registration and monitoring of people with learning disability to help this population maintain and enhance their independence and good health over the entire life cycle. Within this commissioners should consider:

Data collection and sharing on People with learning disability in Birmingham among Health Care agencies, Adult and Communities Department, Children and Young People Services and Central Government agencies (DWP, Home Office, Ministry of Justice), for monitoring and prevention purposes;

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[9] National Indicator 131, extract for Birmingham County Council.

Seamless integration of Adult and Children information and service databases resources;

Widening of registration mechanism (and criteria) to all People with learning disability (above and beyond current SEN mechanism for children and FACS system for adults) for monitoring and prevention purposes;

Integration of medical and FACS definitions of LD person for monitoring and prevention purposes;

The lessons from good practice on the Scotland register of people with learning disabilities

Ensuring the dates and relative causes of death are properly recorded
This in particular will enable commissioners to track the achievement of outcomes set in their commissioning strategy for people with learning disabilities.

Triangulating available data with government policy, NICE and other guidance, and the other sources mentioned above leads us to the remaining suggested priorities for commissioners.

Commissioners should focus on:

- Ensuring learning disabilities becomes a corporate priority for Local Authorities and the NHS, and ensuring every function plays its part. This could be through a multi-agency approach to learning disability where housing, transport, health, social care, third sector and other agencies play their part in implementing government policy through a joint strategic framework.
- Ensuring a smooth transition from childhood to adulthood and from adulthood to old age
- In particular, Identification and reduction of support gaps in transition phases: from childhood to adulthood, from training/education to work, from hospital to settled accommodation, from criminal justice system to the community, from adulthood to old age.
- Introduction of systematic follow ups of people with learning disability in transition and beyond;
- Improving and extending the number of health and social care prevention services tailored to individual and family needs;
- Ensuring effective pathways to address health improvement in people with learning disabilities, improve access to good quality primary care and improve detection and intervention on mental health issues.
- Improving current practices of crisis management
- Reducing length of delayed transfer of care and responsibilities;
- Ensuring appropriate pathways for people with learning disability who exhibit challenging behaviours (whose number and proportion is increasing in the population) and in particular to address safeguarding. Within this it

will be important to ensure routes divert from undue criminalisation of people with learning disabilities.

- Addressing the ethnic disparities in access to services for Asian populations
- Addressing the increasing numbers of Pakistani and Bangladeshi people with learning disability who have critical and substantial needs and the cultural implications relative to social and health workers supporting them.
- This is important given the higher prevalence rate of severe and profound/multiple learning disability and the expected increase of older people in this group in the medium term.
- Reducing delays in assessment and starting of social care packages;
- Reduction of hospital admissions due to injury, poisoning and other conditions deriving from external causes;
- Targeting of people with learning disability with epilepsy to improve management of condition;
- Reduction of obesity prevalence in people with learning disability;
- Improving pathways for carers, young people and young mothers with learning disability;
- Raising awareness of the needs of people with learning disability among non-specialist front line workers in Health Care and Public Services, and providing guidance on good practice, especially for primary care, dental care and mental health.

Introduction

The Joint Strategic Needs Assessment (JSNA) attempts to bring together relevant information about learning disabled people; from modelled predictions to local findings to inform commissioning strategies. Each information source is limited in some way but the intention is that taken together the JSNA provides a 'single Birmingham narrative' about our learning disabled population. The information used in this report is not comprehensive or exhaustive, and indeed we have had recourse to policy and legislation to identify normatively some good practice where the data itself is silent or missing.

The JSNA will focus on describing adults with learning disability and young people with learning disability in transition who receive services in Birmingham.

There is a radical shift in how and where services are delivered with a great deal more emphasis on involving the user in the decision-making process. There are associated changes in commissioning arrangements and partnership arrangements.

Given this, and the comparative lack of data when seen against some other specialties, it is important that this first LD JSNA is seen as a factual benchmarking exercise that must be further developed to keep it current, robust and challenging.

The audience for this report is primarily the commissioners of learning disability services and practitioners involved in strategic, policy or service development or redesign.

What are learning disabilities?

A learning disability is the consequence of events affecting a person's brain development, either before they are born, during their birth or in early childhood. Several factors can affect brain development, including:

- the mother becoming ill in pregnancy;
- problems during the birth that stop enough oxygen getting to the brain;
- the chromosomes of unborn baby expressing defective genes;
- the parents passing certain genes to the unborn baby that make having a learning disability more likely (known as inherited learning disability), or;
- illnesses such as meningitis, or brain injuries in early childhood.

Sometimes it is not possible to identify a cause for a learning disability. In fact diagnosing a learning disability can be difficult - in some cases it is not clear what the learning disability is, or how severe it will be. Often the severity of the disability only becomes clear by the time a child should be talking, walking or reading.

Learning disabilities (LD) are often identified in childhood and affect people into adulthood. The learning disability population often have co-morbidities which are likely to deteriorate rather than improve, so continuity of care and review are very important processes. Most forms of learning disability are obvious by the age of five as this is the age that intellectual function (also known as cognitive ability) can reliably be tested although some learning disabilities can be diagnosed at birth.

More people with learning disability survive into old age though the risk of a person with learning disabilities dying before 50 is much higher than that of the general population, and they may therefore experience additional need or fragility associated with the aging process, and from an earlier age than the general population. Learning disabilities are also often associated with other disabilities and mental health issues, and cardiovascular disease.

Once a child is diagnosed with learning disability, the General Practitioner (GP) can access specialist and professional support from paediatricians, speech and language therapists, physiotherapists and educational and clinical psychologists to help individuals live as full and independent a life as possible. Even after a diagnosis is made, it can be hard to tell how it will affect the person in the future.

Considerable burden may be placed on the parents and close relatives of a person with learning disability. Even when a person with learning disability and their carers receive full support from health and social care services, the patient with learning disability is still likely to face social, environmental and attitudinal barriers[10], which can restrict their participation in society. Policies that increase independence and enablement are important in supporting good outcomes for people with learning disability.

Learning disabilities definitions

For the purpose of quantitative analysis we use the term ‘Learning Disability’ (LD). We use the term person with learning disability when referring generically to an individual with LD. In general, they are people with a permanent reduced ability to learn new skills and live independently as a direct result of impaired intelligence and social functioning, developed in childhood.

A major issue in undertaking a needs assessment is arriving at a “case definition” of the population being considered. Normally the source for this is legislation, policy or established public health and epidemiological practice.

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[10] For example, they may experience high rates of physical and psychological abuse. See section **Error! Reference source not found.**.

This report adopts the definition outlined in the "*Valuing People*" report[11]. The report defines Learning Disability as "including the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support."[12].

On the other hand, for the purpose of collecting information we have also referred to the standard medical conditions associated to learning disability[13][14].

People with learning disability have a range of developmental needs. Learning disability affects the way a person learns and copes with new things in any area of life, not just at school. A learning disability means that it's harder for a person to learn, understand and communicate than it is for other people and this may also mean the individual is more vulnerable to exploitation and abuse. In addition, there may be other needs because of physical disabilities and/or sensory impairments.

Given this wide range of possible needs, people can be assessed with mild, moderate, severe and profound / complex disabilities. The distinction between these assessments is the level of help that they need with their daily living. In practice, people with learning disability may be identified in term of a diagnosis of severity (which is absolute), or in terms of the level of needs (which is relative as it is dependent of the family and social context). Therefore throughout this report we have used different classifications depending on the topic.

In a health context the report will adopt the categorisation of severity of the condition using the guidelines set for GPs to assess "Mental Retardation and related neurological conditions"[15] and applied also by Statement of Educational Needs (SEN) classification for pupils with learning disabilities. Therefore the severity of the learning disability can be divided in four categories:

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[11] Valuing People (2001), p 14.

[12] Valuing People (2001), p 14.

[13] People with learning disability thus includes people with Autism Spectrum disorders below IQ of 70 (ICD-10 F84), Down's syndrome (ICD-10 Q90), Fragile X (ICD-10 Q99.2), Mental Retardation (ICD-10 F7) and Asperger's syndrome (ICD-10 F84.5).

[14] It is worth noting that by definition learning disability does not cover adults or young people in transition who have acquired brain damage or those with only organic mental health problems such as dementia.

[15] Brady S, (2000), p.4.

- **Mild:**
  Mental age in adults from 9 to under 12 years of age. IQ Score in approximate range 50 to 69.

- **Moderate:**
  Mental age in adults from 6 to under 9 years of age. IQ Score in approximate range 35 to 49.

- **Severe:**
  Mental age in adults from 3 to under 6 years of age. IQ Score in approximate range 20 to 34.

- **Profound:**
  Mental age in adults below 3 years of age. IQ Score under 20.

However, when dealing with the social care record, we use the FACS classification adopted by Social Services, which is based on needs and applies to any adult in potential need of support, regardless of the underlying issues.

In this case, people classified according their needs are deemed to be Low, Moderate, Substantial and Critical. These correspond to actual or potential risk to independence, harm or danger to themselves.

- **Critical:**
  Risks to independence / harm or danger may occur in the present time

- **Substantial:**
  Risks to independence / harm or danger may occur either now or in the next three months

- **Moderate:**
  Risks to independence / harm or danger may occur either now or in the next twelve months

- **Low:**
  Risks to independence / harm or danger may occur

In practice people with learning disability in the medical severity class mild - if helped by family members - could be reasonably assessed as being at no or low risk.

However this does not mean that they (and their carers) do not need some degree of support during their lives, especially support aimed to enhance their ability to live with the least possible amount of help from carers and social workers.

As will be discussed in a further section, a number of policies concerning learning disability and people with disabilities recommend adopting prevention policies that ensure independency and a good level of health for disabled people. Unless the totality of people with learning disability is identified and followed, such policies cannot be put in place.

There is also another potential problem with assessing people with learning disability as being at risk of losing their independence. Current policies aim to increase the level of independence of adults with learning disability from carers as a way to improve their quality of life. However this may happen only with a potential increase of risk of harm and danger, as the person with learning disability is less likely to be protected from adverse outcomes if she or he does not live under the supervision of a carer.

Therefore the concept of independence needs to be articulated carefully, whether it means independent living or greater ability to deal with issues without the need for direct help by a carer.

There is no medical ‘cure’ for a learning disability and although the person can get better at ‘coping’ they are more likely to deteriorate over time faster than the rest of the population. They are less likely to be able to sustain good lifestyle habits and may suffer from related conditions, for example having difficulty in swallowing or respiratory problems that make healthy eating and physical activity difficult.

In practice, people with mild and moderate learning disability can be reasonably independent, take up employment and conduct reasonably normal lives, although some support is required to sustain a healthy lifestyle and negotiate some more complex social interactions – for example in dealing with the public administration or private service providers. Specific interventions may be required for some individuals with specific problems (for example challenging and aggressive behaviour).

People with severe and profound learning disability are in practice dependent on continuous support, requiring intensive personal care.

Policies and national indicators

There are several government policies that influence attitudes to and services for learning disabled people and make specific reference to quality of life, effective transitions from child to adult services and improved support for families. A selection of the policy drivers are summarised below

The 1995 Disability Discrimination Act (DDA) and the formation of the Disability Rights Commission were important in terms of driving disability policy. The act seeks to prevent discrimination against disabled people and promote equal opportunities in all areas of life (HMSO:1996). This has important implications for many services such as education, transport, employment and housing. The public sector equality duty under the Equality Act 2010 is further reinforcement of this.

Every Child Matters, Change for Children

Every Child Matters, Change for Children (HM Government: 2004) sets out the Government’s crosscutting national framework to build services around the needs of children and young people in England. This aims for every child to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing. This is underpinned by the Children Act 2004 (HMSO:2004), which provides the legislative basis for this framework. The policy commits Local Authorities and partner agencies to improve the transition to adulthood, especially in relation to disabled young people, and those with learning disabilities.

Disabled children

The Department for Children, School and Families (DCSF) and DH jointly published “Transition: moving on well” (DCSF:2007), outlining good practice on effective transition from children's to adult services for young people with complex health needs or a disability.

Aiming high for disabled children: better support for families (DES:2007), also emphasises focused and effective support for transition and includes the development of a Transition Support Programme, modelled on the Early Support programme but focussed on young disabled people in transition to adulthood.

Valuing People

Valuing People (DH:2001) and *Valuing People Now* (DH:2009) set out how the Government would enable children and adults with learning disabilities and their families to live full and independent lives as part of their local communities. *Valuing People* has four key principles that lie at the heart of the Government proposals:

- Rights: People with learning disabilities have the right to a decent education, to vote, to marry and have a family, and to express their opinions. It is recognised that they may need help and support to exercise these rights.
- Independence: People with learning disabilities have differing needs. In meeting these needs, public services should offer support in a way that promotes their independence.
- Choice: People with learning disabilities should be able to make choices about where they live, what work they do and who should look after them. Given the right help and support, all people with learning disabilities including those with severe and profound disabilities should be able to make choices about their lives.

- Inclusion: This means enabling people with learning disabilities to make use of ‘mainstream’ services and be fully active in their local community.

In particular, the strategy points to making significant improvements in giving people with learning disability much more choice and control over their lives through person centred planning, advocacy and direct payments. The strategy is all about ‘having a life’ with better health, housing, employment, transport, leisure services and social activities.

Valuing People Now set out priorities as follows:

- personalisation – so that people have a real choice and control over their lives and services;
- what people do during the day (and evenings and weekends) – helping people to be properly included in their communities, with a particular focus on paid work;
- better health – ensuring that the NHS provides full and equal access to good quality healthcare;
- access to housing – housing that people want and need with a particular emphasis on home ownership and tenancies;
- making sure that change happens and the policy is delivered – including making partnership boards more effective.

In *Valuing People*, the Department of Health made a commitment to commission “a national survey of people with learning disabilities in order to improve knowledge and provide a stronger baseline against which to evaluate the impact of Valuing People’[16].

The results of this survey (National Survey of People with Learning Disabilities - NSPLD 2003/04) provide the most robust information available on the ‘typical’ life experiences of people with learning disabilities in England (Emerson et al:2005).

Our Health, Our Care, Our Say

Published in February 2006, Our Health, Our Care, Our Say set out the Government’s ideas for the future direction of health and social care community services. Recommendations of particular relevance to people with learning disability are:

More people should be encouraged to use ‘Direct Payments’ and ‘Individual Budgets’ to choose the services that they want;

Health Action Plans (HAP) should include a ‘Life Check’, social care key worker and information on long term medication, how to stay healthy and how to access relevant services;

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[16] DH (2001), p. 114.

Transport arrangements need to be put in place to enable people to access the services that they need;

Long term residential services where the NHS is the patient's landlord to undergo phased closure.

'Health Care for All' and 'Six Lives' Ombudsman Report

Following the publication of the Mencap report 'Death by Indifference' (Mencap:2006) on the deaths of six people with learning disability in social and health care settings, there have been one independent inquiry (Michael Report:2008) and one major investigation carried out jointly by the Local Government Ombudsman and the Parliamentary and Health Service Ombudsman (The Stationery Office:2009).

Although they had different objectives, both investigations confirmed that in some cases there were significant breakdowns of communications between and within health care and social care agencies and teams, and lack of preparedness to deal with the specific needs of people with leaning disability, as well as failure to communicate with, and involve the relatives in the management of the conditions of people with learning disability.

As part of their recommendations it was required that concerned bodies (PCTs, LAs and the regulators for health and social care) should review the state of provision of services to people with learning disability and that the monitoring framework is working effectively, as well as making sure that the PCTs consult with partner agencies and representatives of learning disability organisations to inform the JSNAs.

The Parliamentary and Health Service Ombudsman also reiterated the recommendations of the 'Six Lives' report in June 2010 (Parliamentary and Health Service Ombudsman:2010).

The Autism Act 2009 and "Fulfilling and Rewarding Lives".

The Autism Act 2009 (HMSO: 2009) indirectly introduces a number of provisions that are also relevant to people with learning disability. As noted above, Autism is one of the neurological conditions leading to learning disability and is under the Mental 005DHealth services.

The Act stresses the importance of medical diagnosis as triggers for assessment (and re-assessment if necessary) of needs. It establishes the need for developing effective methods of diagnosis for the condition in relation to the provision of services[17].

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[17] NICE has been tasked with defining national guidelines in September 2011. See DH (2010) "Implementing "Fulfilling and Rewarding Lives" , p. 13.

Furthermore it requires that public services should be able to identify adults with autism regardless of the severity of the conditions, and the provision of appropriate services for each individual[18].

Appropriate services includes supporting good level of independence, health and making sure that civil servants, health and social care workers are appropriately trained to deal effectively with Autistic people, including communicating effectively and appropriately with them[19].

Although the act does not impose the identification of people with autism[20], it requires that public services staff may be able to identify them. It follows that there is a case for a formal process of identification (based on consent) to be put in place so that individuals' records may be flagged to mark their condition. Such 'alerts' may aid staff of public service to adopt the appropriate behaviour and procedures when dealing with these people.

A separate needs assessment report on Autism is in preparation at the time of writing.

National indicators

The three key national indicators relevant to adults with learning disabilities are all service based; NI 131 (delayed transfers of care from hospital), NI 145 (adults with learning disabilities in settled accommodation) and NI 146 (adults with learning disabilities in employment).

Other indicators with an indirect relevance are NI 103a (Children with SEN), NI 117 (Young People Not in Employment, Education, and Training), and NI 135 (Carers receiving needs assessment or review and a specific carer's service or advice and information).

Chapters 0 and 0 below provide an overview of the relevant data. It is worthwhile noting that the effectiveness of delivery of services varies between agencies and locations.

For example, while all children receive an assessment of special education needs within the 26 week standard, Patients with learning disability awaiting transfer from hospital on average wait 59.4 days (2008/9) or 78.2 days (April 2009 to Jan 2010) which is higher than for any other types of disability.

Fewer adults live in settled accommodation (46.5 %) in Birmingham compared to 57.5% in the West Midlands or 65.2% in England. People with learning

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[18] DH (2010), p. 16.
[19] DH (2010), p. 16-17.
[20] DH (2010), p. 16.

disability are less likely to find employment (1.5 %) in Birmingham than in the West Midlands (2.9%) or in England (7.5%)[21].

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[21] ASCAR returns and PAT website data, provided by Birmingham City Council.

Learning disabled populations: local and national

General population demographics

Birmingham has an estimated entire population of 1,033,400 (ONS) in 2010. It makes up approximately 2% of the whole population of England (52,296,500). Birmingham's population is estimated to increase by 4% in 2015 and 7% in 2020.

Figure 2 shows the percentage change in population projections from 2010 to 2030 in 5 years for Birmingham, England and West Midlands.

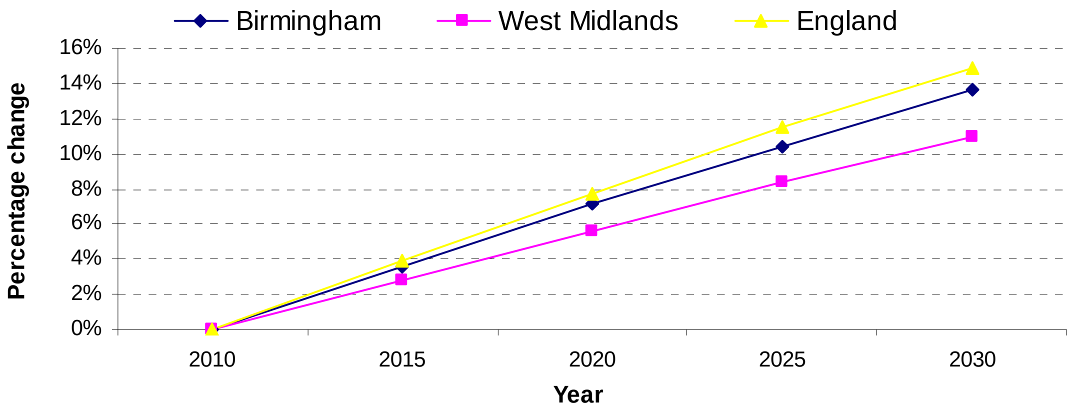

Figure 2 Population estimates for the period 2010-2030 (Source: Office of National Statistics, mid-year population estimates 2010-2030)

The population in Birmingham is estimated to increase by 13.5% in the period from 2010 to 2030 of which;

- 14.3% increase in Birmingham East and North PCT
- 12.9% increase in Heart of Birmingham Teaching PCT
- 13.4% increase in South Birmingham PCT

Age and gender

The population of the city is of very young age compared to the rest of England. According to ONS estimations, 21% of the population in 2010 is in the age group 0-14 (17.4% in England), 25.3% is in the age group 15-29 (20.2% in England).

Figure 3 shows the population pyramid for 2010 for Birmingham and England respectively.

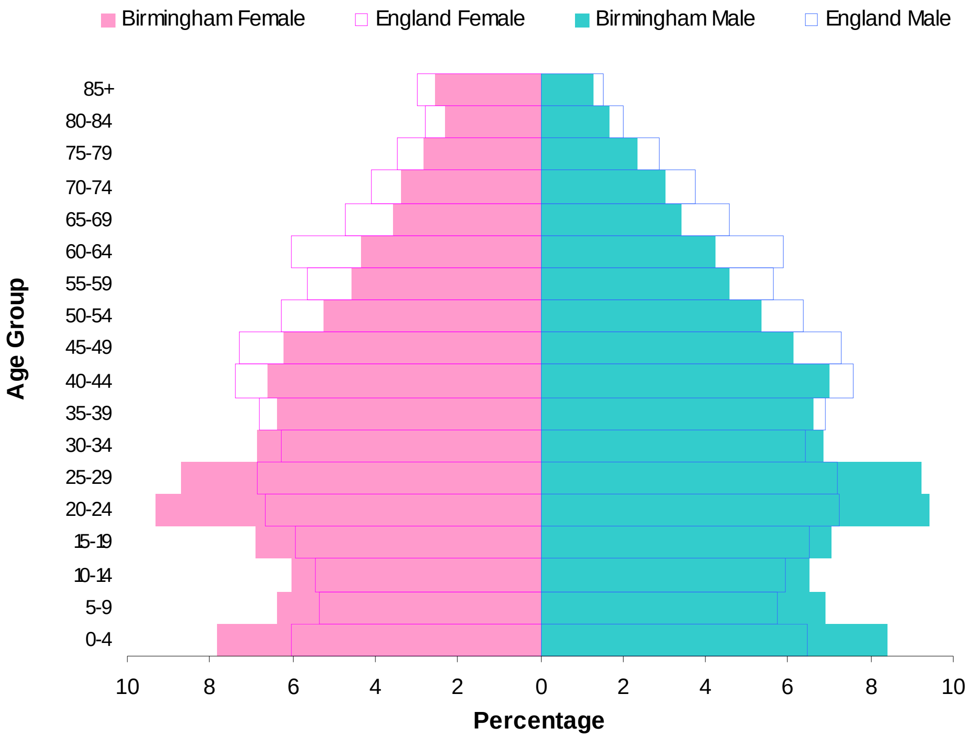

Figure 3 Population by age group and gender for Birmingham and England, 2010 (Source: Office of National Statistics, mid-year population estimates 2010)

Regardless of the overall population change, each age group behaves differently in the next 20 years. Table 1 shows the percentage change in the period 2009-2030 for adult population by age group.

Age Group	**2015**	**2020**	**2025**	**2030**
People aged 18-24	-5%	-10%	-7%	3%
People aged 25-34	17%	18%	13%	10%
People aged 35-44	-7%	2%	14%	16%
People aged 45-54	8%	4%	-2%	7%
People aged 55-64	2%	11%	18%	14%
People aged 65-69	11%	7%	15%	27%
People aged 70-74	-4%	8%	4%	13%
People aged 75-79	2%	1%	14%	11%
People aged 80-84	0%	7%	8%	24%
People aged 85 and over	10%	20%	39%	56%

Age Group	2015	2020	2025	2030
Total population aged 18-64	3%	5%	7%	10%
Total population 65 and over	4%	8%	15%	24%
Total population - all ages	4%	8%	11%	14%

Table 1 Population change by age group (2009 Baseline), Birmingham City Council (Source: PANSI and POPPI)

Ethnicity

Birmingham has the most diverse ethnic population in the United Kingdom. Estimates for 2007 mid-year population show that 62.2% of Birmingham's population is 'White British'. However the White British population varies widely with age. In the age group 0-19 the White British population is only 54% while in the retirement age it is 77%. In a study commissioned by the Birmingham City Council in 2007 (Cathie Marsh: 2007) the percentage of school children of White British ethnicity was only 42.2%.

These statistics demonstrate that the White population has a much older age structure compared to all other ethnic groups. In 2007 the Office of National Statistics estimated that:

- 70% of the adult population in Birmingham is of White Ethnicity (89% England and 90% West Midlands).
- 19% of the adult population in Birmingham is Asian or Asian British (5% England and 6% West Midlands).
- 7% of the adult population in Birmingham is Black or Black British (3% England and 2% West Midlands).
- 3% of the adult population in Birmingham is Chinese or Other Ethnicity (2% England and 1% West Midlands).
- 2% of the adult population in Birmingham is Mixed Ethnicity (1% England and 1% West Midlands).

Projections from the Cathie Marsh Centre (Table 2) show that the Black and Minority Ethnic community (BME) will increase by 2026. These estimates show that the population of 'Pakistani' ethnicity is the biggest group among other minorities. And by 2026 this minority will make up one fifth of the population of the city.

Ethnicity	2011	2016	2021	2026
White	60.6%	56.1%	51.8%	47.7%
All Non White	39.4%	43.9%	48.2%	52.3%
Pakistani	15.1%	17.1%	19.1%	21.0%

Ethnicity	2011	2016	2021	2026
Indian	5.9%	5.9%	5.8%	5.7%
Caribbean	4.6%	4.3%	4.0%	3.7%
Bangladeshi	3.1%	3.6%	4.0%	4.3%
African	1.8%	2.5%	3.3%	4.1%
Chinese	0.9%	1.0%	1.1%	1.2%
Other	8.0%	9.5%	10.9%	12.1%

Table 2 Projected population change in Birmingham by ethnic groups 2011-2026 (Source: Cathie Marsh Centre for Census and Survey Research, 2007)

The Black African community is expected to have the greatest relative increase as share of the Birmingham population (from 1.8% to 2.5% in 2016 and 3.3% in 2021, a growth in relative terms of 39% and 32%, respectively.

Learning disability demographics in Birmingham

It is very difficult to estimate the total number of people with learning disabilities in England. This is because there is no clear consensus on how the learning disability is defined and therefore the statistics may vary widely. Furthermore different studies look at different degree of severity of the condition.

Finally, and more important, the databases of people with learning disability in Birmingham are geared to only register the most severe end of the spectrum of learning disabilities. The only potential source of information about all people with learning disability is represented by SEN records of children in the education system.

Provided that a statement of educational needs is requested, a child will be assessed and registered as having learning disability regardless of the degree of severity of the condition. However this information, even if collected for several years up to now would provide a view of the learning disability population valid only for the younger cohorts.

A useful rule of thumb is based on the fact that learning disability is directly related to intellectual development. As such, individuals could be defined as having learning disability if their IQ score falls below 70. By definition, the IQ score across the general population worldwide follows approximately the normal distribution with mean equal to 100 and standard deviation equal to 15.

This means that at least an approximate 2.28% of the general population will have an IQ score below 70 and thus have learning disability. As the IQ testing procedure does not take into account individuals with brain damage and disorders, the fraction of people with learning disability is by default higher than 2.28%, but this generally applies to the more severe forms of learning disability[22]. On the same basis it could be assumed that the approximate number people with mild learning disability are 2.24% of the general population[23].

In terms of the Birmingham population[24], these percentages would translate into an approximate learning disability population of at least 23,560 individuals, of which 23,150 would have mild learning disability. If we were to consider only the adult population[25], then we would have at least 17,829 Adults with learning disability, of which 17,517 would have mild learning disability.

For comparison, the Joint Commissioning Strategy for Services for People with Learning Disabilities, (2006) report estimates for 2006 of 29,135 people with learning disability, of whom 4,020 would have severe or profound learning disability and 25,115 would have mild or moderate learning disabilities[26]. Other DH estimates[27] for Birmingham - which take into account its ethnic profile - suggest that 2.47% of Birmingham adults are learning disabled in 2009. The same source indicates an increase of adults with learning disability from 18,451 (2009) to 20,776 (2030), as well as an increase in adults with learning disability aged 65+, from 2,817 (15%) in 2009 to 3,525 (17%) in 2030.

For comparison, a critical review of 43 papers (Roeleveld et al.:1997) showed that the prevalence of learning disability varied from 2 to 85 per 1,000 of the population. The review estimated that the average prevalence of learning disability was 30 per 1000 for mild learning disabilities and 3.8 per 1000 for more severe learning disabilities.

The health needs assessment of people with learning disability in Scotland in 2004 identified some of the most relevant prevalence studies for learning disability, as shown in Table 3.

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[22] That is, there are more people with IQ score less than 50 than the distribution of IQ scores would otherwise suggest. See Fewtrell L et Al (2003), p. 11.

[23] Following the convention adopted earlier on, people with mild learning disability have IQ scores falling between 2 and 3.33 standard deviations from the mean. Following the normal distribution, 2.28% of the population has score below 70 and 0.04% of the population has a score below 50. Therefore, at least an approximate 2.28%-0.04% = 2.24% of the population should exhibit a mild form of learning disability.

[24] ONS 2007 Mid Year Estimate adjusted for 2009: 1,033,400 people.

[25] ONS 2007 Mid Year Estimate adjusted for 2009: 782,011.

[26] Joint Commissioning Strategy for Services for People with Learning Disabilities, (2006), p. 16.

[27] PANSI (Projecting Adult Needs and Service Information System). http://www.pansi.org.uk/.

Year	Age group	Geography	N	Study type	Prevalence (per 1,000)				
					Mild	**Moderate**	**Severe**	**Profound**	**Total**
1997	Lifespan	Worldwide	N/A	Critical review of 43 prevalence studies	34		3.8		37.5
1998	Median age 10.8 yrs	Norway	185	Population based on 1980-1985 birth cohort	3.5	1.5	0.4	0.8	6.2
1999	Not specified	France	1150	Retrospective survey of 1976-1985 birth cohort	N/A		3.5 Combined		N/A
2001	Lifespan	USA	945,091	Non-institutionalised population, cross sectional survey 1994-1995	N/A	N/A	N/A	N/A	7.8
2002	20 yrs +	Leicestershire, England	105	Population based, cross sectional administrative prevalence 1991	N/A	N/A	N/A	N/A	3.6
2002	14 - 20 yrs	Ontario, Canada	225	Population based screening study in 1994	3.54		3.64 Combined		7.2
2003	11.5 yrs	Northern Finland	105	Population based 1985-1986 birth cohort	7.49	1.71	0.75	1.28	11
2003	Children	Western Australia	3,426	Population based 1983-1992 birth cohort	10.6		1.4		12.0 (2.3 per 1,000 not specified)

Table 3 Table 3: Studies of the prevalence of people with learning disabilities in the population (Source: Health Needs Assessment Report, People with Learning Disabilities in Scotland, 2004)

It is clear that the prevalence rates vary widely between countries and it is difficult to understand the extent of this variation, if it represents a genuine difference in prevalence rate between geographical areas or if it is a result of study design.

Figure 4 shows the ethnic and age breakdown of people with learning disability known to the Adult and Communities Directorate over the 2006/07 to 2008/09 period. In the age range 18 to 64 the BME people were 30% of the total. Of these, 12.3% are Asian or Asian British, and 11.5% Black or Black British. Overall the Asian people were, on average, 12.2% of the total and the Black people were 10.4% of the total.

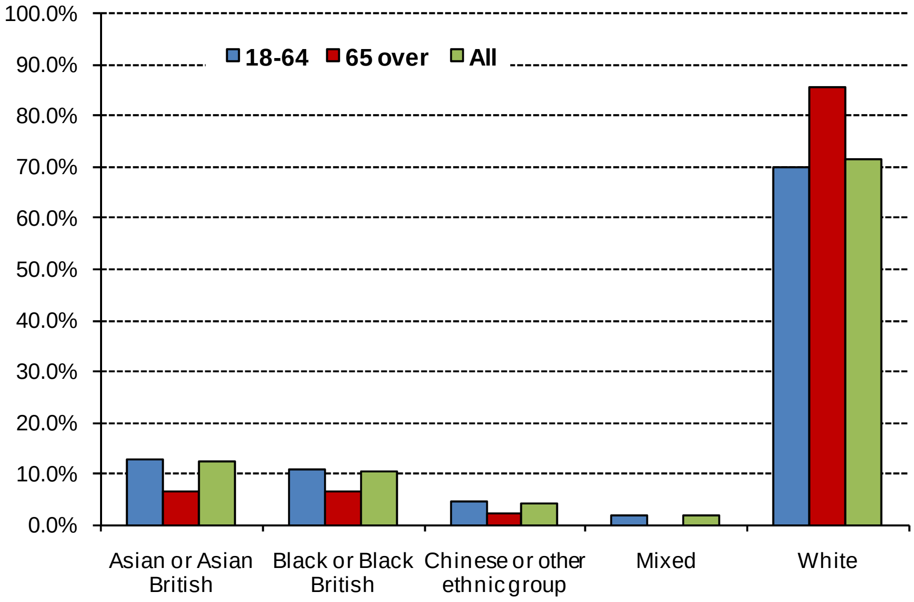

Figure 4 Number of adults with learning disability known to the services in Birmingham. Three years average 2006/07 to 2008/2009 (Source: Referrals, Assessments and Packages of Care (RAP), 2006/07 to 2008/09 in Birmingham)

Figure 5 shows how the percentage of non-white service user population known to services has changed over the years for the age group 18-64 and 65+.

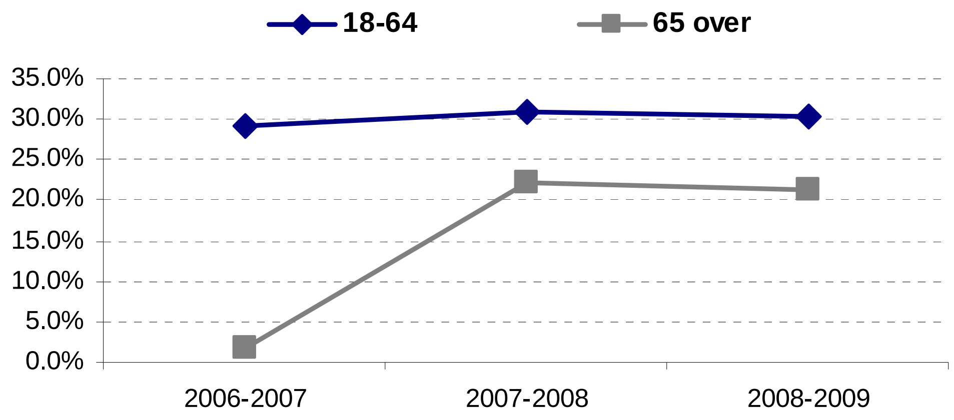

Figure 5 Percentage of non-white population with learning disability in Birmingham over three consecutive years (Source: Referrals, Assessments and Packages of Care (RAP), 2006/2007 to 2008/2009 in Birmingham)

It is unclear what caused the increase of the working age non-white service user population from to 2006/2007 to 2007/2008, but this major increase may be related to changes in the quality of the data or a change in patterns as well as changes in the population demographics.

People with learning disability known to Birmingham City Council Adult Services: age, gender, ethnicity, and severity.

In this section we use the information collected by different databases[28] used by Birmingham City Council (BCC) to deliver services to adult people with disabilities.

The data is updated to the 31st of March 2009. For comparison with the general population we use the ONS mid-year 2007 estimates for Birmingham[29].

The database systems hold individual records of users of services, their carers, and the services delivered to both. The analysis focuses on the demographic composition of people with learning disability and their carers.

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[28] The principal source or records is the CareFirst system. In addition data is collated from other services databases. The dataset used in this study is used as base for the preparation of RAP returns records.

[29] The figures are adjusted using the 3-year averaged ONS mortality rate for males and females at one year for the general population per each age group. For example, the 2007 male 16 years-old count is recalculated subtracting twice the fraction estimated to have died within one year. This procedure is necessarily imprecise (mortality rates are assumed constant over two years, they are assumed to be the same across ethnic groups; emigration and immigration are also not considered). However this procedure does allow for some degree of consistency between the two sets of data when comparing age groups and birth cohorts. Excluding 16 and 17 years old from the 2007 dataset would have implied a baseline difference of about 30,000 individuals.

Age and birth structure

We start by looking at the age structure of the service users with learning disability, split by gender, and compare it with the age profile of the adult Birmingham population (Figure 6).

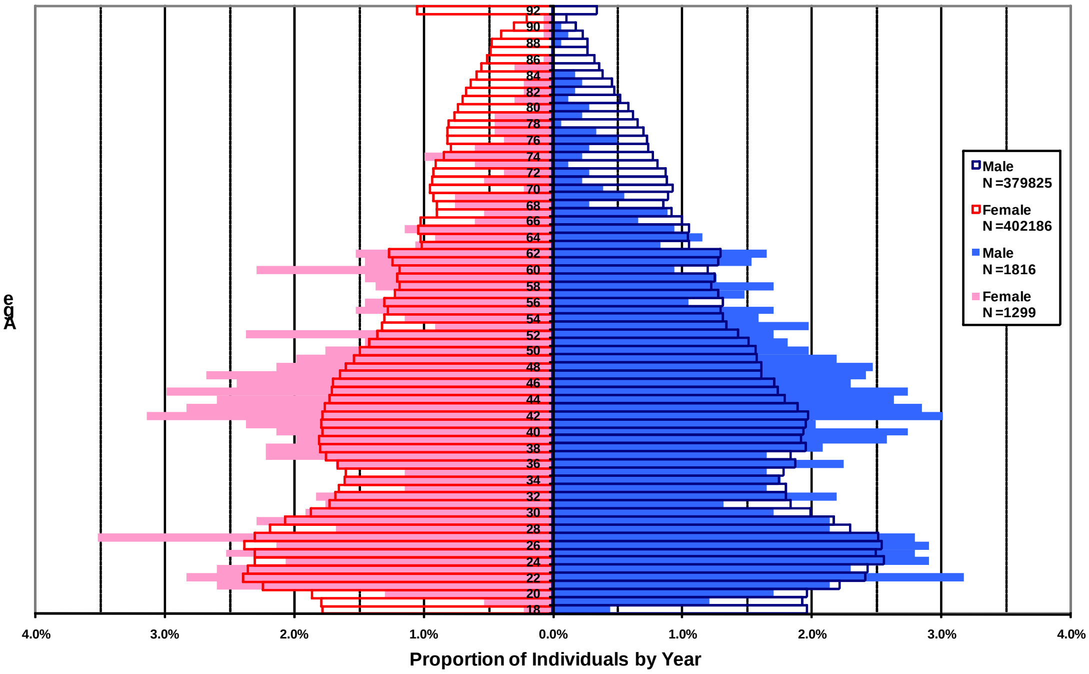

Figure 6 Age Pyramid of people with learning disability of BCC at 31/03/2009 compared to general population. People with learning disability: 3,115. Population estimate: 782,011. BCC figures in colour, ONS in outline (Source: BCC Business Information Unit FY 2008/09; Modified ONS mid-2007 estimate)

The graph in Figure 6 shows that the ages range of service users with learning disability is more compressed compared to the rest of the general population. This is due chiefly to the lower life expectancy of the people with learning disability compared to non-learning disabled individuals.

Only 8.6% of service users with learning disability were older than 65, compared to 19.4% in the general population. This means that as far as the recorded client with learning disability population is concerned, the odds of being older than 65 are less than half of those of the general population.

Figure 6 also shows that males are prevalent in the younger age groups. Older females seem to outnumber males, in line with the general population.

Figure 7 shows the distribution of service users with learning disability by year of birth. The pattern of peaks and troughs is basically the same from after the war (post 1945).

Older cohorts of service users with learning disability form a smaller proportion of the total compared to the general population, due to lower life expectancy for people with learning disability.

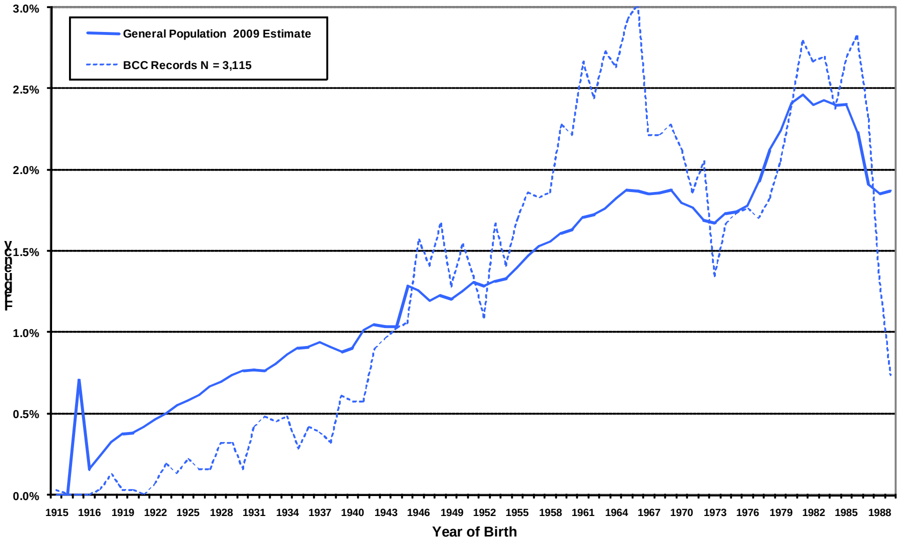

Figure 7 Relative size of birth cohorts of people with learning disability of BCC at 31/03/2009 compared to general population. Number of people with learning disability: 3,115. ONS estimate: 782,011 (Source: BCC Business Information Unit FY 2008/09; Modified ON

Both Figure 6 and Figure 7 show a dip in the proportion of individuals in the younger age and birth cohort (18-20 years old). This dip is likely to be due to current administrative practices, rather than to a demographic shift. The possible causes of this dip will be discussed in more detail in chapter 6.

Ethnicity

The population of service users with learning disability in the BCC databases at close of fiscal year 2008/09 was composed of 3,115 individuals recorded as alive and as potential or actual recipients of services. The ethnic breakdown of this population compared with general population breakdown is described in Figure 8 below[30].

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[30] For comparative purposes we use ONS ethnic group definitions.

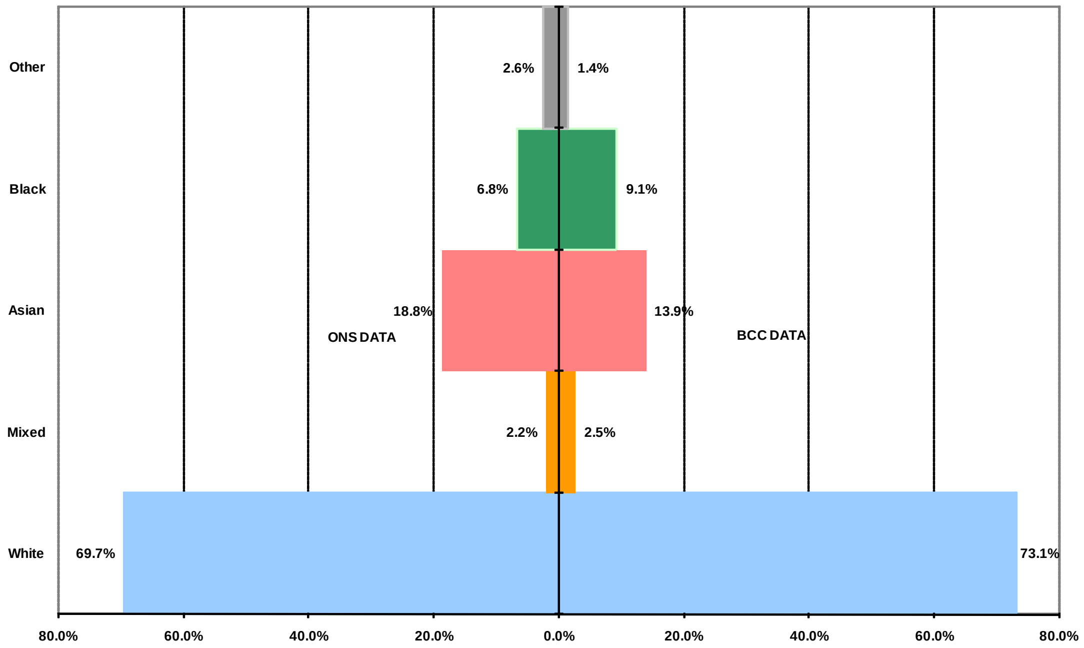

Figure 8 Ethnicity of people with learning disability of BCC at 31/03/2009 compared to general population. Number of people with learning disability: 3,115. Estimated adult population size: 782,011 (Source: BCC Business Information Unit FY 2008/09; Modified ONS

The graph suggests a discrepancy between the ethnic breakdowns of service users with learning disability and the general population. This difference is found to be significant[31] chiefly because the Caribbean ethnic group is overrepresented among the BCC users with learning disability compared with the general population.

The bulk of the Black ethnicity group with learning disability are represented by Caribbean people (86.0%), while the Asian Community is mostly represented by Pakistani and Indian[32] service users with respectively 62.3% and 26.5%. These three ethnic groups will be further analysed in the following chapters and sections.

Table 4 below provides a more detailed breakdown by of the Black and Asian Ethnic groups. We have omitted the Mixed and Other groups as the small numbers associated do not enable meaningful comparison with the general population.

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[31] The test was based on a Generalised Linear Model (GLM) Regression of the figures of adults in Birmingham, by ethnicity, from the BCC record and the ONS adjusted figures. An interaction between the ethnic classification and the source of data was included and found to be highly significant (p-value < 0.001). This means that the distribution of people with learning disability across ethnic groups is significantly different from the one of the general population.

[32] This category includes Gujerati, Sikh and Kashmiri people for the sake of comparison. There were only 30 Bangladeshi people (6.9% of Asian people with learning disability). This is a small figure with respect to the general population (10.9%) data but the number being these small no firm conclusion can be drawn whether there are specific issues concerning the Bangladeshi population.

BCC Ethnicity Classification	N	%
Black – Other	19	6.7
Black African	21	7.3
Black-African Caribbean	245	86.0
Total Black	285	100.0
Asian Other	19	4.4
Bangladeshi	30	6.9
Pakistani	269	62.3
Indian	88	20.4
Gujerati	3	0.7
Kashmiri	5	1.2
Sikh	18	4.2
Total Asian	432	100.0

Table 4 Ethnicity of Asian and Black people with learning disability of BCC at 31/03/2009 (Source: BCC Business Information Unit FY 2008/09.)

Given the use of approximate estimates for the general population these findings come with a caveat. However they are consistent with the possible existence of cultural and language barrier to access to services.

Severity and Needs

The BCC administrative records place service users with learning disability in four categories in terms of needs, using the ‘Fair Access’ (FACS) categories. Table 5 below shows the breakdown in absolute and relative terms.

FACS Definitions	No FACS	Low	Moderate	Substantial	Critical	Total
People	626	36	90	491	1872	3,115[33]
People %	20.1%	1.2%	2.9%	15.8%	60.1%	100.0%

Table 5 Breakdown of people with learning disability by FACS definitions (Source: BCC Business Information Unit FY 2008/09)

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[33] Discrepancy with totals form other tables is due to missing information on one client about services used.

The table shows that the BCC recording system captures only partially the extent of needs of service users with learning disability, with 20.1% of people with learning disability receiving services without a FACS definition. This is chiefly due to the fact that service records are not stored centrally.

Chapter 5 and 6 will analyse in more detail the features of this group, by considering their demographic composition (age, ethnicity, location, and services received). We can anticipate that the five FACS groups differ from each other significantly in terms of their age[34] and ethnicity structure.

In particular, the data indicates that Asian service users with learning disability are significantly less likely to get a FACS classification as Critical and Substantial compared to White people with learning disability. This fact results in Asians are relatively more common amongst the ‘No FACS’ group compared to Whites[35].

Some people with learning disability may receive service through different channels and from different units within BCC, each of them with their own records. Therefore people may be supported without going through a FACS assessment.

Table 6 shows that only a small number of service users with learning disability are explicitly provided support services for people with learning disability who have additional physical (PD) and/or mental health (MH) conditions[36].

Status	LD Only	LD and one additional condition	LD and two other conditions	Total
No FACS	617	3	0	620
Low	36	0	0	36
Moderate	90	0	0	90

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[34] A Kruskal-Wallis test of distributions (performed with R package) finds significant differences in the age structure ($p<0.001$) of the 5 groups.

[35] A generalised linear model test was carried out on the breakdown figures of people with learning disability according to FACS status (low and moderate class being merged into one), sex and ethnicity (5 ONS classes). The reference category was defined by No FACS status, White, Male. The combined effect of ethnicity and FACS status was found to have a highly significant ($p < 0.01$) negative effect on the counts of Asians in FACS categories substantial and critical.

[36] This may well be due to the fact services provided to client with learning disability by default are in essence the same as for people with physical disability, so that both conditions are covered without being explicitly addressed by the service. The small numbers in the table refer to individuals whose records indicated explicitly services related to either PD or MH, such as MH or PD accommodations, House adaptations, hearing equipment and/or therapy, special phones, etc. The discrepancy in totals with **Error! Reference source not found.** above is due to matching people to a standardized set of services.

Status	LD Only	LD and one additional condition	LD and two other conditions	Total
Substantial	487	2	0	489
Critical	1,853	15	1	1,869
Total People	3,083	20	1	3,104

Table 6 Breakdown of People with learning disability by FACS definitions and multiple conditions (Source: BCC Business Information Unit FY 2008/09)

Table 7 shown below suggests an expected association between needs and number of separate services assigned to any client with learning disability. However, the way people with learning disability without FACS are split by the number of services received seem to be different from the split of the people with learning disability with FACS.

No of Services	1	2	3	4	5	Total
Critical	373	907	469	102	18	1,869
Substantial	156	237	82	12	2	489
Moderate	40	39	11	0	0	90
Low	26	9	1	0	0	36
No FACS	401	153	54	12	0	620
Total People	996	1,345	617	126	20	3,104[37]

Table 7 Breakdown of people with learning disability by FACS definitions and number of services provided (Source: BCC Business Information Unit FY 2008/09)

Analysis shows that people with learning disability without a FACS tend to receive as many services as people with FACS low and moderate[38]. This fact suggests that most people with learning disability without a FACS would be normally classified in the low and moderate categories of needs. However the

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[37] Discrepancy with previous client totals is due to use of a set of services restricted to actual service providers instead of including generic support.

[38] The test was based on a Generalised Linear Model (GLM) Regression of the **Error! Reference source not found.** numbers. Columns of number service 3, 4 and 5 were collapsed in a '3+' category. The interaction between FACS categories and number of services delivered was found to be highly significant (p-value < 0.01). In particular, Substantial and critical people with learning disability were more likely to receive two and three or more service compared to those without FACS. Moderate people with learning disability were more likely to receive two services compared to people with no FACS, but no difference was observed for 3 or more services. No significant difference was observed between Low need people with learning disability and people without FACS. For the difference in totals compared with **Error! Reference source not found.**, see note **Error! Bookmark not defined.** above.

breakdown of services delivered to people by type of needs (Table 8) may indicate differences between groups of people.

It is not clear if the spread across services of each FACS group is different from one group to the next. Further testing shows however that there is a significant difference in the distribution of services between the No FACS group and the other ones[39].

In chapter 6 this data will be analysed in more detail. It is however possible to check if the pattern of usage of services generates 'natural' groupings and if this groupings relates to the demographic characteristics of the people with learning disability, using cluster analysis.

In this instance cluster analysis did not point to any particular cluster of people in relation to either the FACS classification or the demographic characteristics. The analysis nevertheless revealed a clear clustering of people depending on whether they received professional services or not. In particular, those receiving professional support are mostly associated with White people (346 out of 380, or 91.1%) and with over 65s (242 out of 380, or 63.7%).

Services	No FACS	Low	Moderate	Substantial	Critical	Services
Adaptations	10	0	0	1	19	30
Appointee & Receivership	15	1	2	3	111	132
Day Care	148	4	21	131	606	910
Equipment	19	1	1	15	66	102
Direct Payments	14	2	6	32	129	183
LD Accommodation	35	1	7	99	814	956
PD Accommodation	1	0	0	1	11	13
MH Accommodation	2	0	0	1	6	9
Elderly Accommodation	2	0	0	6	33	41
Home Care	30	0	11	121	336	498
Bharosa[40]	6	0	0	0	0	6
Respite	2	0	0	0	6	8
Meals	10	0	0	5	3	18

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[39] **Error! Reference source not found.** was modified merging the low and moderate groups, plus services related to home care and accommodation were aggregated. The figures were then modelled using GLM regression, setting professional services and No FACS as the reference categories.

[40] Family support service for Asian families.

Services	No FACS	Low	Moderate	Substantial	Critical	Services
Other Support	76	8	18	95	325	522
Total Services	370	17	66	510	2465	3428

Table 8 Breakdown of services to people with learning disability by FACS definitions and services provided (Source: BCC Business Information Unit FY 2008/09)

A combined picture of people with learning disability in Birmingham: age, gender, ethnicity.

The analysis of the composition of the learning disability population in Birmingham can be enhanced if we split the client base by ethnic groups.

Figure 9 shows the age composition of the Caribbean community.

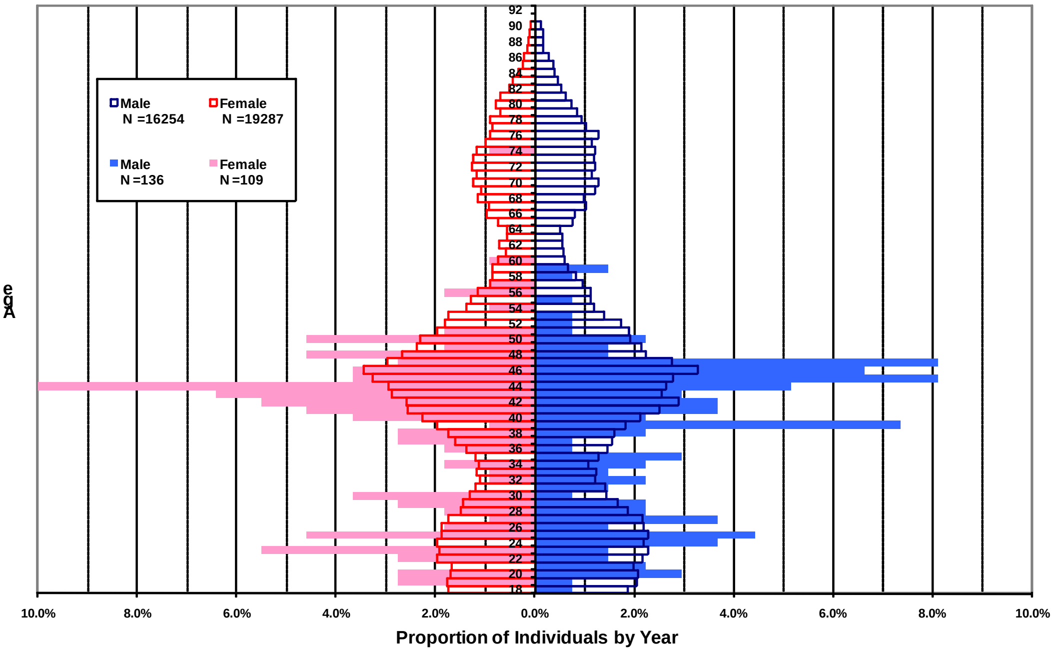

Figure 9 Age Pyramid of people with learning disability of BCC at 31/03/2009 compared to general population. Number of Caribbean people: 245. BCC figures in colour, ONS in outline (Source: BCC Business Information Unit FY 2008/09; Modified ONS mid-2007 estimate)

The age profile of people with learning disability broadly follows the patterns of the general population, once the lower life expectancy patterns are taken into account. A similar pattern can be observed in relation to the Pakistani community, as shown in Figure 10.

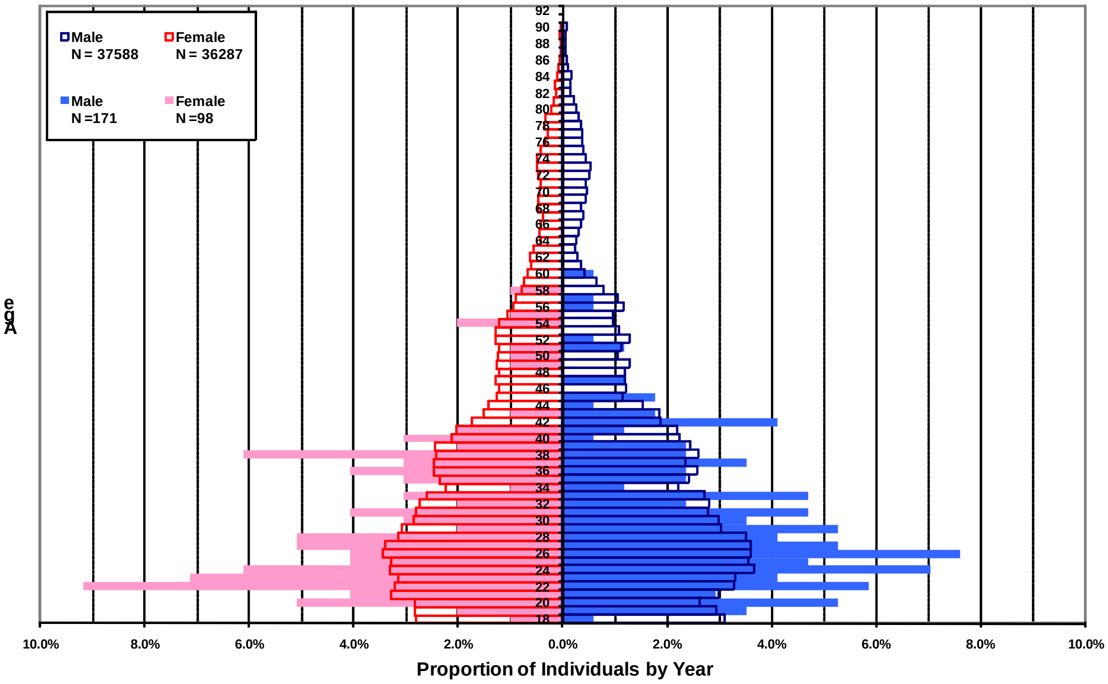

Figure 10 Age Pyramid of people with learning disability of BCC at 31/03/2009 compared to general population. Number of Pakistani people: 245. BCC figures in colour, ONS in outline (Source: BCC Business Information Unit FY 2008/09; Modified ONS mid-2007 estimate)

A completely different pattern is shown by the Indian people with learning disability[41] (third largest minority ethnic group among people with learning disability) in Figure 11 below.

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[41] The 'Indian' label also includes self reported Sikhs (19), Kashmiri (5) and Gujerati (3).

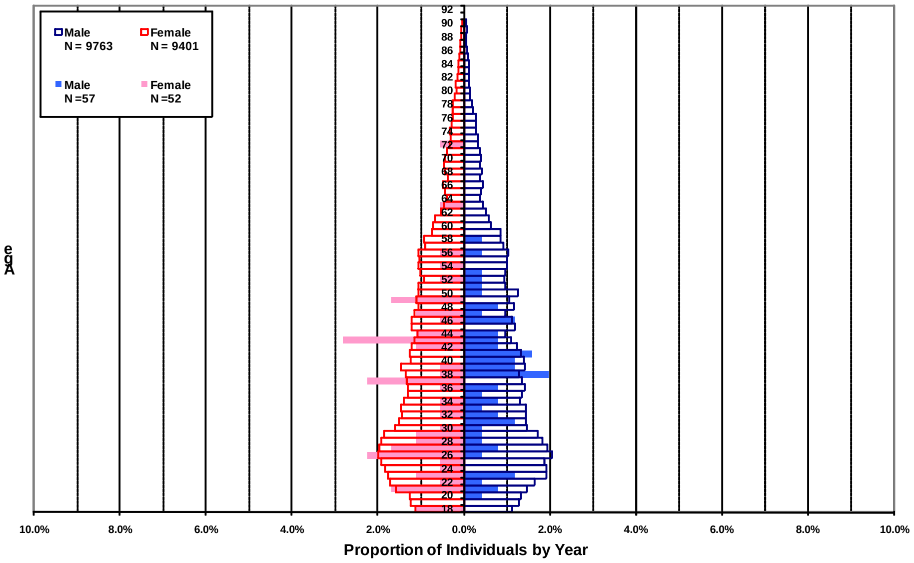

Figure 11 Age Pyramid of people with learning disability of BCC at 31/03/2009 compared to general population. Number of Indian people 109. BCC figures in colour, ONS in outline (Source: BCC Business Information Unit FY 2008/09; Modified ONS mid-2007 estimate)

Life expectancy appears to be much higher than for the other groups. Occasionally females with learning disability seem to outnumber their male counterparts. The small size of these groups suggests caution about drawing any firm conclusions on the different patterns of these three communities.

However a test on a combined dataset of White, Indian, Pakistani and Caribbean People with learning disability indicates that given age, ethnicity, and gender in the BIU set and the General Population:

There are more Caribbean and Pakistani People with learning disability than we would normally expect[42].

There is weak evidence for a less than expected presence of Indian People with learning disability[43].

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[42] A generalised linear model (GLM) test was carried out over the cell count of breakdown figures of the Birmingham general population estimates for 2009 and BIU figures of LD client, broken down by age, sex, and ethnicity. General population figures discounted the LD numbers for precision's sake. The age range was restricted to 18 to 64, to allow for migration patterns of the BME communities – i.e. people born after the war. The analysis was corrected for over dispersion of the values. The data was analysed as proportions of individuals over the total in the age range. Age was treated as a banded rank variable. The interaction effect ethnicity, LD status for Caribbean and Pakistani was found to be positive and significant ($p < 0.05$) compared to the white equivalent group.

[43] Output from regression described in note**Error! Bookmark not defined.**. The finding was significant only at $p<0.1$.

Disability Employment Service Records (Birmingham City Council DES Unit): Age, Gender, Ethnicity

The Disability Employment Service (DES) unit of the Birmingham City Council provide recruitment and training services and employment to people with learning disability aged 16 to 74. The typical DES client has multiple disabilities, such as LD and hearing, or mobility, or visual impairment (PHIT:2010a). The list of current and past DES service users has been processed to provide a dataset for demographic analysis[44].

The DES service user dataset is potentially complementary to the BIU dataset. DES service users are mostly younger than their counterparts in BIU records, and their LD condition is associated with other disabilities, which make them roughly comparable to the FACS ‘moderate’ category. In fact DES service users do not greatly overlap with Adult and Community Care service users. There are relatively few matches[45] between DES and BIU records.

Age and Gender Structure

Figure 12 shows the age composition of active DES service users by the end of FY 2008/09 compared to the general population for the age range 18 to 64[46].

---

[44] The initial set reported 1731 records of service provided to 930 people over the past years. After checking for potential duplicates and data entry errors on date of birth and provision of services, the dataset has been reduced to 865 people supported by DES over the years and still on records. Of these, 246 were registered as receiving a service by 31/03/2009.

[45] The extent by which DES people appear in other BCC databases will be discussed later.

[46] The age range is different from the one quoted above only because of the age range of valid records. In this case the youngest people were 18 years old.

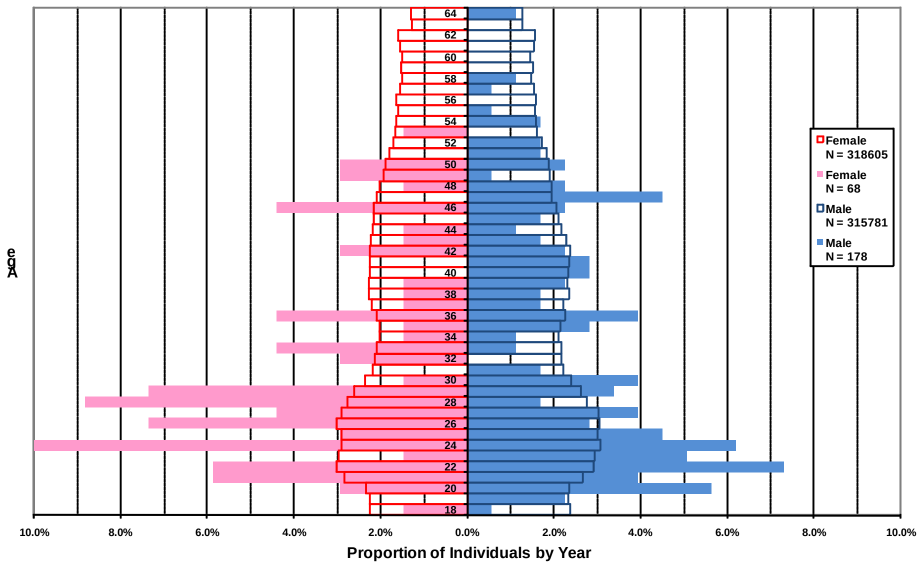

Figure 12 Age pyramid of people with learning disability using DES at 31/03/2009 compared to general population, aged 18 to 64. Number of DES service users: 246. Estimated adult population size: 634,385. DES figures in colour, ONS in outline (Source: DES; Modified ONS mid-2007 estimate[47])

The diagram suggests (like the BIU records) a fairly different distribution in terms of age between people with learning disability and the general population. More than 50% of DES service users are in the 18 to 30 years old age range, compared to about 35% for the general population.

Figure 13 describes the distribution across birth cohorts for the years 1944-2009 (18 to 65 years of age) of LD DES service users[48] and the General Population. The general birth trends are roughly followed by the DES population.

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[47] DES Unit records active to FY 2008/09; Modified ONS mid-2007 estimate.

[48] Due to the small number of people we have used a smoothed line (3 years Moving Average) to represent them.

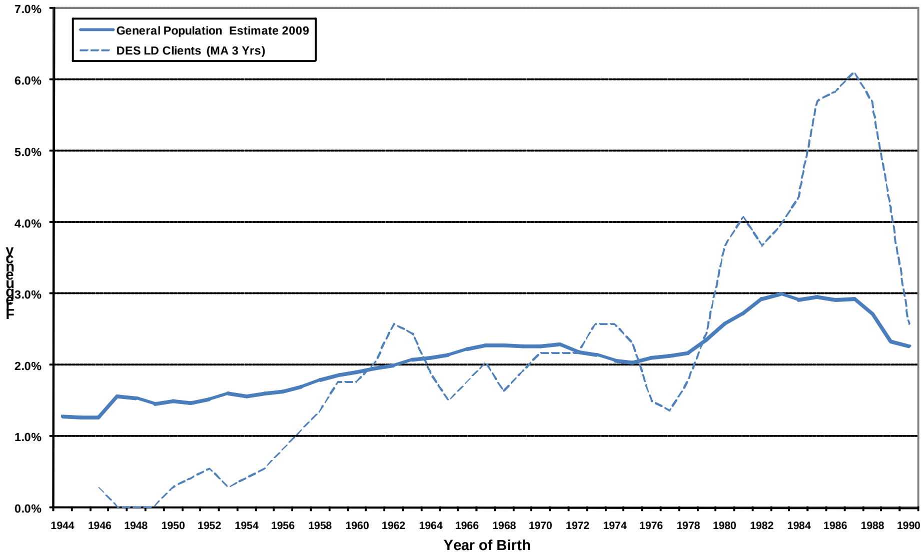

Figure 13 Relative size of birth cohorts of people with learning disability using DES at 31/03/2009 compared to general population. Number of People with learning disability: 246. Estimated adult population size: 634,385 (Source: DES; Modified ONS mid-2007 estimate[49])

Those born before 1960 appear to be under represented compared to their contemporaries in the general population. Conversely, those born before 1980 seem to be over represented compared to their contemporaries in the general population.

In the first case we may assume that the demand for work related services is considerably reduced[50] for the 1944-1960 birth cohorts (i.e. those aged 50+ approximately), whereas the 1980-1990 birth cohorts are more prevalent among DES service users compared to the general population.

Ethnicity

The ethnic breakdown of the DES LD service user base mirrors to an extent the breakdown already observed for the Adult and community Care Department records.

The Asian community is under represented[51], with a greater than expected weight given to the White, Black, and Other Ethnic communities.

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[49] DES Unit records active to FY 2008/09; Modified ONS mid-2007 estimate.

[50] Either because there is little need for additional support past the corresponding are range, or because the people are increasingly unable to work past a certain age. This explanation will be explored in more detail in chapter**Error! Reference source not found.**.

[51] The test was based on a Generalised Linear Model (GLM) Regression of the figures of adults in Birmingham, by ethnicity, from the BCC record and the ONS adjusted figures. An interaction between the ethnic classification and the source of data was included and found to be highly significant (p-value < 0.01). This means that the distribution of DES LD People across ethnic groups is significantly different from the one of the general population

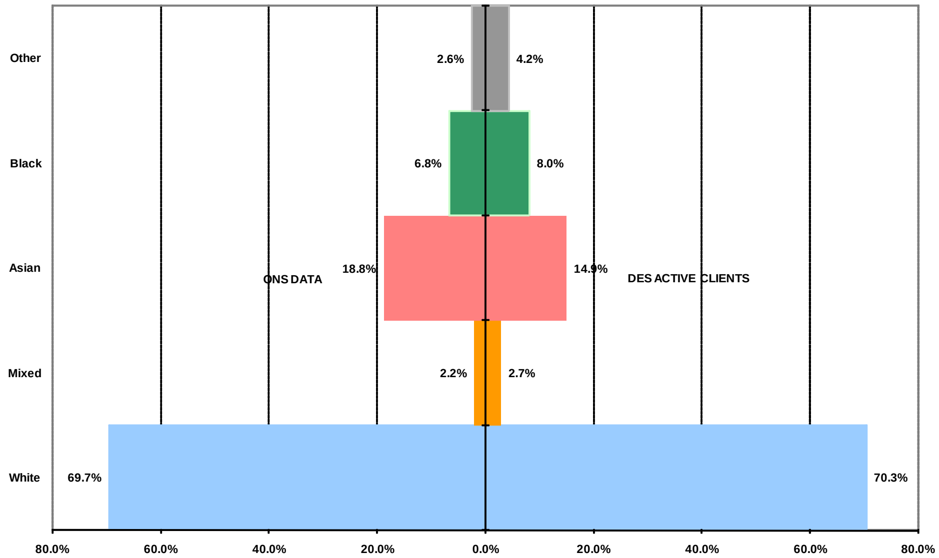

Figure 14 Ethnicity of People with learning disability of DES at 31/03/2009 compared to general population. Number of People with learning disability: 242[52]. Estimated adult population size: 634,385 (Source: DES; Modified ONS mid-2007 estimate[53])

A combined picture of people with learning disability in Birmingham: age, gender, ethnicity

As we have done for BCC client base, we split the DES client base also by ethnic groups. In this case the dataset allows only for a split between White and BME groups.

Figure 15 below shows the age composition of the White community. Interestingly these seem to be a predominance of younger female People with learning disability, whereas males are more evenly spread out the age range, not unlike the general population.

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[52] The baseline is lower than the previous charts because there is no ethnicity information for four (4) people.

[53] DES Unit records active to FY 2008/09; Modified ONS mid-2007 estimate.

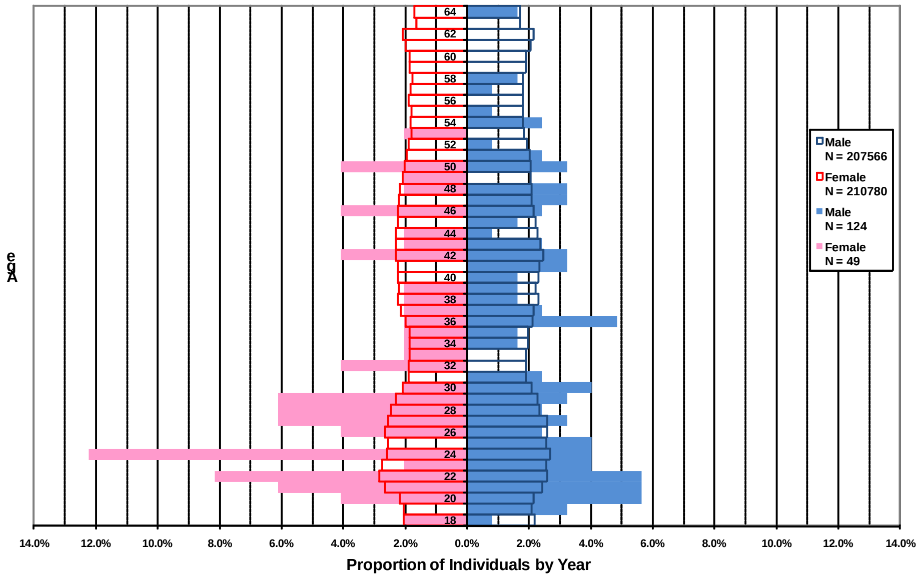

Figure 15 Age pyramid of the people with learning disability accessing DES belonging to the White Ethnic Group at 31/03/2009 compared to general population, aged 18 to 64. Number of DES users: 173. Estimated adult population size: 418,346. DES figures in colour, ONS in outline (Source: DES; Modified ONS mid-2007 estimate)

The corresponding age pyramid for BME people is shown in Figure 0.3. The small group size does not allow for firm conclusions, but also in this case most female service users seem to be of younger age.

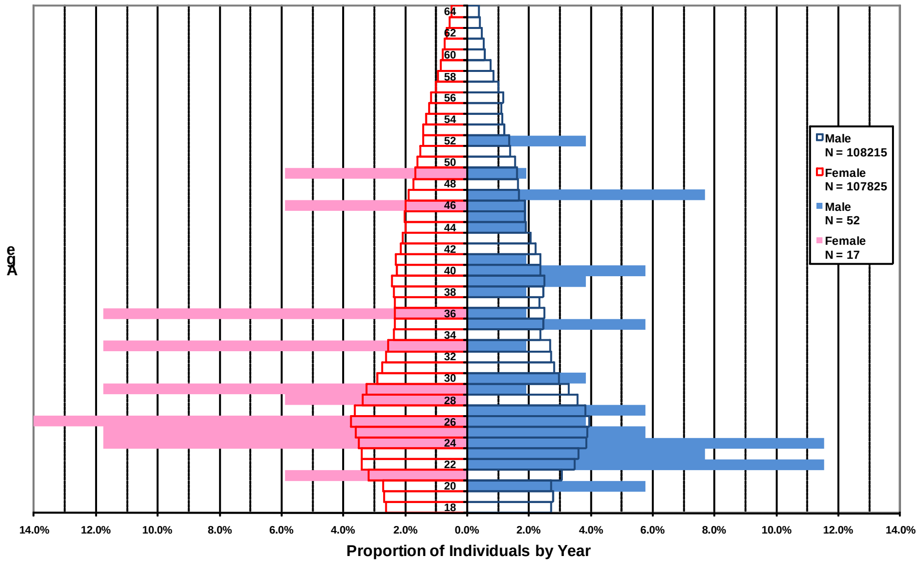

Figure 16 Age pyramid of the people with learning disability accessing DES belonging to the BME Group at 31/03/2009 compared to general population, aged 18 to 64. Number of DES users: 69. Estimated adult population size: 216,040. DES figures in colour, ONS in outline (Source: DES; Modified ONS mid-2007 estimate)

Statement of Educational Needs Records (Birmingham City Council DQU unit): age, gender, ethnicity, and severity

The analysis focuses on the set of 2,377 records of learning-disabled children that have been granted a SEN status in the Birmingham LEA, updated to March 2010. This dataset enables a comparison with older birth cohorts as expressed by the BIU and DES datasets.

Age and gender structure

The age and gender structure of the SEN population is at odds with the general population equivalent. Figure 0.4 shows that children with learning disability have a bulge where the general population shows a bottleneck.

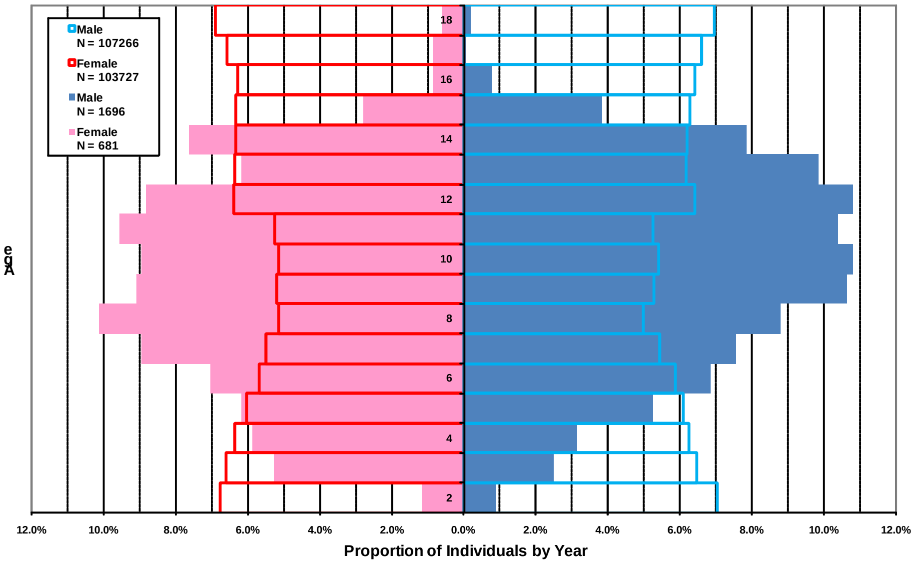

Figure 17 Age pyramid of the children with learning disability with SEN at 31/03/2009 compared to general population, aged 2 to 18. Number of SEN children: 2,377. Estimated population size: 210,993. SEN figures in colour, ONS in outline (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

The discrepancy can be explained by the fact that children are assessed as learning disabled at different ages, rather than anything to do with birth or development of condition patterning.

Therefore there will be a consistent group of children not yet identified as LD either because in pre-school age (most likely) or because the LD condition will become apparent later in life, and also due to the different ability to access SEN process depending on the family background.

Ethnicity

The breakdown by ethnicity illustrated in Figure 0.5 suggests a greater weight of BME children compared to the general population.

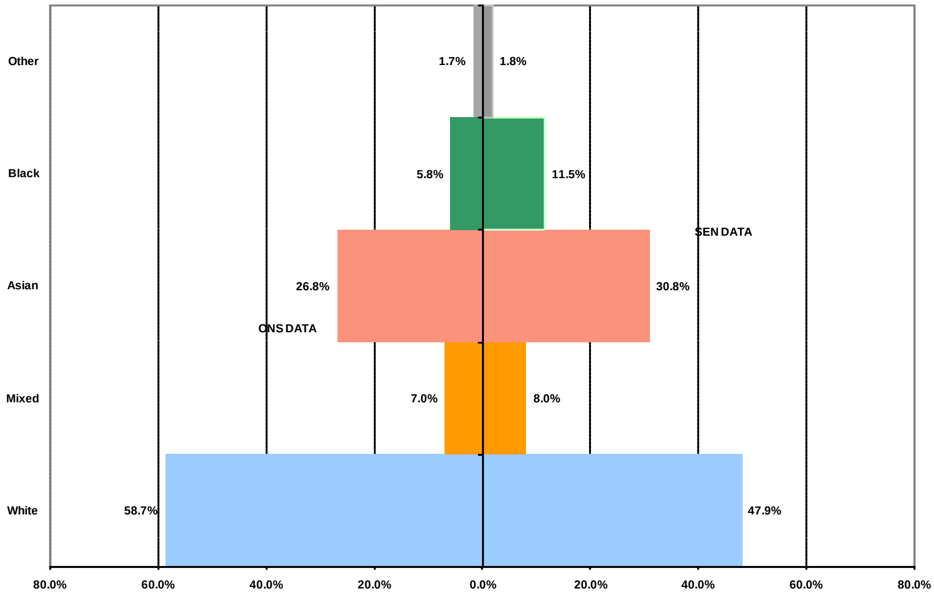

Figure 18 Ethnicity of SEN children with learning disability at 31/03/2009 compared to general population. Number of children with learning disability: 2,354[54] *. Estimated population size: 210,99*[55]*1 (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)*

A simple statistical test[56] does indicate than in effect:

BME children with learning disability are more common in the SEN group compared to the general population

Asian female children are far common in the SEN group compared to the general population

The first finding is consistent with current literature and previous studies on Birmingham's learning disability population[57]. The second finding is of interest because it indicates a future trend that it is quite different from the current ethnic and gender structure of the learning disability population, as shown by the previous section. The following section will explore the data in more detail.

A combined picture of children with learning disability in Birmingham: age, gender, ethnicity

The following charts look at the age distribution of different ethnic groups. For simplicity's sake the charts will refer only to the White, Asian and Black ethnic groups[58].

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[54] The baseline is lower than the previous charts because there is no ethnicity information for 23 children.
[55] The baseline is lower than the previous chart because of rounding of estimates.
[56] GLM Poisson regression of breakdown by source of data, gender and ethnicity.
[57] See section **Error! Reference source not found.** for discussion.
[58] The data has been tested for significant differences between the age distributions of the ethnic groups including other (GLM regression, Poisson distribution saturated model including

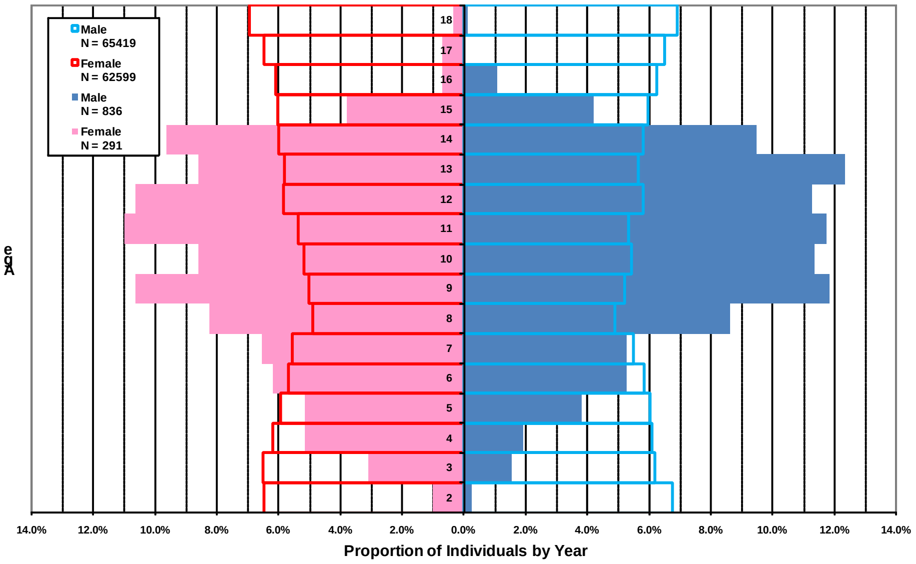

Figure 19 Age pyramid of the White children with learning disability (SEN at 31/03/2009) compared to general population, aged 2 to 18. Number of SEN children: 1,127. Estimated population size: 128,018. SEN figures in colour, ONS in outline (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

Figure 19 shows the age structure for the white community. The discrepancy in structure is compared to the general population noted earlier; is replicated for the white community. It is worth noting that there is an apparent difference between males and females in the sense that females are more evenly spread out than males.

Figure 20 below shows the age profiles for the Asian community. In this case the opposite appears to be true, that is, SEN females are less evenly distributed than their male counterparts. Statistical tests[59] have highlighted that there is an overrepresentation of Asian children in the SEN population. Figure 0.8 on the next page highlights an interesting difference: Asian children seem to have a greater presence at earlier ages compared to White children. This might be due to higher rates of severe forms of learning disability among the Asian community[60], so that children with the condition are detected at an earlier age compared to the White community.

A statistical test confirms that there are significant differences across ethnicity, gender and age groups[61].

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age, sex, ethnicity, source of data (SEN vs ONS records). Asian children have been found to be more present among SEN children than expected. The data has been analysed further by considering only the Asian children in comparison with White children. Pakistani and Bangladeshi children were found to be more prevalent than expected, with a similar – but not significant – result for Indian children)

[59] See note 58.

[60] See Chapter **Error! Reference source not found.** on Health.

[61] GLM regression, Poisson distribution saturated model including age, sex, ethnicity (White vs. Asian).

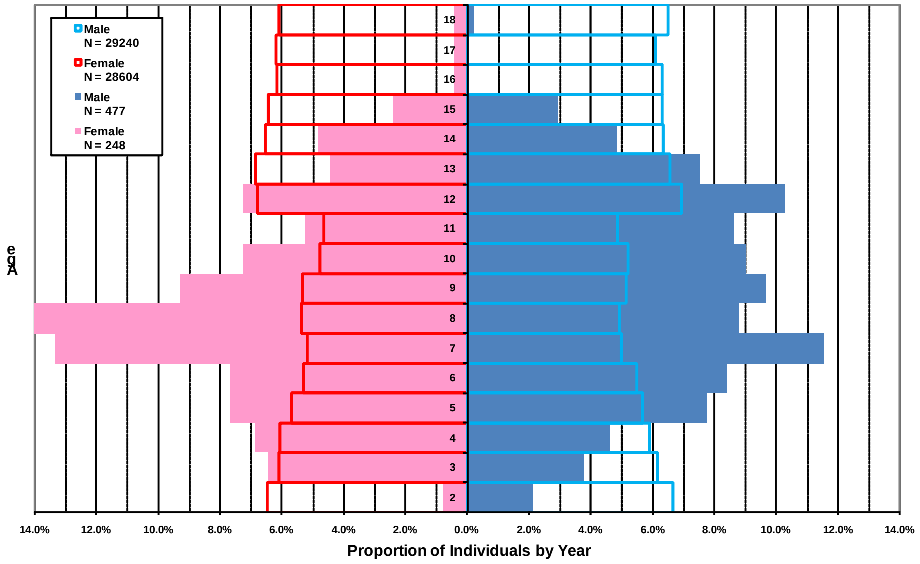

Figure 20 Age pyramid of the Asian children with learning disability (SEN at 31/03/2009) compared to general population, aged 2 to 18. Number of SEN children: 725. Estimated population size: 57,844. SEN figures in colour, ONS in outline (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

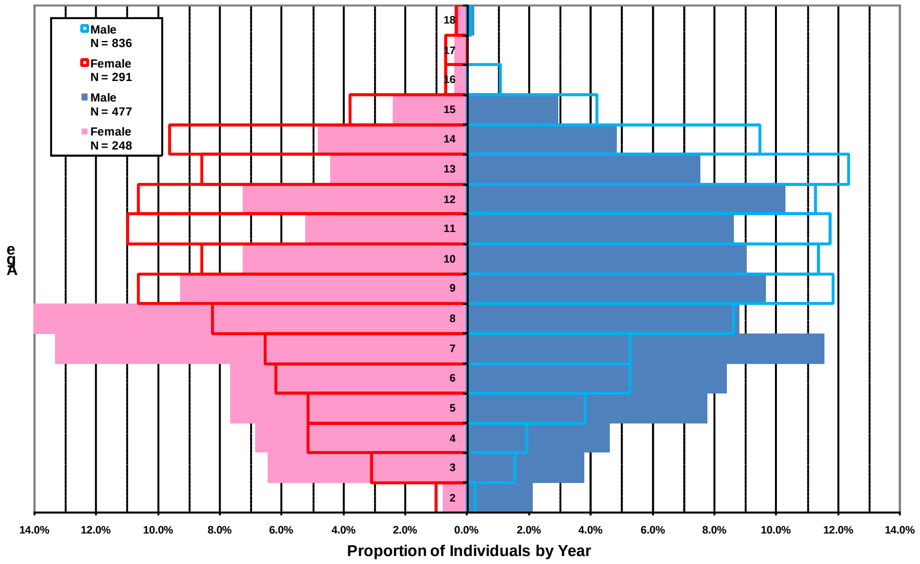

Figure 21 Age pyramid of the Asian vs. White children with learning disability (SEN at 31/03/2009) compared to general population, aged 2 to 18. Number of Indian children: 725. Number of White children: 1,127. Indian figures in colour, White in outline (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

The black community age patterns are shown in Figure 0.9. The pattern of this chart is quite different from the previous ones. Female SEN children are much more evenly distributed over the ages to male ones, and also in comparison to the other charts.

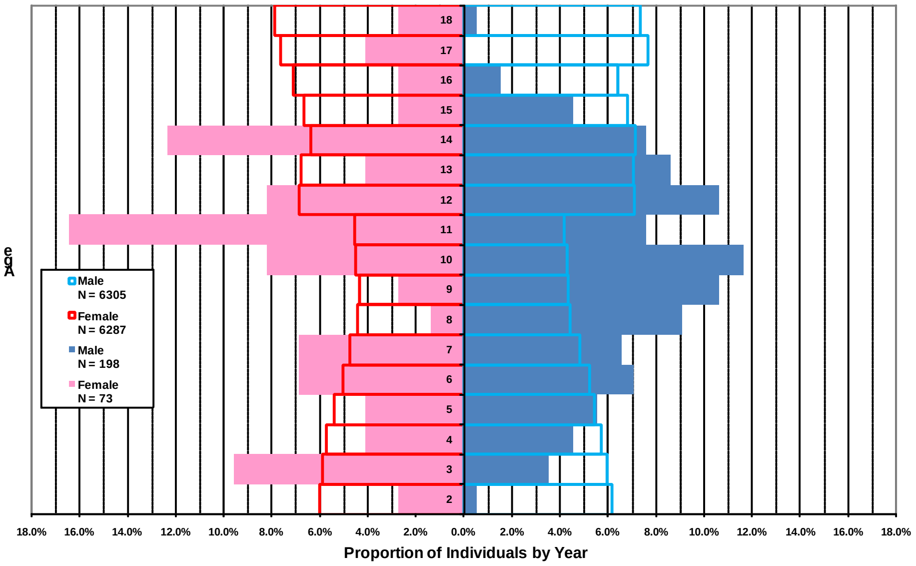

Figure 22 Age pyramid of the Black children with learning disability (SEN at 31/03/2009) compared to general population, aged 2 to 18. Number of SEN children: 271. Estimated population size: 12,592. SEN figures in colour, ONS in outline (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

Life expectancy information from administrative data

SEN data may be considered as a prime candidate for population projections, given its general higher quality and coverage. However an important limitation to this use of the data is the poor information available on life expectancy of people with learning disability.

This point on the general availability of life expectancy information will be discussed later in section 0, but we can note that the information available in BCC administrative data is limited.

An examination of BIU records for Fiscal Year 2005/06 to 2008/09 has yielded 239 records of individuals who died between 2002 and 2010[62]. However the general quality and coverage of this data is poor before Fiscal Year 2006/07. There are also discrepancies with RAP returns count for some years.

Therefore life expectancy estimates based on this data are likely to be biased and show a large margin of uncertainty. To this extent, any planning considering a general learning disability register for Birmingham should include as a key objective the systematic collection of dates of death and relative cause of death.

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[62] The records had been updated to July 2010.

Learning disability population and deprivation in Birmingham

Birmingham is one of the most deprived cities in the country. In 2007, Office of National Statistics published the Index of Multiple Deprivation (IMD) which ranks Birmingham as the 10th most deprived Local Authority in England. More than half of Birmingham population lives in the most deprived quintile (20%) nationally. It is well accepted that deprivation is usually associated with poorer health.

A study of 5.18 million English children of aged 7-15 (Emerson:2009) investigated the relationship between learning disabilities and household deprivation. This study used data from 2008 School Census to identify the number of children with Special Education Needs Statement linked to learning disabilities. Their findings show:

In general terms, the more deprived the area, the greater the identification of moderate and severe learning disability. (i.e. there is a positive (approximately linear) association between the extent of area deprivation and rates of identification of Moderate and Severe learning disability. This association is stronger for Moderate learning disability.)

No conclusion could be derived regarding the association between profound learning disability and Autistic Spectrum Disorder.

Applying these findings to the local context we can assume that the prevalence of mild learning disabilities would be higher in Birmingham than the English average. The main problem is that the administrative data available to Birmingham City Council does not capture the majority of people with learning disability. This is due to the fact that:

Mostly people with complex needs are known to the service which usually have severe learning disabilities, and these are a minority of the entire learning disability population

People in affluent areas might be less likely to acquire services, as they may be cared for by the family and close relatives.

Cultural norms in minority ethnic groups may mitigate against approaching statutory social care agencies for support or the populations may not be able to do so effectively.

Therefore administrative data from the City Council on the number of people known to the services will provide a necessarily skewed picture of the learning disability population and its socio-economic composition.

Estimates for learning disabled population in Birmingham

Current estimates and projections: age, gender, ethnicity, and severity.

A study commissioned by the Department of Health in 2004 (Emerson:2004) to estimate the number of people with learning disability (PWLD) in England shows that 2% of the total population have a learning disability and 90.7% of them are aged 20 or over.

Table 9 summarizes the finding of seven studies in the past 40 years in the UK. While the studies are not directly comparable, they point towards an upward trend in the prevalence of learning disability.

Age	**Salford 1960**	**Wessex 1963**	**NE Scotland 1966**	**N Ireland 1975**	**N Ireland 1986**	**Leicester shire 1991**	**Leicester shire 1995**
20-29	3.45	2.82	3.2	4.90	4.86	4.79	5.02
30-39	3.78	2.13	2.1	4.67	4.72	4.44	4.44
40-49	2.47	1.82	2.0	2.55	3.64	3.39	3.66
50-59	1.71	1.23	1.8	2.08	2.12	2.83	3.17
60+	0.37	0.51	1.3	1.30	1.24	1.22	1.39
Adults	2.25	1.57	2.0	3.04	3.28	3.22	3.44

Table 9 Learning disability prevalence estimates in the UK (1960-1995) (Source: McGrother, Prevalence Disability and Need in Adults with Severe Learning Disability, 2001)

A more recent study showed that the number of PWLD would also increase in the period 2001-2011 (Emerson:2008). The study argued that apart from the changes in the future size and composition of the English population in the next 10 years there are three other factors that are likely to lead to an increase in the age specific prevalence rate:

- Increase in the proportion of younger with learning disability from south Asian communities
- Increase in survival rates of babies, children and adults with severe and complex disabilities
- Reduction in the mortality of older with learning disability.

A Birmingham based study commissioned by the Joint Commissioning Strategy for Services for People with Learning Disabilities estimated for 2006 a learning disability population of 29,135, of whom 4,020 would have severe or profound learning disability and 25,115 would have mild or moderate learning disability[63].

Figure 23 shows a prevalence rate calculated by the Institute for Health Research at Lancaster University in 2004. The data indicates that Birmingham will have a very different trend from the rest of the country.

This difference in behaviour is linked to Birmingham's population characteristics compared to national trends. In England child population is expected to fall up until 2017.

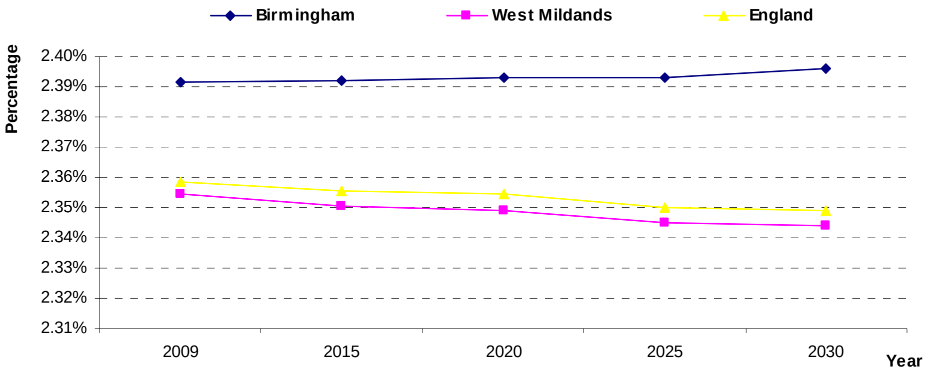

Figure 23 Estimates for prevalence of adults with learning disabilities in Birmingham, West Midlands and England (Source: Projecting Adult Needs and Service Information Systems, (PANSI))

In order to calculate the prevalence rate this study adjusted the prevalence to take into consideration the ethnicity and mortality components of the population. However this rate is calculated by using the adjustments nationally. As Birmingham has a large South Asian community, the overall learning disability prevalence is probably underestimated.

Age trends

Figure 24 illustrates the application of these predictions to the population of Birmingham. There is an estimated increase in the adult with learning disability population from 18,451 (2009) to 20,776 (2030).

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[63] Joint Commissioning Strategy for Services for People with Learning Disabilities, (2006), p. 16.

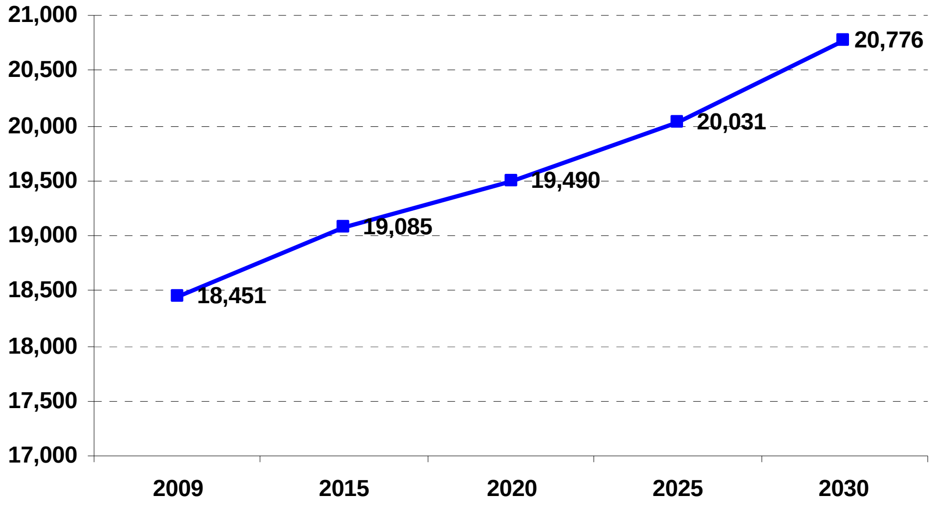

Figure 24 Number of adults with learning disabilities in Birmingham (Source: Projecting Adult Needs and Service Information Systems, (PANSI))

Figure 25 shows that the increase in adults aged 65+ is estimated to rise from 2,817 (15%) in 2009 to 3,525 (17%) in 2030.

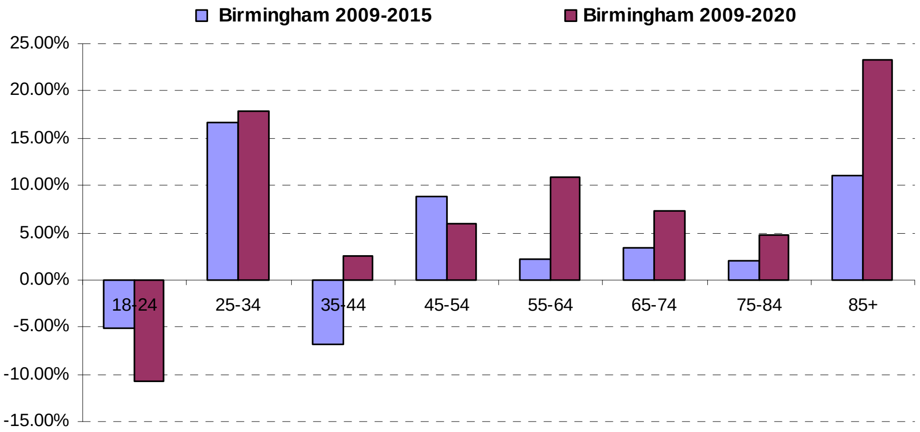

Figure 25 Percentage change in the population with learning disability in Birmingham by age group, 2009-2015 and 2009-2020 (Source: Emerson 2004, Office of National Statistics mid-year population estimates, PHIT)

These predictions also do not take into account Birmingham's ethnicity profile, mortality (i.e. both increased survival rates of young people with severe and complex disabilities) and reduced mortality among older adults.

That said the chart does show a continued growth in the number of Adults with learning disability in the next decade. Approximately 5% increase by 2020 and 12% by 2030. However these overall estimations mask very distinct changes in the age profile of the population. The figure shows the percentage change in the total number of adults by age group.

The 85+ age group will undergo the greater increase in the next 10 years whereas the young adult population will undergo a decrease. This increased demand in the older age group is of particular significance for strategic planning of services because these are more likely to be the most vulnerable people with complex needs and high demand for services.

Gender

Various studies have investigated the relationship between gender and learning disability. Evidence suggests that the prevalence of learning disability is higher in males. This is because some causes of LD are genetically sex-linked and associated with the male gender.

A study by Emerson and Hatton (2008) showed that for moderate and mild LD the ratio of girls to boys was approximately 1:1.8 among children. However, for profound LD this ratio is much smaller which suggests that the relationship between severe LD and gender is less strong than for less severe forms of LD.

In 2011 the projection of people with learning disability suggests that overall 58.2% of people with learning disability aged over 15 in Birmingham are males. However the percentage of males with learning disability varies with age.

In young adults the percentage of males in Birmingham is approximately 60% whereas in the older age group this percentage decreases down to 48% (80+). This decrease is related to the fact that females have a higher life expectancy. This decrease will be less marked in the next decade.

Figure 26 shows the relationship between gender and sex in the population with learning disability in this decade.

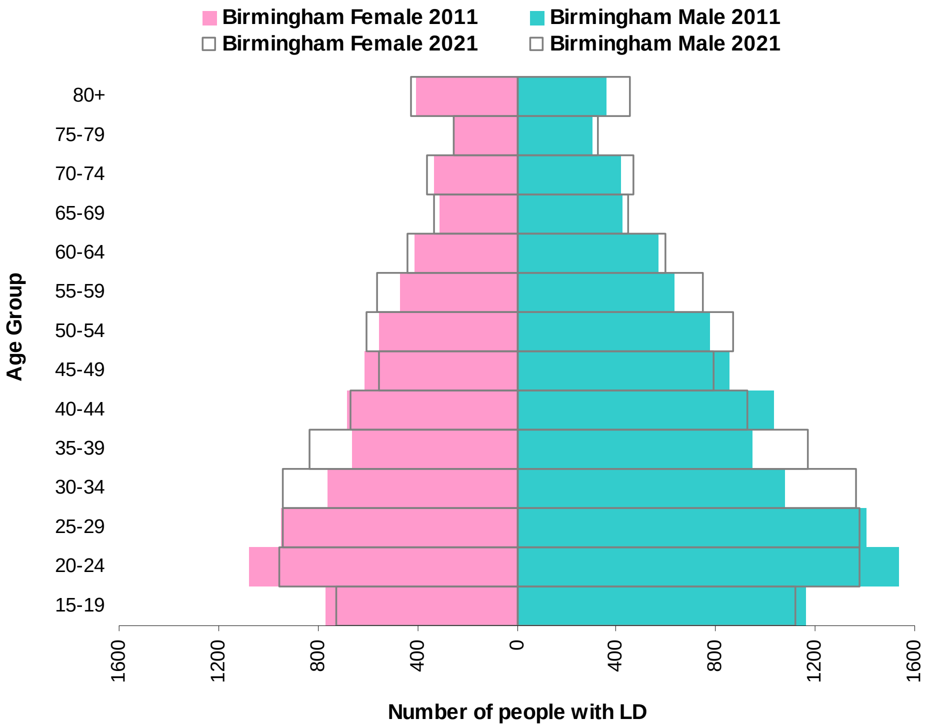

Figure 26 Projections of people with learning disabilities in Birmingham by age group and gender for 2011 and 2021 (Source: Emerson 2004, Office of National Statistics mid-year population estimates, PHIT)

- There is evidence that supports the relationship between the prevalence of learning disability and ethnicity. Previous studies have reported:
- Higher rates of more severe learning disability among South Asian groups in UK (Emerson et al.:1997); (Emerson and Hatton:2004)
- Higher rates of less severe learning disability among African-American US children and indigenous Australians
- Higher rates of pervasive disorders Afro-Caribbean British children.

According to Emerson however, many studies suffer from small sample sizes and the variation may be related to the deprivation of the area or other factors[64]. In the same paper Emerson reported that minority ethnic status was, in general, associated with lower rates of identification of intellectual and developmental disabilities[65].

The exceptions to this general pattern were represented by higher rates of identification of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish Heritage, and higher rates of identification of more severe forms of intellectual disability among children of Pakistani and Bangladeshi heritage.

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[64] Emerson (2009) p. 6.
[65] Emerson (2009) p. 6.

Ethnicity

A first study on minority ethnic groups was commissioned by the City of Birmingham in 1998 (Emerson and Robertson:2001) to provide information on the future needs of adults with learning disability.

This study estimated that by 2011 there will be 504 adults with learning disabilities from minority ethnic groups aged between 20 and 29. Assuming equal mortality, inflow and outflow across minority ethnic groups, 348 of these adults will be South Asian, 101 Black, 40 of mixed parentage and 15 from ‘Other’ ethnic groups.

The study forecasted that 56% of young adults (age 20-39) who have learning disabilities in Birmingham in 2011 will belong to a minority ethnic group.

Table 10 shows the estimated figures for Birmingham in 2011.

Age	Total	White		South Asian		Black		Other	
		N	As %	N	As %	N	As %	N	As %
0-4	154	88	57%	44	28%	11	7%	11	7%
5-9	493	227	46%	189	38%	48	10%	29	6%
10-14	482	201	42%	203	42%	52	11%	26	5%
15-19	566	191	34%	278	49%	71	13%	25	4%
20-24	658	269	41%	280	42%	78	12%	32	5%
25-29	593	215	36%	276	47%	76	13%	26	4%
30-34	494	233	47%	197	40%	51	10%	13	3%
35-39	530	275	52%	194	37%	50	9%	12	2%
40-44	516	342	66%	111	22%	51	10%	12	2%
45-49	482	311	64%	89	18%	73	15%	10	2%
50-54	334	259	78%	43	13%	23	7%	8	2%
55-59	215	201	93%	7	3%	2	1%	5	2%
60-64	192	167	87%	18	9%	5	2%	3	1%
65-69	97	95	99%	0	0%	0	0%	1	1%
70-74	73	68	93%	2	3%	1	2%	1	1%
75-79	43	43	99%	0	0%	0	0%	1	1%
80+	51	50	99%	0	0%	0	0%	0	1%

Total	5,973	3,235		1,931		592		215	

Table 10 Estimates for the population with learning disability in Birmingham in 2011 by age and ethnicity (Source: Emerson and Robertson (2001), p. 223)

Combined view of estimates of current population with learning disability

The analysis of administrative records enables an assessment of the reliability of the estimates discussed in section 0. Prevalence rates in children and numbers of adults with learning disability collated from various sources can put in perspective current estimates and provide basic indications on the possible extent of the demand for services.

However, given the current fragmented state of the datasets available, the lack of access to individual records, and the criteria by which the data is collected in the first place, it is not possible to improve estimates of the current and future population with learning disability in Birmingham.

It is important to recognise the need for a redesign of the collection, maintenance and use of data on people with learning disability to better enable monitoring, commissioning and future planning.

Using FACS criteria alone for establishing a register would impose a relatively high threshold for admission to the registers. This raises the difficult issue that if registration is linked to the provision of services (either social or health care) and welfare payments, those with low level need or those not accessing services will be excluded from registration. It is accepted that the differences between registration and service eligibility would need detailed consideration.

That said, the direct consequence of the present framework is that the majority of People with learning disability (i.e. those at the mild end of the severity spectrum) may not be identified, offered appropriate low level or higher level services or followed up once they reach adulthood[66] – with the partial exception of Disability Employment Service unit, although they also cover only those people with learning disability who have other disabilities besides learning disability.

The following sections will show that at present most adults with learning disability are not known to health and social care registers, therefore making monitoring activity and low level support programmes impossible.

Prevalence rates according to SEN records

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[66] In effect the records of potential people with learning disability who approach the Adult and Communities Directorate but who do not receive services following FACS assessment are also kept. However, they are a relatively small number compared to those receiving services. In 2008/9 the known Adults with learning disability were 3,219, against 3,044 adults in RAP records and 3,115 adults with service records in the same period. (Communication from Business Information Unit, 13/10/2010).

The SEN records of children offer a reliable estimation of the true prevalence rate of LD in the population because:
Birmingham City Council is one of the most efficient LAs in the processing of SEN requests and achieves near total coverage of the school population[67].

The SEN process relies on medical diagnosis and therefore it has a low threshold for admission to the register. It follows that the entire range of severity on the learning disability condition is covered, unlike the administrative social care, health care, and welfare support records.

Figure 0.5 is based on SEN records of children in Birmingham. The records are not in the definitive version used for the school census, but they are reliable enough to provide a basic estimate of prevalence of learning disability rates in the children population of Birmingham.
The prevalence rate is calculated comparing birth cohorts of SEN children with the estimates for the general population. The tailing off may be due to:

- Children being identified as learning disable at later age with “milder” learning disability[68].
- Children directly going to special schools at young age.
- Children exiting the school system earlier than 16 because of health issues.

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[67] See **Error! Reference source not found.**, section **Error! Reference source not found.** showing the NI 103 statistic for Birmingham**.**

[68] Although it is possible to conclusively diagnose learning disability by the age of 5, analysis (Kruskal-Wallis test) of the SEN records used in this report has shown that milder forms of LD are acknowledged later than more severe forms. The median age for SEN registration for mild and specific LD children was 8.9 years; for moderate learning disability, 8.2 years; for severe learning disability 4.5 years; for profound and multiple learning disability 3.3 years. Furthermore the range of registration ages for each severity status was relatively wide, except for profound and multiple learning disability.

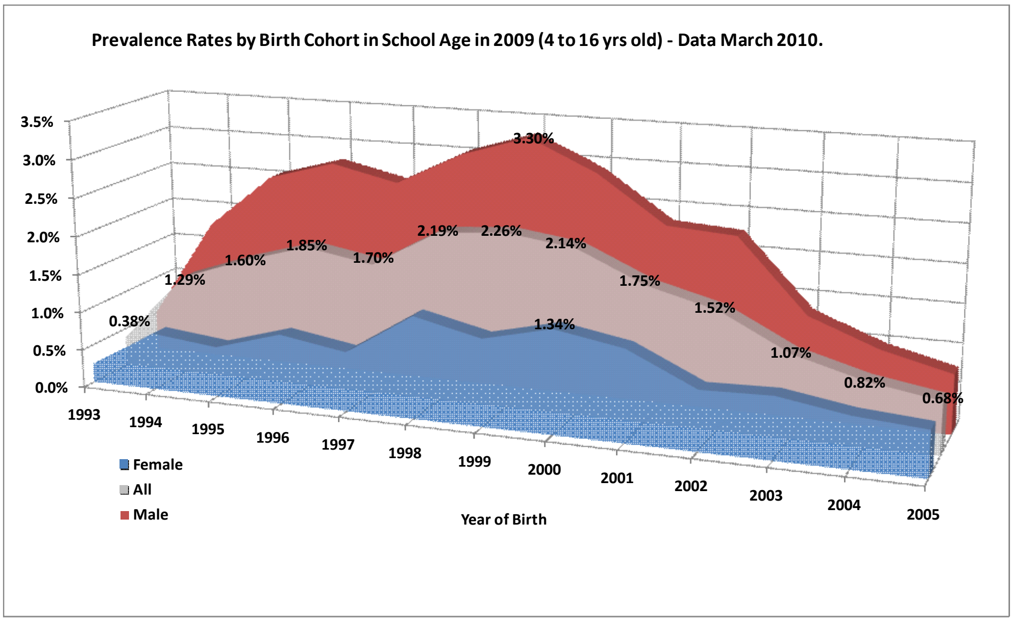

Figure 27 Prevalence rates in the 4 – 16 age range in Birmingham. SEN records updated to March 2010. Number of children with learning disability: 2,322. Estimated general population size: 160,214 (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

The prevalence rate is in the 0.7% to 2.3% range, with prevalence amongst males peaking at around 3.3%, and in females at 1.3% and most birth cohorts have a prevalence rate above 1.0%.

In aggregate the prevalence rate is 1.5%. However, given the typical ages at which registration takes place for children with learning disability[69], the most representative rates are probably those of the birth cohorts after 2001 (i.e. 1.6% and upwards).

These figures are in good agreement with the projections for adult LD prevalence rates reported in Figure 22. The projections indicated that the rates would increase from 2.3% to 2.4% between 2009 and 2030. The figure is also in agreement with basic prevalence rate estimates (2.28%) linked to the medical definition of learning disability[70] and past literature on the subject (3.0%)[71].

The following Figure 0.6 shows the prevalence rate for children in the severe and profound and multiple learning disabilities. We assume this group to be roughly representative of the condition of typical FACS assessed adults.

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[69] See note 68.

[70] See note 23

[71] See Roeleveldt et Al (1997) p. 129.

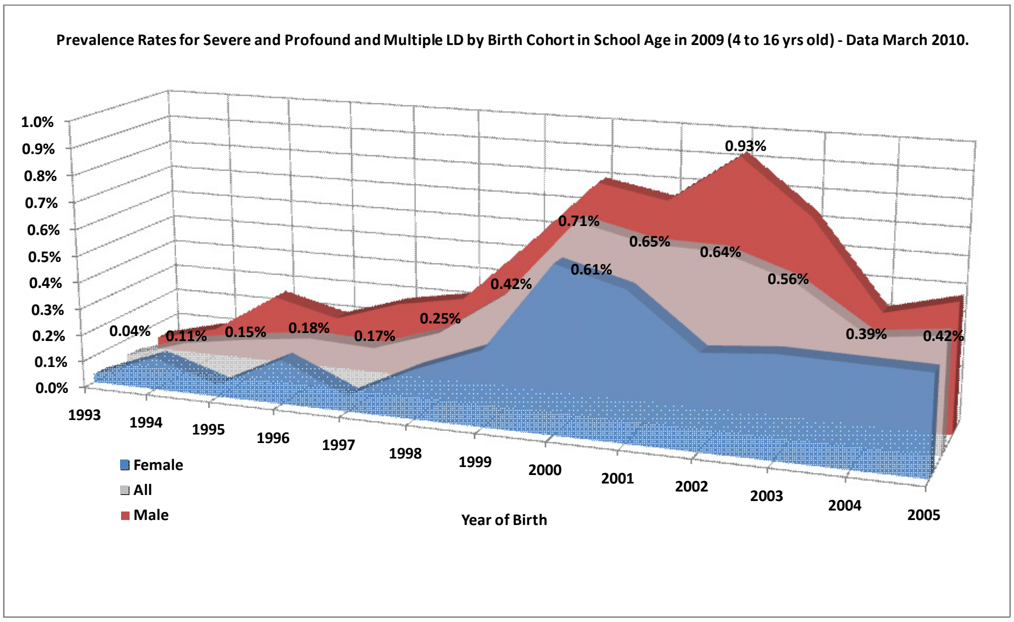

Figure 28 Prevalence rates in the 4 – 16 age range in Birmingham for severe and profound and multiple categories. SEN records updated to March 2010. Number of children with learning disability: 557. Estimated general population size: 160,214 (Source: DQU Birmingham City Council; Modified ONS mid-2007 estimate)

As noted before, children at the most severe end of the learning disability spectrum may be exiting the school system at an earlier stage, presumably for health reasons. However, most children (84.3%, 470 out 557) were born after 1997.

In this group the prevalence rate ranges between 0.39% and 0.71%, peaking at 0.93% for males and 0.61% for females. In aggregate the prevalence rates are 0.50% (0.38% for females and 0.62% for males)[72]. Table 11 below compares this result with approximate prevalence rates for adults derived from other sources.

Source	Estimate	Numerator	Baseline	Year
BIU All known[73]	0.42%	3,312	782,011	2009-2010
BIU	0.40%	3,115	782,011	2009
BIU RAP records	0.39%	3,044	782,011	2009
BIU & DES[74] records	0.50%	3,884	782,011	2009-2010

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[72] Accordingly the general population baseline is 93,644 in total.

[73] Includes any certified adults with learning disability who has approached Adult and Communities directorate but that has not been included in service databases. We do not consider the sum of this individual with DES people as done below as we have no information to decide upon overlaps between these and DES numbers.

[74] 867 People have been identified in the DES service records. A match with BIU records based on DOB, gender, ethnicity, ward of residence has identified a possible overlap of 98 people.

Source	Estimate	Numerator	Baseline	Year
GP LD QOF Register	0.47%	3,643[75]	782,011	2009
DWP	0.45%	3,500	782,011	2009
JCBLD	0.53%	4,020[76]	759,029[77]	2006-2007
SEN records (Children)	0.50%	470	93,644	2010
Literature review	0.38%	2,972[78]	782,011	2009

Table 11 Prevalence estimates for severe forms of learning disability in Birmingham (Source: Various)

Given the lack of benchmarks to compare the different criteria of severity classification, and the lack of access to individual records, it is not possible to conduct rigorous tests on the equivalence of these estimates.
However, the estimates are in close agreement with each other. It is reasonable to assume that current admission criteria for adults with learning disability registers are de facto not incorporating the vast majority of people with learning disability in Birmingham. As such, they provide a basis for service planning only to a limited extent and only for the people with most severe forms of learning disability.

While the discrepancy with regards social care and welfare agencies is consistent with the assessment criteria used[79], it is unclear why QOF registers (which refers to any adult with learning disability) should be severely underestimating the LD adult population. The coincidence with the child rates referring to severe and profound multiple learning disability condition may imply that GP registers de facto identify only this class of patients with learning disability, whereas milder learning disability conditions are overlooked or not explicitly reported to health care workers.

Implications for learning disability registration procedures in Birmingham

The discrepancy between adults with learning disability registration figures and LD children's' registration figures has been highlighted in the literature[80] on national LD prevalence rates. The data reported above is a confirmation of

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Hence we have 3,115 plus 769 individuals, for a possible total 3,844 LD People. This is a rough estimate as no up to date information was available for more than half of the people (i.e. still being served by DES) at August 2010.

[75] Adjusted figures reflecting current administrative boundaries in Birmingham.

[76] 2006 estimate.

[77] ONS Mid-Year estimates 2007.

[78] See Roeleveld et Al (1997) p. 130 for general Severe and Multiple Retardation (SMR) estimate.

[79] Respectively: FACS, which is based to potential and actual risk to harm and independence, and Disability Living Allowance benefits.

[80] See for example Emerson E and Hatton C (2008), p. i and the interview with the author (PHIT:2010c).

a generalised situation due to the use of social care criteria in the registration of people with learning disability.

The key issue is that registration at present is geared up to the provision of complex sets of services, which may be HAP (Health Action Plans) or personalised care packages (Adult and Community Care LA departments), or DLA benefits.

Given the figures in Table 11, it may be that the current procedures identify the majority of people with learning disability with more complex needs. However there is currently no possibility of identifying overlaps and completely missed people with learning disability[81]. It is also not possible to identify people appearing on one register but not in others, so that an unknown number of eligible people with learning disability may at present not be fully assisted by one or more agencies. Pathways for service users as well as a common register would go some way towards solving this challenge.

People with learning disability with milder conditions may not be eligible for services with Adult Community and Care agencies, because eligibility would imply at least a potential risk of harm and loss of dependency, which is probably not the case for most people with learning disability settled in the community with the support of family and friends.

The same people would not be considered eligible for DLA benefits and evidence from carer consultation is that some do not know their entitlement or how to apply for it. It is also apparently undetected by GP QOF registers.

This administrative framework leads to a situation whereby an unknown proportion of the learning disable population cannot be helped to preserve health and independency following predictable traumatic events such as:

- Family carers passing away or becoming frail
- Onset of physical or mental illnesses following accidents, unhealthy lifestyle and typical co-morbidities
- Becoming involved in the criminal justice system
- Ageing

In fact, being unknown, preventive measures cannot be systematically put in place[82] for people with learning disabilities. As a key objective of current policies on disability is the fostering and preservation of independence and

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[81] Unless access to individual records is granted for analysis. Current statistical techniques can determine the component of people being missed by all registers and provide a good estimate of the "true" population of people with complex needs. A more detailed of these issues is discussed later in Chapter 6. It would not, however, help to identify people with "Mild" learning disability because these individual do not typically appear in the first place in the registers.

[82] Except as a consequence of safeguarding referrals. But that would imply that a situation of crisis has already developed with potentially serious consequences.

health, this is not possible under the current registration regime[83]. Current practice means that the need for support for the majority of people with learning disabilities and their carers cannot be planned and delivered effectively across all domains of care and support.

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[83] It is worth noting in this context that in Birmingham that the DES unit provides essential support to young people with learning disability to get them in employment: still, their remit is restricted only to people with learning disability who have another form of disability besides learning disability, typically represented by some form of impairment in sight, hearing, or mobility.

Health

Reported health disparities in people with learning disabilities include increased mortality, increased morbidity, increase in negative determinants of health e.g. higher levels of obesity, access to services and quality of services accessed.

In September 2006, the Disability Rights Commission published its report ‘Closing the Gap’ (DRC:2006) on the health inequalities experienced by people with learning disabilities. The report cited a greater incidence of cancer, coronary heart disease, respiratory disease and mental health problems.

In Birmingham there are over 2000 Health Action Plans (HAP) for young people age 18 – 25 recorded within the GP Disability Database. It has been acknowledged that processes need to be implemented to join up various data systems to enable HAP information to be broken down into different categories. Colleges have also requested that all young people with disabilities who are beginning studies with them receive a HAP.

The Clinical Nurse Lead for Health Facilitation in the South Birmingham Primary Care Trust Specialist Learning Disability Service has identified 3,750 adults with learning disabilities in Birmingham who are considered to have significant health risks and would be appropriate to be registered with primary care services for a yearly health check. This is based on the outcome of an initial research pilot conducted in Birmingham (Brady:2004).

Co-morbidities (Long Term Conditions, Autism and Mental Health)

Some health conditions are more associated with having a learning disability. Everyone with Down syndrome, for example, has some kind of learning disability, and so do most people with cerebral palsy. People with autism may also have learning disabilities, and around 30% of people with epilepsy have a learning disability. The Disability Rights Commission report ‘Closing the Gap’ (DRC:2006) highlighted that adult with learning disability are much more likely than other people to have significant health risks and problems. Health screening shows high levels of unmet physical, sensory and mental health needs (Barr et al.:1999, Howells:1986).

People with learning disabilities are also at increased risk of many other physical or neurological conditions. These include:

- Epilepsy
- Physical disabilities
- Congenital heart problems

- Incontinence
- Hearing impairments
- Visual Impairments
- Dementia

Furthermore, as life expectancy increases for people with learning disability they become increasingly susceptible to developing Dementia. In Birmingham a specific support group (GOLDD) has been set up to help people with learning disability and Dementia. As part of the activities of this group it has also been reported the occurrence of one case of Early Onset Dementia (in the mid-twenties) in a client with Down Syndrome, whose carers reported particular problem in finding adequate support for the dementia condition, as services are normally geared up for much older people[84].

In general therefore, dementia is an emerging co-morbidity for Patients with learning disability which presents challenges of their own.

GPs hold information on the number of patients their patients with learning disabilities which may be recorded under a number of different codes. The Quality and Outcome Framework (QOF) requires practices to produce a register of patients aged over 18 years that has gone some way to improving this coding.

A number of practices within HoB tPCT have signed up to a system (MSD Informatics) that collates the data entered onto GP databases to enable searches for particular conditions to be performed. However, such searches are only as reliable as the accuracy and completeness of the coding within each practice. Currently this system covers just over 90% of the PCT practice population.

Table 12 provides the gender and the breakdown of the registered population in the PCT area.

	Number of people on GP Register			**Number recorded with LD[85]**			**Percentage with LD**		
Age	**Male**	**Female**	**All**	**Male**	**Female**	**All**	**Male**	**Female**	**All**
<5	17,399	11,249	28,648	7	6	13	0.0%	0.1%	0.0%
5-14	20,954	19,788	40,742	125	44	169	0.6%	0.2%	0.4%
15-24	24,757	25,175	49,932	163	96	259	0.7%	0.4%	0.5%
25-34	29,722	24,943	54,665	134	78	212	0.5%	0.3%	0.4%

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[84] Communication from Ms Linda Jackson, Joint Commissioning Team for Learning Disabilities, 21/10/2010.

[85] Search based on patients with a READ code of E3...%Mental retardation, Eu7..% [X] Mental retardation, Eu81z "[X] Developmental disorder of sc or 918e on the LD register.

	Number of people on GP Register			Number recorded with LD[85]			Percentage with LD		
Age	**Male**	**Female**	**All**	**Male**	**Female**	**All**	**Male**	**Female**	**All**
35-44	23,719	17,110	40,829	110	96	206	0.5%	0.6%	0.5%
45-54	16,005	13,456	29,461	102	72	174	0.6%	0.5%	0.6%
55-64	9,753	8,576	18,329	42	32	74	0.4%	0.4%	0.4%
65-74	6440	6,678	13,118	18	20	38	0.3%	0.3%	0.3%
75-84	3971	4,349	8,320	5	8	13	0.1%	0.2%	0.2%
85+	937	1,463	2,400	0	1	1	0.0%	0.1%	0.0%
Totals	153,657	132,787	286,444	706	453	1159	0.5%	0.3%	0.4%

Table 12 Number and proportion of people recorded with learning disability in HoB tPCT (Source: HoB tPCT, February 2010)

The MSD system also enables the recording of co-morbidities, such as epilepsy or a mental health condition to be reported. Table 13 and Table 14 give the respective age and gender breakdowns.

	Number recorded with learning disability			Number on Epilepsy register			Percentage of Patients with learning disability on Epilepsy register		
Age	**Male**	**Female**	**Total**	**Age**	**Male**	**Female**	**Total**	**Age**	**Male**
<5	7	6	13	0	0	0	0.0%	0.0%	0.0%
5-14	125	44	169	10	9	19	8.0%	20.5%	11.2%
15-24	163	96	259	15	18	33	9.2%	18.8%	12.7%
25-34	134	78	212	20	13	33	14.9%	16.7%	15.6%
35-44	110	96	206	17	20	37	15.5%	20.8%	18.0%
45-54	102	72	174	20	12	32	19.6%	16.7%	18.4%
55-64	42	32	74	6	5	11	14.3%	15.6%	14.9%
65-74	18	20	38	5	1	6	27.8%	5.0%	15.8%
75-84	5	8	13	0	1	1	0.0%	12.5%	7.7%
85+	0	1	1	0	0	0	0.0%	0.0%	0.0%
Totals	706	453	1,159	93	79	172	13.2%	17.4%	14.8%

Table 13 Number of patients recorded with learning disability on the GPs Epilepsy register (Source: HoB tPCT, February 2010)

	Number recorded with LD			Number on MH register			Percentage of Patients with learning disability on MH register		
Age	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**
<5	7	6	13	0	0	0	0.0%	0.0%	0.0%
5-14	125	44	169	0	0	0	0.0%	0.0%	0.0%
15-24	163	96	259	6	4	10	3.7%	4.2%	3.9%
25-34	134	78	212	16	9	25	11.9%	11.5%	11.8%
35-44	110	96	206	19	10	29	17.3%	10.4%	14.1%
45-54	102	72	174	20	11	31	19.6%	15.3%	17.8%
55-64	42	32	74	12	10	22	28.6%	31.3%	29.7%
65-74	18	20	38	2	4	6	11.1%	20.0%	15.8%
75-84	5	8	13	1	3	4	20.0%	37.5%	30.8%
85+	0	1	1	0	0	0	0.0%	0.0%	0.0%
Totals	706	453	1,159	76	51	127	10.8%	11.3%	11.0%

Table 14 Number of patients recorded with learning disability on the GPs Mental Health register (Source: HoB tPCT, February 2010)

Table 15 shows that of the recorded 1,159 Patients with learning disability, 172 (14.8%) have epilepsy, and 127 (10.6%) have a mental health condition.

Condition	N	%
Epilepsy	172	14.8%

Table 15 Co-morbidities of people with learning disability in HOBt PCT[86] (Source: HoB tPCT, February 2010)

About a third of people with a severe or profound learning disability currently using services have an autistic spectrum disorder (Harker and King: 2004). Epilepsy is relatively common in people with Autistic Spectrum Disorders and Asperger's syndrome with 20-30 % of people going on to develop epilepsy usually in their early teenage years. Morgan (Morgan et al.:2003) estimated the community prevalence of epilepsy in PWLD to be 16.1 % compared with 0.4-1% in the general population (Chadwick:1994).

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[86] The numbers may overlap due to people with multiple conditions. Also the figures are different between table 14 and 15 as table 14 includes young people and children, whereas table 15 counts only adults.

Table 16 forecasts adults with Autistic Spectrum Disorder in Birmingham. A separate report on autism and autism spectrum disorder is in development.

Age	2009	2015	2020	2025	2030
18-24	1,294	1,230	1,159	1,201	1,337
25-34	1,583	1,846	1,867	1,792	1,740
35-44	1,395	1,295	1,421	1,594	1,619
45-54	1,165	1,259	1,217	1,144	1,244
55-64	913	931	1,009	1,076	1,040
Total	6,350	6,561	6,673	6,807	6,980

Table 16 Predictions for adults with Autistic Spectrum Disorder in Birmingham (Source: Projecting Adult Needs and Service Information Systems, (PANSI))

People with Down syndrome are more likely than the general population to develop hypothyroidism with the incidence increasing with age particularly over the age of 40 (Rooney and Walsh:1997).

Table 17 gives projections for adults with Down syndrome in Birmingham.

Age	2009	2015	2020	2025	2030
18-24	81	77	72	75	84
25-34	99	115	117	112	109
35-44	87	81	89	100	101
45-54	73	79	76	72	78
55-64	57	58	63	67	65
65+	5	5	5	6	6
Total	402	415	422	432	443

Table 17 Predictions for Adults with Down Syndrome in Birmingham (Source: Projecting Adult Needs and Service Information Systems, (PANSI, POPPI))

People with learning disability have been reported to have substantially lower bone density than the general population (Aspray et al.:1998) and it has been reported that this group of people are more at risk of bone fractures.

Another study (Jancar and Jancar: 1998) found that bone fractures were found to occur more frequently between the ages of 40 and 49. PWLD are often prescribed large number of medications and it is recommended that these medications are reviewed regularly. There is evidence that some of these drugs being taken may be ineffective, result in severe side effects or lead to an increased chance of falling or slipping.

In a study of institutionalised PWLD gastro-oesophageal reflux disease was diagnosed in 50% of the residents with an IQ of less than 50. Early detection and treatment is needed to allow treatment with medication and reduce need for surgery (Bohmer et al.:2000).

The identification and diagnosis of mental health problems in people with learning disability is very difficult. A range of screening tools have been used for assessment of mental health but these show a wide variation in results. It is thought that these mental health problems are related to a number of factors including exposure to negative social conditions, social exclusion and brain trauma. Episodes of mental illness are experienced by a quarter of the general population at some point in their lives.

However, it has been estimated (Smiley:2005) that the point of prevalence of mental health problems lie between 30 and 50 % of the PWLD. Estimated rates of specific mental ill health from population based studies range from 1.5% of the population for bipolar affective disorder and agoraphobia to 20% of the population for dementia in people aged 65 and over. Schizophrenia was assessed to be present in 3% of this population (Smiley:2005).

Mortality and life expectancy

A significant change in the learning disability population is the rising numbers of people aged 60 or over who are likely to require services. As health care and standards of living improve, the life expectancy of the population with learning disabilities is moving towards that of the general population although many will experience the problems of ageing earlier than their counterparts in the general population and there is still an increased risk of early death. (Hollins et al.:1998; Carter and Jancar:1983).

The risk of dying under the age of 50 for PWLD is 58 times greater that of the general population, however if people survive beyond 50 years of age then the age of death approaches the median for the rest of the population (Hollins et al.:1998). The main cause of death for PWLD people is respiratory disease with other causes including cardiovascular disease related to congenital heart disease, and cancer. The most common cancers diagnosed in PWLD are cancer of the oesophagus, stomach, gall bladder and leukaemia.

The most frequent cause of death is respiratory disease. Cooke (Cooke:1997) reported the mean life expectancy of male with learning disability of 67.2 years and female 69.2 years; Carr (Carr:1994) noted a systematic increase in the life expectancy in the last decades.

Predictors of early mortality in PWLD include severity of the learning disability, level of mobility, ability to feed oneself and Down syndrome (Strauss et al.:1998; Van Allen et al.:1999). People with a diagnosis of epilepsy are also likely to have a shorter life expectancy (Leestma et al.:1989).

Dental health

Local data on dental health of people with learning disability is not available at present. UK data shows that dental ill health is more common in PWLD. A sample of people on the Sheffield adult learning disabilities register (mean age 36) were found to have on average, 7.5 missing teeth (Tiller et al.:2001). Many of the dental health problems are related to issues around difficulty in cleaning teeth and gums both due to malocclusion and refusal to clean teeth.

Dental problems include periodontal disease, problems with oral mucosa and dental caries. Good oral health contributes to the overall quality of life of the individual including the ability to eat and drink. Poor oral health has been reported to be related to respiratory disease in older people (Terpenning:2005).

Hearing and sight problems

There is no information on the local population concerning hearing and sight problems. Current literature reports a greater frequency of hearing and sight problems in individuals with learning disability compared to the general population. Non-correctable visual impairment has been reported in 10% of adults with 7-fold more people with learning disability in need of sight correction than general population (Warburg:1994). People with Down syndrome are more likely to experience age-related cataract problems after the age of 30.

Hearing problems are often experienced due to impacted ear-wax (Crandell and Roeser:1993). Early onset age-related hearing loss in a community sample of PWLD was estimated to be between 25-42% (Evenhuis et al.:1992).

Lifestyle: smoking, physical activity and obesity

The Health Survey for England (HSE) for 2006 reported that 22% of the general population were smokers[87]. The National Survey of People with Learning Disabilities (NSPLD) (Emerson et al.:2005) found just under one in five (19%) People with learning disability smoked cigarettes.

The NSPLD (Emerson et al.:2005) indicates that one in seven (15%) people with LD reported having physical exercise three or more times a week. One in two (46%) did have some exercise which made them sweat[88].

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[87] Derived from HSE 2006 Report, Vol 1, Tab 8.1.

[88] The HSE 2006 Report does not offer directly comparable figures. However the report indicates that 34% of people aged 16 and over report moderate or vigorous activity of at least 30 minutes' duration in the four weeks prior to the interview (one to five days a week).

Of the 1,159[89] Patients with learning disability recorded in the MSDI dataset by HOBt PCT, 837 (72.2%) were obese.

Table 18 provides a breakdown by age and gender.

Gender	<5	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	0	53	107	111	93	86	39	13	4	0	506
Female	1	17	63	60	79	57	26	19	8	1	331
Total	1	70	170	171	172	143	65	32	12	1	837

Table 18 Number of people with learning disability in HOBt PCT that also are in the GPs Obesity register (Source: Source: HoB tPCT, February 2010)

Obesity is common in PWLD and is related both to specific learning disability conditions e.g. Down’s syndrome and Prada-Willi disease and due to poor nutrition and eating habits. Chronic constipation is common in this group of patients due to the drug schedules and lack of mobility (Stewart et al.:1994). Less than 10% of adults with LD have a balanced diet containing fruit and vegetables (Robertson et al.:2000).

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[89] Inclusive of children and young people.

Services and care pathway

The Birmingham Learning Disabilities Joint Commissioning Board identified in its 2006 report three levels of services that are needed for learning disability people[90]:

Universal services: They are community based and open to the general population e.g. leisure, work, primary and other health care, health promotion; self-care in health, transport and lifelong learning opportunities. There will be a need to address barriers facing people with learning disabilities such as making information easier to understand and accessibility.

Targeted services: They are aimed at specific vulnerable groups including people with learning disabilities such as housing finder services, preparation for work and advocacy. These are often provided by the third sector usually with funding from the public sector. Disability Employment Services is specifically tasked with supporting people with learning disability (together with people with other disabilities) through training, job search and employment services.

Services based on assessments of need for named individuals with more complex needs: Currently these are largely assessed and care managed by the Children, Young People and Families Directorate, Adults and Communities Directorate and the Specialised NHS Learning Disability Services.

Individual people with learning disabilities require differing combinations of the three levels of service at different times in their lives. The care pathway for people with learning disability can be divided into a number of areas:

- NHS services
- Social Care
- Support for Carers
- Transition
- Safeguarding

NHS services

Patients with learning disability in GP Surgeries

There are 3,643 people with LD 18+ in 2008/9 as recorded on the GP registers in Birmingham[91]. The overall population registered with GPs in Birmingham for 2008/2009 is 1,086,874, but this includes also those aged less

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[90] Birmingham Learning Disabilities Joint Commissioning Board: “Joint Commissioning Strategy for Services for People with Learning Disabilities”, 2006, p. 14.

[91] The actual figure is 3,808 but it has been adjusted to reflect administrative boundaries.

than 18. Using ONS adult population estimates for 2009 the prevalence rate is 0.47%[92].

The number of people registered with GPs is an over-estimate as it is not routinely and accurately updated for duplicates or deaths. Taking into account the figures discussed in section 2.4.2, it is unlikely that the QOF register is comprehensive.

Figure 29, showing the prevalence of LD by ward[93], comes therefore with a caveat.

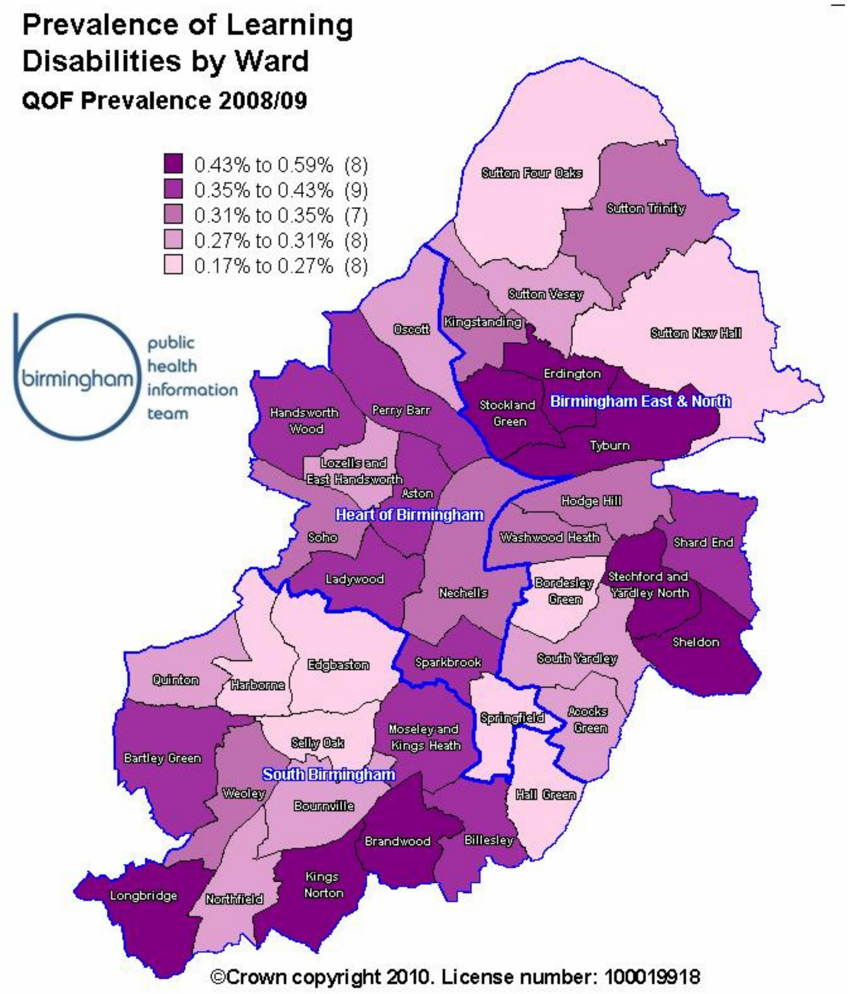

Figure 29 Learning disability prevalence by ward Source: QOF 2008/8009, PHIT.

The health elements of individual continuing care packages for the three Birmingham PCTs are commissioned from a range of providers.

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[92] The estimate is 782,011, and it is an adjusted (with mortality rates) figure based on the Mid-2007 estimates.

[93] The figures are adjusted to reflect the general population distribution by ward.

Table 19 gives the numbers of people who received assistance in 2005/6. People may have received more than one service in the year.

Type of service and provider	Under 18's	18- 64	65+	Total
South Birmingham PCT				
Active complex cases using LD community nursing services.	170	567	26	763
Specialist LD hospital assessment and treatment places	/	14	/	14
Psychiatry	350	1,300	/	1650
Clinical Psychology	1,300	9,800	1,200	12,300
Physiotherapy	52	199	38	289
Occupational Therapy	1	140	9	150
Dietetics	1	446	34	481
SLOT supported living packages	/	16	/	16
Forensic services	/	69	/	69
Adult day centres	/	28	/	28
Adult respite care	/	186	/	186
People in care homes and care homes with nursing funded by the NHS using care services provided by South Birmingham PCT	/	60	24	104
Other providers:				
Specialist LD hospital assessment and treatment places	3	28	/	31
People in care homes / care homes with nursing funded by the NHS with care provided by independent providers	/	196	51	247
Adult day services	/	6	/	6

Table 19 People in Birmingham who received a learning disability specialist health service in 2005/6 (Source: Birmingham Learning Disabilities Joint Commissioning Strategy report, 2006)

Hospital admissions of patients with learning disability

Hospital admission information gives information on the prevalence/incidence of co-morbidities and several medical aspects related to being learning disabled. The Birmingham data comes from the 2007/08 Hospital Episode Statistics (HES) set, covering details of all admissions to NHS hospitals in England.

It includes private patients treated in NHS hospitals, patients who were resident outside of England and care delivered by treatment centres (including those in the independent sector) funded by the NHS. This analysis considers the entire single stay/spell of treatment in hospital for patients living in the Birmingham area.

The conditions considered are as the case definition and included Autism Spectrum disorders below IQ of 70 (ICD-10 F84), Down syndrome (ICD-10 Q90), Fragile X (ICD-10 Q99.2), Mental Retardation (ICD-10 F7) and Asperger’s syndrome (ICD-10 F84.5) for sake of comprehensiveness.

These records are in practice restricted to those patients which have been admitted at least once in hospital on account of their learning disability condition as primary cause, or for whom it was deemed necessary to report their associated learning disability condition. Due to the several co-morbidities associated with learning disability, many admission events experienced by people with learning disability may not necessarily be recorded as related to patients with learning disability.

While this is not a comprehensive view of the health needs of this group of people, if we look at 3 years’ worth of data (Table 20) we can see that on average each year 656 Patients with learning disability were admitted to hospital (425 males and 231 females).

Gender	2005/2006	2006/2007	2007/2008	Average 2005/6 to 2007/8
Male	399	442	435	425
Female	214	257	223	231
All	613	699	658	656

Table 20 Number of hospital admissions for patients with learning disability (Source: Hospital Episode Statistics (HES) 2005 - 2008, PHIT)

Table 21 shows that 70% of the Patients with learning disability are under 25 years of age. They exhibit a number of conditions: Epilepsy, Down syndrome and Autism being the most common (Table 22).

Age Group	2005/2006	2006/2007	2007/2008
0-9	203	248	283
10-19	116	147	135
20-29	64	54	62
30-39	63	62	41
40-49	53	66	48

Age Group	**2005/2006**	**2006/2007**	**2007/2008**
50-59	49	50	41
60-69	41	50	29
70-79	17	15	17
80+	7	7	0
Total	613	699	656[94]

Table 21 Number of hospital admissions for patients with learning disability by age group (Source: Hospital Episode Statistics (HES) 2005 - 2008, PHIT)

Condition	**Number of related Admissions**
Mild LD	78
Moderate LD	22
Severe LD	9
Cerebral Palsy	15
Epilepsy	113
Down syndrome	223
Congenital Hypothyroism	5
Asperger	41
ASD no Asperger	196
Unspecified, Profound and other LD and related condition[95]	100

Table 22 Number of hospital admissions for patients with learning disability (LD) by condition (2007/8) (Source: Hospital Episode Statistics (HES) 2007/2008[96], PHIT)

With regard to Epilepsy, HOB tPCT (Table 13) reports by itself 172 Patients with learning disability in the QOF LD registers. Without attempting to project this PCT's figures over Birmingham as whole, it is clear that people with learning disability and epilepsy are particularly at risk of hospital admission and should be monitored closely.

More generally, the majority of patients with learning disability are of white origin (60%) followed by Asian or Asian British (17.8%) (Table 23).

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[94] The discrepancy between table 16 and 17 for the 2007/2008 period is presumably due to lack of age information for two patients.

[95] The data has been aggregated and renamed due to Data Protection regulation.

[96] The total is not included because of double counting due to individuals with multiple conditions

Ethnicity	Average for 3 Years
Asian or Asian British	17.8%
Black or Black British	6.0%
Mixed	2.7%
Chinese or Other Ethnic Groups	1.9%
White	60.0%
Not known	11.6%

Table 23 Percentage of patients with learning disability admitted to the Hospitals by ethnicity in 3 years (Source: Hospital Episode Statistics (HES) 2005 - 2008, PHIT)

Figure 30 shows the rate per 1,000 of LD hospital admissions by Patients with learning disability by ward, average over 3 years (2005/6 to 2007/8).

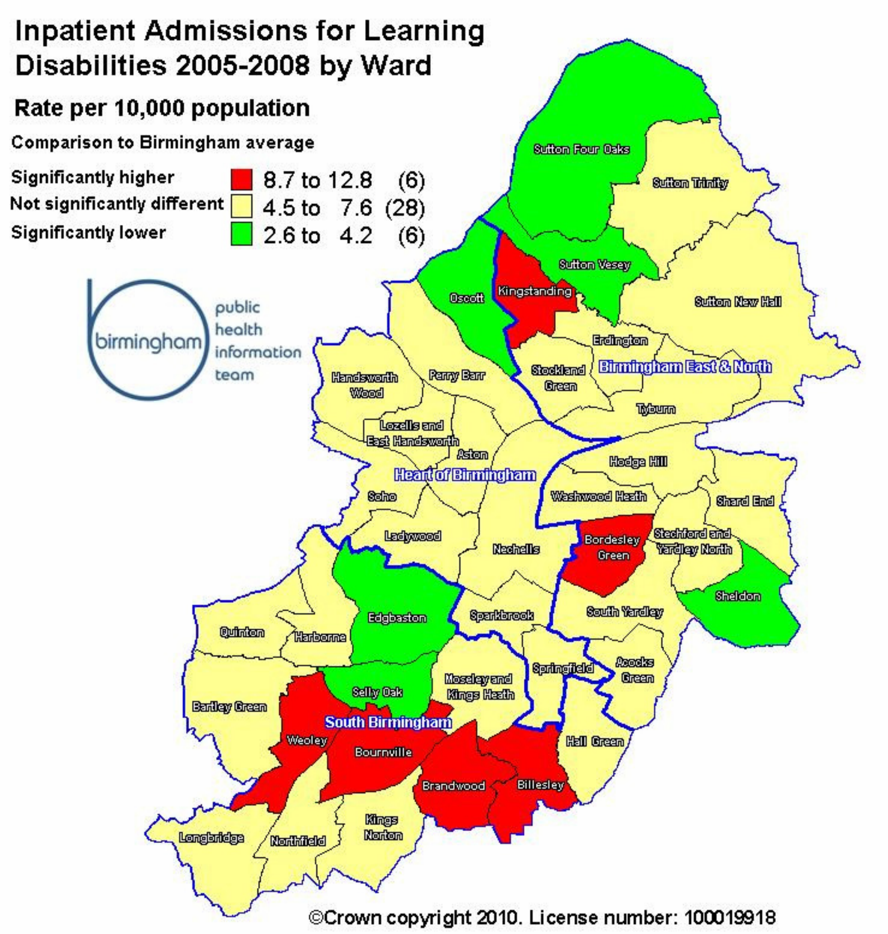

Figure 30 Rate per 1,000 of LD Hospital Admissions for 3 years, 2005 – 2008 (Source: Hospital Episode Statistics (HES) 2005 - 2008, PHIT)

Figure 31 compares the reasons for admission (expressed as a rate per 1,000 averaged over 3 years) between Patients with learning disability and the general population.

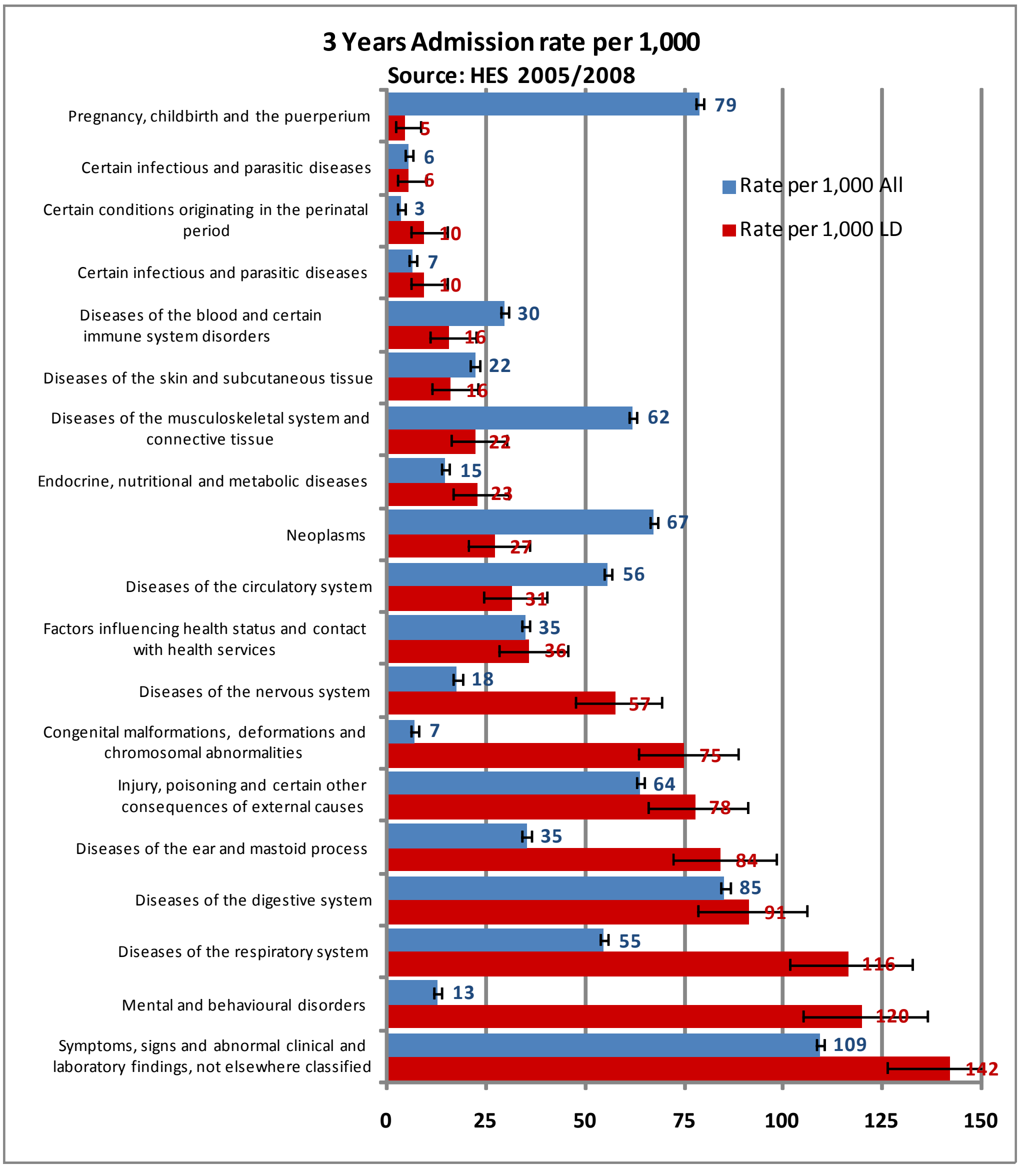

Figure 31 Comparison between LD admissions and general all admissions for three years. (Source: Hospital Admission Records (HES) 2005/2008)

As it would be expected there are significantly higher admissions for mental and behavioural disorders, congenital malformations, deformations and chromosomal abnormalities and diseases of the nervous system, being directly related to being learning disability.

It is worth noting that the commonly quoted co-morbidities for this group are reflected in their higher hospital admissions (e.g. diseases of the respiratory system, diseases of the ear and mastoid process and endocrine, nutritional and metabolic diseases).

This group appear to have significantly (see error bars) higher hospital admission rates over the general population for injury, poisoning and certain other consequences of external causes.

It is worth noting that one of the cases of failure of care for People with learning disability reviewed by the Ombudsmen for health and local government (The Stationery Office:2009) concerned a 30 year old men in a respite care home setting who died in the aftermath of breaking his thigh bone in a fall. The circumstances of the fall remained unclear following the investigation by the ombudsmen.

This high admission rate for this type of causes has relevant implications for prevention and Safeguarding activities and it should be studied separately.

There is also a strong indication about the higher than average requirement for hospital admissions for symptoms, signs and abnormal clinical and laboratory findings for patient with learning disability.

There are significantly lower admissions for diseases of the circulatory system and neoplasms compared to the general population.

Other services

Among other initiatives such as HAP packages, PCTs in Birmingham offers also other services. One of them is the campaign Eye2Eye (Brady:2008) carried out in collaboration with the SeeAbility charity and targeted at people with LD affected by visual impairment.

The campaign focused on:

- “Ensuring that people with learning disabilities accessed services in line with need.
- Social inclusion of people with multiple impairments by ensuring that their visual impairments were taken into account, in relation to individual plans and programmes”[97].

Eye2Eye was carried out for three years till the end of 2008, and then further extended for another year.

This campaign highlighted a number of issues, but the recurrent theme was represented by barriers to access linked to the current administrative arrangements.

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[97] Brady S, (2008) p. 7.

Prison and criminal justice system

The Literature on offenders with learning disability

The Criminal Evidence Act 1984 stipulated that anyone with learning disabilities when arrested should have access to an 'appropriate adult' to support for them whilst at the police station and to help them understand what was happening. It is estimated that whilst around 15% of people arrested fall into this category, and around only 4% are afforded this access [98].

As reported in Loucks (Loucks:2007), Mottram and Lancaster (Mottram and Lancaster:2006) estimated that approximately 5,000 prisoners on any given day in England and Wales were learning disabled and a further 19,000 were possibly borderline.

These figures equated to around 32% of the adult prison population. With this amount of prevalence the 2009 DH Report 'Valuing People Now' commented that this particular group of people are one of the most socially excluded groups in both normal and prison society.

Another study (Beebee:2010) confirmed this, noting that once in the prison system this particular group of prisoners are less likely to be included in rehabilitation education within prison, and are more likely to be the subject of violence or bullying and to re-offend. This creates a follow on problem within the court system and ultimately the prison system, because of a lack of knowledge of that arrestee's problems.

The research programme 'No One knows' carried out by the Prison Reform Trust confirms this view. This study asked prison officers and prisoners of their experience of the Criminal Justice system. The interim report (Talbot:2007), following interviews with prison officers suggested officers found that prisoner records had not been updated properly, procedures for referring prisoners that fall into this category to appropriate services are unclear and prisoners with learning disabilities are consistently excluded from elements of prison activities that would prevent them from re-offending.

Prison staff further commented (Talbot:2007) that they do not feel they have enough training on how to deal with prisoners with mental or learning disabilities, they also complained that they would like more strategic and operational direction on how to deal with prisoners who fall into this category.

In order to address these issues, the (Public Service Agreement) PSA 16 was developed in 2007. Its stated aim was to improve the situation and increase the amount of people in the Criminal Justice Systems into settled accommodation, employment, education and training.

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[98] Beebee J (2010), p.36.

It is apparent that whilst improvements are forthcoming with the education of the police and prison officers on how to deal with prisoners and those arrested who are learning disabled, part of the issue lies with lack of knowledge of the education standard and health (mental or otherwise) of individual cases. Therefore, whilst PSA 16 has caused a rethink, enough is still not being done.

Beebee's article (Beebee:2010) confirms this view. It concluded that people with learning disabilities do not get a fair and equitable service from the Criminal Justice system which considering the estimated prevalence within the Justice system, obviously needs to be addressed.

With regards to Birmingham's situation, it is difficult to have an estimate of the population of offenders with learning disability, who, at discharge, may be returned to the family and/or residence of origin (if any) in Birmingham. This is potentially one of the most fraught issues in supporting people with learning disability, given the compounded problems of finding rehabilitation support and health and wellbeing assistance.

People with learning disability at risk of contact with the justice system

A review of literature on MH illnesses in people with learning disability suggest that the prevalence rate in problem behaviours (From self-harm to demanding behaviour passing through physical aggression) is between 10 to 15 percent of the LD population known to education and social care agencies[99].

To put these issues in context, it is useful to consider projections of people who exhibit challenging behaviours. These individuals - particularly in people who may not be in touch with health and social services - may be at greater risk of committing criminal acts and being sent to prison.

Table 24 forecasts the number of adults with challenging behaviours in Birmingham.

Age	2009	2015	2020	2025	2030
18-24	31	30	28	29	32
25-34	38	44	45	43	42
35-44	33	31	34	38	39
45-54	28	30	29	27	30
55-64	22	22	24	26	25

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[99] Smiley E (2005) p. 221. However this result should be qualified by the fact that a Cochrane review on the subject (Hassiotis and Hall:2007) concluded that there is limited evidence available on the subject and no firm conclusion can be reached on the prevalence rates.

Total	152	157	160	163	168

Table 24 Predictions for adults with challenging behaviours in Birmingham (Source: Projecting Adult Needs and Service Information Systems, (PANSI))

It is possible that a substantial part of these adults is represented by People with learning disability. As in 2008/09 there could have been up to 3,884 adult People with learning disability known to Adult and Communities Services (see Table 11), 40 to 60 (10 to 15%) Adults with learning disability could represent between 25 to 40% of the forecasted population with challenging behaviour in Birmingham.

Beebee (Beebee:2010) reports an estimate that 26% of those known to community learning disabilities teams engage in behaviour that would be considered an offence if legal proceedings were pursued.

The same article reports that up to 9% of those arrested have been found to have an IQ below 70, thus being clinically learning disable[100]. For comparison, Home Office statistics of individuals ending up in custody under section 136 of the Mental Health Act 1983 show that in 2008 in Birmingham alone there were 422 individuals placed in custody for offences ranging from assault, drink driving, criminal damage, arson and similar serious charges[101].

This is an area which needs a separate fact-finding exercise and will require close collaboration with courts, probationary services and police force, to assess possible annual volumes of ex-offenders with learning disability being returned to the community of origin and effective ways to help them avoiding re-offending and settling in the community.

Adult social care services

Meeting the clinical definition of learning disability does not give automatic access to support services. An evaluation of specific social need is also undertaken, based on the FACS criteria. The focus of the adult social care service is to:

Assess the needs of adults with learning disabilities and their carers and undertake reviews of care

Educate and make providers aware of the needs of adults with learning disability

Negotiate placements and co-ordinate the care of adults with learning disabilities

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[100] Beebee J (2010) p. 36.
[101] West Midland Police Statistics Section 136 Mental Health Act statistics for 2008

Within this framework, there are a number of channels by which people with learning disability may get in touch with, or referred to, the BCC units providing services to Adults with learning disability. The report outlines three areas: Transition to Adulthood, Transfer of Care from Hospitals, and Safeguarding procedures.

Transition to adulthood

Most young people have a straightforward journey from childhood to adulthood. For a minority, for example those with learning difficulties or disabilities, care leavers, young people with severe learning disabilities and/or those with complex needs, their transition to adulthood can be more challenging.

This group of young people with learning disability- who have had extensive support throughout their lives and often have significant family needs - will require services which enhance their independence and are designed to support smooth transition into adult services.

Table 25 shows results of a 2005 analysis of the likely future needs for adult care and support services of the current population of teenagers with learning disabilities and complex needs. This study pointed out a possible net addition of people to adult services agencies of nearly 300 people over 9 years.

Age Group	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**29**	**21**	**Total**
Number	15	25	39	52	57	53	33	14	1	289

Table 25 Number of Birmingham Special Needs Register (SEN) in 2005 receiving children's services and likely to require care and support as adults (Source: BCC 2005)

The Birmingham Transition Framework, supported by the Brighter Futures Strategy, concentrates mainly on the 13-25 age range and is first initiated within schools and offered to young people who have a Statement of Special Educational Need.

Within this context, a person-centred Planning tool had been created (Transition pathway) focused on children and young people with learning disability aged 13 to 19. This is being implemented across the council to improve transition arrangements[102].

By July 2010 most target schools and all special schools were trained to use the transition pathway and approximately 260 person centred transition plans (Pathways Plans) had been developed[103].

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[102] BCC (2010) p. 30.
[103] BCC (2010) p. 30.

The Careers Service (Connexions) has the responsibility to undertake a transition assessment report during the first term of Year 9 (age 14 years). Each young person is allocated a Personal Advisor to liaise with them and their parents/carers.

Nearly a quarter of the population of Birmingham are children and young people i.e. 0 – 25. It is estimated that approximately 47,000 of these CYP have some form of a disability or additional need, of which circa 8,000 are known either to Disabled Children Social Care Services or SEN (PHIT:2010b).

Whilst in age they range from 0 – 25 it is clear that once reaching 13, these citizens will need assistance to move from childhood to adulthood. Every Child Matters, Change for Children gives a national framework that provides assistance for local authorities to take this forward by building transition services that give a safe environment for this to happen for both CYP and their carers.

Via the ‘Brighter Futures – Transition to Adulthood Framework’ (BCC:2008) a transition pathway was established.

Table 26 shows those currently receiving transition support.

Age	People with MH	People with PD	People with LD	All People
18	2	5	81	88
19	6	14	67	87
20	4	9	84	97
21	11	15	103	129
22	11	11	88	110
23	18	8	81	97
24	27	14	91	132
25	31	13	86	130
Total	110	89	681	880

Table 26 Young People People (aged 18 to 25) supported by Transition Unit, Children Unit, BCC at 15/10/2008 (Source: Adult and Communities BCC 2008)

It is estimated by this team that they currently receive around 80 children and young people (CYP) a year into their programme, which begins at 13 but concentrates on those who 16 and older. This is done because up to 16 CYP who fall into this group are adequately monitored and cared for by social services, schools and carers alike.

However, it is clear that once attaining this age many are lost in the system. It has been identified by the transition team that:

There are no dedicated health care services for children and young people with learning disability once leaving school, and whilst 80 may be passed to the Adult and Communities Care services, it is obvious many more are left without the support they need[104].

Many parents of children and young people with LD have a higher health risk because once their children are 16+ may become in many cases more difficult to handle physically and indeed those with MH problems may be inclined to strike out at their carers. If a young person has been getting mental health services this will continue until they are 19 years old through Child and Adolescent Mental Health Services.

There is a distinct lack of co-ordination on linking various data sources in order to provide an overall picture of the true figures of children and young people with LD in Birmingham who require this service

Many children and young people currently in specialist schools tend to leave on attaining their 19th birthday or before[105]. Once this occurs, they no longer have contact with either the transition service or other social services, so they are not supported adequately, leading to a negative perception of the service. It also leads to several problems including an increase in health problems and anti-social and criminal activity.

The current situation therefore is potentially liable to create situations in which People with learning disability are at risk of harm. An example of the consequence of breakdowns in the handing over of responsibilities between schools and adult care service is given by a case reviewed by the ombudsmen for local government and health care services (The Stationery Office:2009). A client with profound and multiple disabilities was discharged by a special school at the age of 19, and shortly after died after a brief illness. The review concluded that local authority agencies failed to handle properly the move into an adult care environment. The failure was identified as lack of a systematic and person centred approach.

Another fact that has emerged from discussions with the transition team was the poor perception children and young people and their carers/parents have of the service and indeed adults and communities in general; particularly by the ethnic minority communities within Birmingham. This in itself is an issue because many BME families do not have one child or young person with LD but several.

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[104] While at school they have a specific health support service, but in the age between 16 and 19 there is no specialist service available. This gap raises risks especially for those CYP with LD and MH condition (PHIT: 2010b).

[105] Although a small fraction may stay until they are 25 years old.

The framework designed by the BCC (BCC:2010b) looks to rectify these problems by:

- bringing together the various data sources, to enable a broader picture to be developed;
- possible centralisation of all the relevant social care organisations that deal with children and young people with LD and / or mental health problems;
- ensuring that a transition plan is put forward for all CYP with LD and / or MH by their school leaving age.

It is anticipated that this would then prevent children and young people from dropping out of the system and ensure they were served more proactively and offered the same kind of services available to the remaining children and young people across the city.

However it is recognised (BCC:2010b) that at present this system works only within the confines of the FACS registration criteria. Those people with learning disability not meeting the FACS thresholds (or who did not receive a SEN) can experience a sudden change of level of support, from a comprehensive one to basically zero, except from what may be provided by the family.

The current approach is to invite young people with learning disability, who are in or approaching transition, and their carers to information events to help to maintain contact with Adult Social Services. However it is acknowledged that in this way People with learning disabilities and families who do not keep in touch may end up contacting BCC agencies only when a crisis point has been reached[106].

Disability employment services (DES)

The DES was established by BCC to provide disabled[107] people across the city with effective training and confidence building to enable them to move successfully into a permanent employment post. Its services include mock interviews, helping with CVs and other employment readiness work. Alongside this is active training by professional, experience team members that provide the disabled person with the skills / qualifications necessary to move on.

Their main training activities are via Shelforce and Forward 4 Work. Shelforce provide training in various manufacturing and assembly areas; they are a non-profit organisation and have contracts with local government to produce house fittings, they teach recognition of hand tools, materials and drilling machines along with how to use them safely. The students (employees) are additionally

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[106] BCC (2010) p. 29.

[107] Importantly, 'disabled' covers the whole wealth of physical and mental disabilities, including people who have depression after being out of work for long periods of time.

provided with a recognised national qualification if they complete the course; average length of the training / employment is 3 years.

Forward 4 Work provides training in retail, floristry, grounds maintenance, catering, horticulture, office administration and mail house. This encompasses a garden centre that sells on bedding plants in Nechells, a catering service that provides drinks and sandwiches to local businesses and full training in any of the areas of choice, so that the recipient has the equivalent recognised national level of training as a non-disabled person.

Referrals for the DES come from various sources including Adults & Communities, GPs, Mitre and Seetec. Gaps may arise in the future with the withdrawal of certain funding sources. As it happens in other areas, many 18+ People with learning disability will be not followed up on account of their age (PHIT:2010a; PHIT: 2010b).

Feedback from DES to the report researchers also points out that many People with learning disability now receiving training in college may have been ‘missed’ by Adult and Communities department, as they were usually not registered for support with any of the BCC service databases (PHIT:2010a).

A recent BCC report (BCC:2010b) also notes that the scope of DES activities is severely curtailed by time-limited funding contracts, each with its own spending rules set by central government, thus limiting the ability to make long term plans.

Transfer of care from hospitals

The National Indicator 131 (NI 131) is a measure of delayed transfers of care from hospital, expressed as a rate per 100,000 population aged 18+. A delayed transfer of care occurs when a patient is ready for transfer from a hospital bed, but is still occupying a bed. A patient is ready for transfer when;

- A clinical decision has been made that the patient is ready for transfer and
- A multi-disciplinary team decision has been made that the patient is ready for transfer and
- The patient is safe for discharge/transfer

Birmingham’s performance on this indicator lies in the lower quartile for England. The West Midlands region has the worst record for delayed transfers with Coventry, Birmingham, Sandwell and Dudley making the greatest contributions to these rates.

There were 2002 adults in 2008/9 who had delayed transfers from hospital and 1,886 between April 2009 and Jan 2010.

It is possible to extract information specific to learning disability people.

In 2008/9 there were 25 adult patients with learning disability awaiting transfer from hospital and on average it took 59.4 days for this to happen (ranging from 2 to 248 days).

In contrast the 146 physically disabled adult patients awaiting transfer from hospital on average took 30.3 days for this to happen (1 to 221 days).

Between April 2009 and Jan 2010 there were 25 adult patients with learning disability awaiting transfer from hospital and on average it took 78.2 days for this to happen (ranging from 4 to 328 days).

In contrast the 131 physically disabled adult patients awaiting transfer from hospital on average took 28.2 days for this to happen (2 to 200 days).

In 2008/9 the reasons for delay were largely because of the time waiting for an assessment and getting public funding agreed. The first 10 months of 2009/10 indicate that in addition to these reasons there are pressures on residential and nursing places becoming available. However it is not be possible to decide if these delays are accidental rather than structural without additional information.

As noted earlier the transition between one care setting and another is a critical one. The review of a case in which a client with learning disability died shortly afterwards a discharge from an hospital to a care home (The Stationery Office:2009) highlighted a failure by a PCT to provide adequate standards of nursing care, arrange for the move to the client to a care home setting, discharge the client with learning disability safely, and communicate adequately with the family. The ombudsmen also found that the service failure was partly related to the fact that the client was affected by learning disability.

It is important to note that the national indicator does not include children. There is some anecdotal evidence to suggest that there are children, with particularly complex health care needs, that wait a very long time in hospital while they await the necessary package of care.

Safeguarding

Birmingham Safeguarding Vision is “To promote and protect individual human rights, independence and well-being and secure assurance that vulnerable adults stay safe, are effectively safeguarded against abuse, neglect, discrimination, embarrassment or poor treatment, are treated with dignity and respect and enjoy a high quality of life”.

The Birmingham Safeguarding Adult Board (BSAB) is responsible for meeting these objectives. It is attended by the senior members of the Council and PCTs, through five sub groups. Multi-agency procedures are used to discipline allegations of abuse.

The Safeguarding Vulnerable Adults (SOVA) process is detailed in policies and procedures. Each year, an annual report is produced showing the numbers, types of abuse, and outcomes of the investigations (across all care groups and ages).

The data suggests a short term upward trend of increases both in the total number of referrals (Table 27, from 495 in 2007/8 to 619 in 2008/9) and in the number of referrals for people with learning disability (Table 28, from 115 in 2005/6 to 256 in 2008/9) that are completed within the year. Most alerts were referred by the NHS or the Police.

Agency	**2007/08**	**2008/09**
NHS	314	408
Police	157	108
Housing Agencies	24	55
Probation	0	0
Care Quality Commission	0	48
Total	495	619

Table 27 Number of all safeguarding alerts by member agencies of BSAB (Source: Birmingham Safeguarding Adults Board, Annual report 2009)

Table 28 reports numbers from all agencies. A larger number and a higher percent of safeguarding referrals were for people with learning disability; 280 out of 495 or 57% in 2007/8 compared to 509 out of 619 or 82% in 2008/9.

Client Group	**2005/2006**		**2006/2007**		**2007/2008**		**2008/2009**	
People with LD	Referrals	Completed referrals	Referrals	Completed referrals	People with LD	Referrals	Completed referrals	Referrals
	146	115	236	129		146	115	236

Table 28 Total number of alert referrals for people with LD (Source: Birmingham Safeguarding Adults Board, Annual report 2009)

The reasons for the increase were tentatively identified in the report as due to an increase in staff awareness in the agencies responsible for referrals and to data cleansing work carried out in preparation of the roll out of the CareFirst6 software system[108].

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[108] Birmingham Safeguarding Adults Board (2009), p. 61.

Although the data refers to a different period, an indication of the type of the abuse is given in Table 29. Physical abuse was 30.3% of the total, and 20.0% were emotional/mental or psychological abuse.

Type of Abuse	**Percentage of People with learning disability**
Discriminatory	3.0%
Emotional/Mental/Psychological	20.0%
Financial or Material	13.3%
Institutional	6.2%
Neglect and Acts of Omission	15.5%
Physical	30.3%
Sexual	6.7%
Not Known at This Time	5.0%

Table 29 Percentage of referrals of people with learning disability by type of abuse, April 2009 to November 2009. Baseline: 792 referrals (Source: Birmingham Safeguarding Adults Board, Safeguarding Information Request)

Current provision of services

Every year Birmingham City Council provides process indicator information on adult community care regarding the Referrals, Assessments and Packages of Care and this section considers trends and main points of interest. The number of people with learning disability receiving services each year can be found in Table 30.

Year	**Number of people with learning disability**
2004-2005	2,861
2005-2006	3,307
2006-2007	2,760
2007-2008	2,965
2008-2009	3,044

Table 30 Number of people with learning disability receiving services by year[109] *(Source: Referrals, Assessments and Packages of Care (RAP), 2004/2005 to 2008/2009 in Birmingham)*

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[109] The number of people receiving services during 2008/2009 is actually 3,131. In the RAP return it is reported as 3044 which is an underestimate because some of the people were not identified at the time of RAP submission.

Figure 32 shows the age distribution of the people with learning disability receiving services in 2008/9. More than 90% of the services are provided to people with learning disability in the age group 18-64.

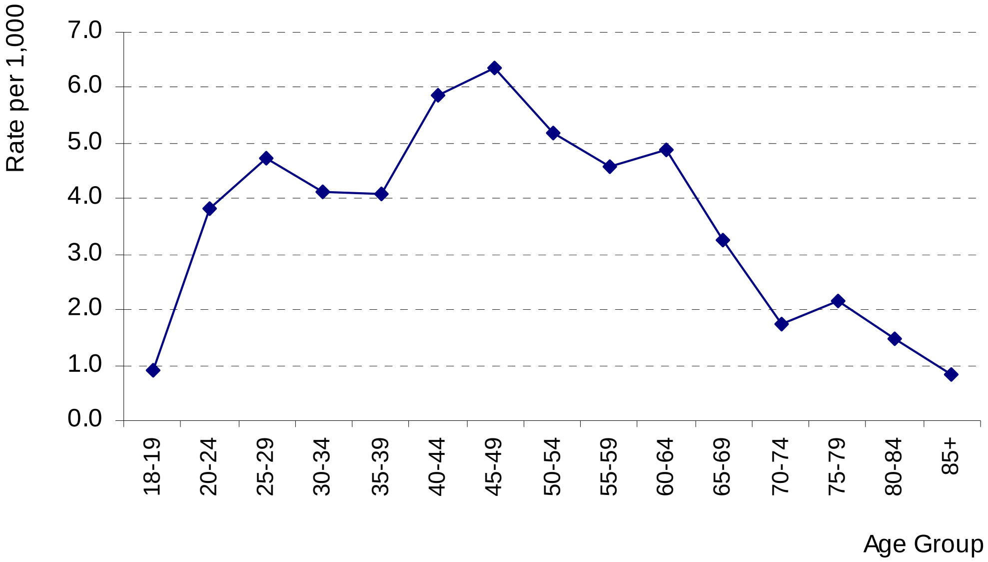

Figure 32 Age distribution of people with learning disability receiving services in 2008/2009 (Source: Referrals, Assessments and Packages of Care (RAP), 2008/2009 in Birmingham)

This information is given by age and gender in Figure 33.

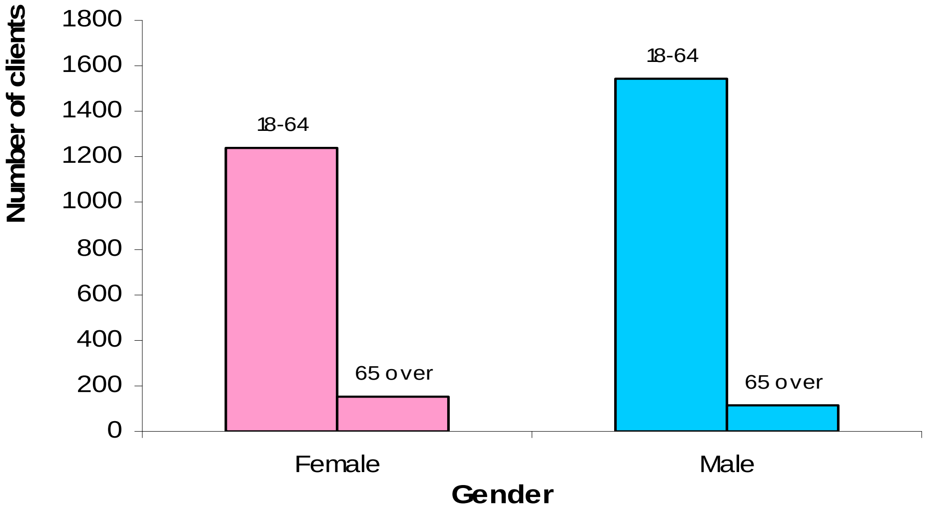

Figure 33 Number of people with learning disability receiving services in 2008-2009 by age group and gender (Source: Referrals, Assessments and Packages of Care (RAP), 2008/2009 in Birmingham)

Figure 34 provides the breakdown by ethnic group.

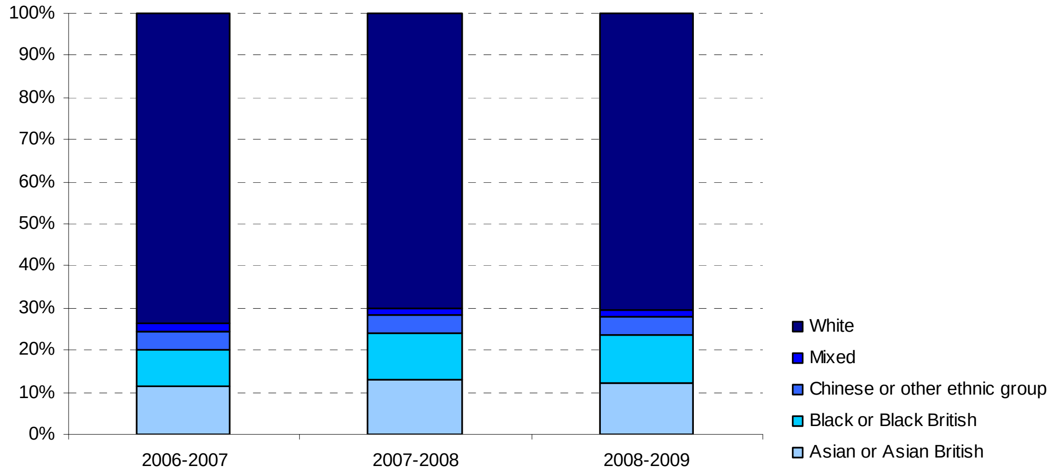

Figure 34 Percentage of people with learning disability receiving services by ethnicity and year (Source: Referrals, Assessments and Packages of Care (RAP), 2006/2007 to 2008/2009 in Birmingham)

There are more males receiving services than females. The majority of service users with learning disability are of white origin (70.43%) followed by Asian or Asian British (12.25%).

It is interesting to note the length of time from first contact to completed assessment for new people with learning disability (2008/2009) compared to other client types. These People with learning disability were 250 in total, and they waited a longer length of time for completed assessments and service provision than physically disabled, mental health, substance misuse people or other vulnerable people.

This delay reflects the difficulties in assessing and providing service to this group. As many as 43.3% wait more than 3 months for the assessment of services (Table 31) and 48.3% wait more than 6 weeks for the provision of the services (Table 32).

Time bands	**PD**	**LD**	**MH**	**Substance misuse**	**Other vulnerable people**
Less than or equal to 2 days	20.78%	7.51%	28.53%	51.70%	21.03%
More than 2 days and less than or equal to 2 weeks	12.68%	10.92%	14.66%	23.81%	16.11%
More than 2 weeks and less than or equal to 4 weeks	41.27%	11.60%	22.91%	2.04%	33.95%
More than 4 weeks and less than or equal to 3 months	23.51%	26.62%	20.58%	22.45%	26.45%
More than 3 months	1.76%	43.34%	13.32%	0.00%	2.46%

Table 31 Length of time from first contact to completed assessment for new people whose assessments were completed during 2008/2009, by primary client type. N = 250 (Source: Referrals, Assessments and Packages of Care (RAP), 2008/2009 in Birmingham)

Time bands	PD	LD	MH	Substance misuse	Other vulnerable people
Less than or equal to 2 weeks	66.61%	31.03%	76.59%	51.47%	63.59%
More than 2 weeks and less than or equal to 4 weeks	16.95%	18.10%	6.88%	16.18%	17.37%
More than 4 weeks and less than or equal to 6 weeks	6.40%	2.59%	5.45%	0.00%	6.72%
More than 6 weeks	10.04%	48.28%	11.08%	32.35%	12.32%

Table 32 Length of time from completed assessment to receipt of all services for new people for whom all services were put in place in 2008/2009 by primary client type. N = 250 (Source: Referrals, Assessments and Packages of Care (RAP), 2008/2009 in Birmingham)

Three main categories of services are provided to people with learning disability; community based services, residential care and nursing care (Table 33).

Year	Community based services	Residential care	Nursing care
2004-2005	1,929	822	165
2005-2006	2,017	1,082	234
2006-2007	1,677	1,026	57
2007-2008	1,838	1,079	53

Table 33 Number of people with learning disability receiving services by year and type (Source: Referrals, Assessments and Packages of Care (RAP), 2004/2005 to 2008/2009 in Birmingham)

The number of people receiving different types of community based services from 2005/6 to 2008/9 (home care, day care, meals, direct payments, professional support, equipment and adaptations, other) can be found in Figure 35.

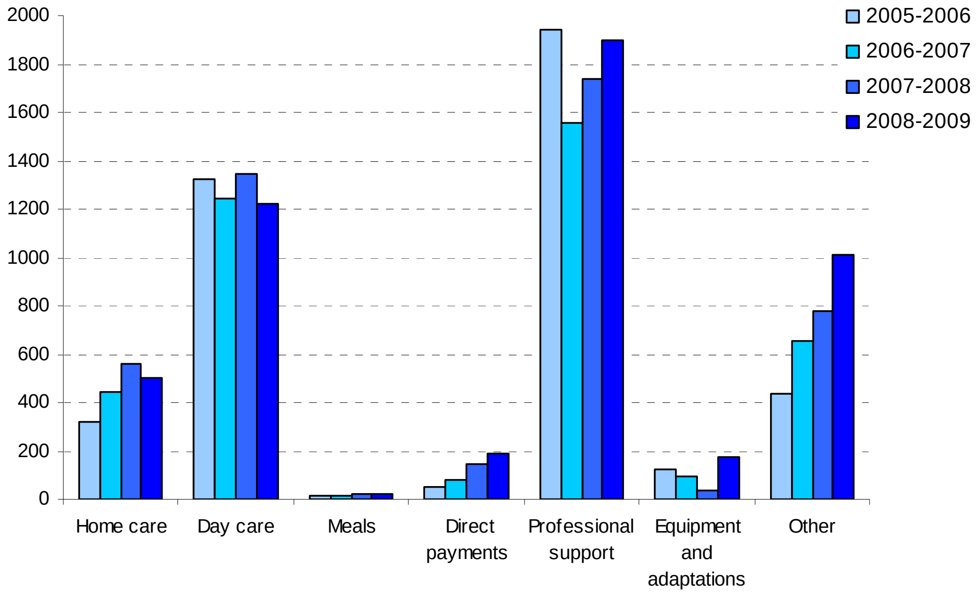

Figure 35 Number of people with learning disability receiving community based services by service type and year (Source: Referrals, Assessments and Packages of Care (RAP), 2005/2007 to 2008/2009 in Birmingham)

It is worth noting that Direct Payments have shown the strongest increase between 2005/06 and 2008/09, quadrupling in size. This reflects an emphasis on a personalisation of services and increasing the capacity of people with learning disability to make individual decisions on the services and goods they need.

In the next page Figure 36 provides the distribution of people groups across different age bands. The graph shows that the age structure is roughly consistent across the Fair Access Care Services (FACS) groups[110]. It is unclear whether this reflects the nature of the selection process or rather the demographic structure of the learning disability community in Birmingham.

The large size of the unknown category[111] may be altering the overall picture, but it is worth noting that this category follows a double peak structure like for the other categories, suggesting an overall homogeneity in the age groups across FACS types.

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[110] The order of severity of condition expressed by the FACS categories does not follow the natural ranking to allow visual inspection.

[111] It represents 20% of the total count. Source ‘Moving On’ study based BCC records for FY 2008/2009.

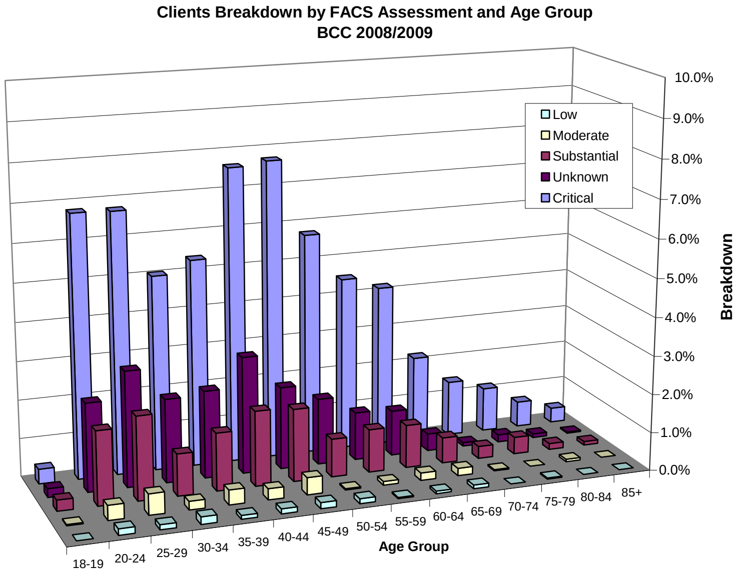

Figure 36 Percentage of people with learning disability receiving services by FACS type over total numbers in 2008/2009. N = 3,044 (Source: Referrals, Assessments and Packages of Care (RAP), 2008/2009 in Birmingham)

Support for carers and advocacy

Carers

Many carers in England (49%) are aged 65 and over, and another 44% are aged 44 to 64. Of these carers, 14% look after one or more children[112]. A number of people with learning disability live at home with their family members acting as carers. In the majority of cases the main carer is the mother.

National indicator NI 135 (See Figure 0.1) provides an indirect view of the situation in Birmingham, as it refers to all known carers that have received ‘needs assessment or review and a specific carer's service or advice and information’.

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[112] “Personal Social Services Survey of Adult Carers in England - 2009-10”, p.5. This last survey indicates that 49% of carers are aged 65 and over.

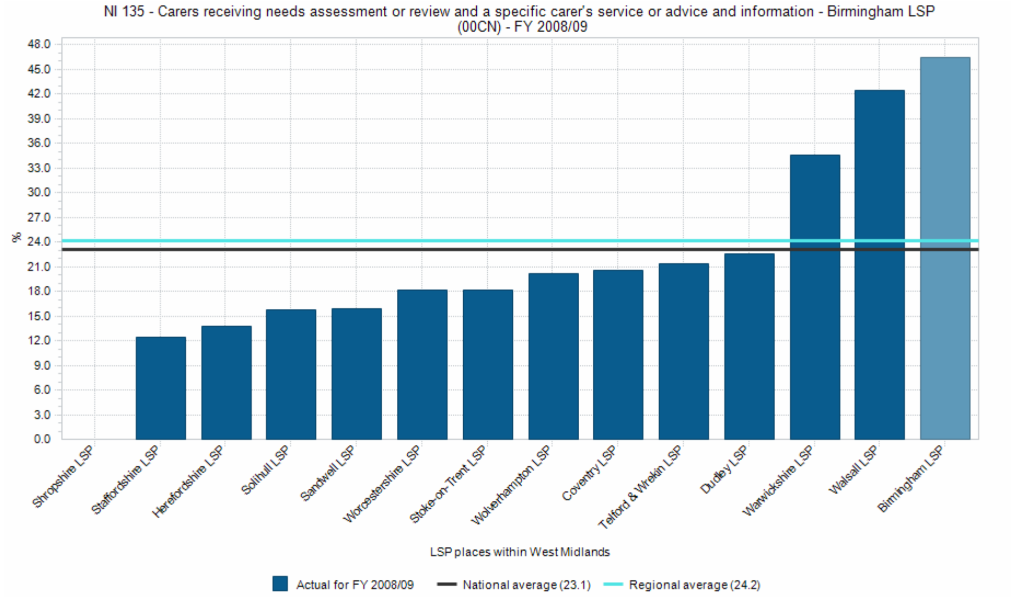

Figure 37 Carers receiving advice or needs assessment (Source: Places Analysis Tool, ASCAR 2008/8009, PHIT)

Although Birmingham is performing well relatively against regional and national figures, more than half of carers did not receive (or ask for) information nor did they undergo a needs assessment.

The National Strategy for Carers (DH:2008) states that carers have a right to have their own health needs met. People with mild learning disabilities may not be known to social services until the person has a major crisis and hence neither person nor carer will be known to the service.

Anecdotal information and evidence from carers suggests that the parents of a child with learning disability go through a number of stages as they learn to cope with changing caring responsibilities and come to terms with what the child can achieve. Services provided for the child also take into account the family situation and the challenges faced by the family.

Valuing People (DH:2001) suggests that a quarter of carers looking after People with learning disability become known to social services when they can no longer cope. This can result in a large strain on social services that were not previously aware of these people.

Recommendations to help carers include:

- Better information systems so that more people are known to social services.
- Older family carers are visited annually by social services.
- Specific arrangements for black and minority ethnic groups are made where there may be problems related to language.

- Carers are registered with a GP and seek treatment or respite care when necessary.

National estimates suggest that the number of people with learning disability with moderate or severe condition living with parents in Birmingham will increase from 1,446 in 2009 to 1,670 in 2030 (Table 34).

Age	2009	2015	2020	2025	2030
18-24	528	503	476	501	560
25-34	402	487	510	509	513
35-44	334	312	346	388	394
45-54	141	153	146	140	158
55-64	41	42	46	49	45
Total	1,446	1,497	1,524	1,587	1,670

Table 34 Predictions for moderate or severe condition living with parent(s) in Birmingham (Source: Projecting Adult Needs and Service Information Systems, (PANSI))

The number of people aged over 45 (with parents that will be older) will increase from 182 to 203 over the same period. The following tables show a trend in carers' numbers consistent with the predictions of Table 34.

Table 35 indicates that formal carers over 65 have steadily increased between 2006/07 and 2008/09.

Year	18-64	65+	Total
2005/2006	96	32	128
2006/2007	849	18	867
2007/2008	671	23	694
2008/2009	837	30	867

Table 35 Number of carers assessed or reviewed by age group of the client with learning disability (Source: Referrals, Assessments and Packages of Care (RAP), 2005/2006 to 2008/2009 in Birmingham)

Table 36 indicates that also the number of informal carers has picked up between 2007/08 and 2008/09.

Year	Number of Carers
2005/2006	98
2006/2007	847

Year	Number of Carers
2007/2008	691
2008/2009	860

Table 36 Number of informal carers receiving different types of services provided as an outcome of an assessment or review (Source: Referrals, Assessments and Packages of Care (RAP), 2005/2006 to 2008/2009 in Birmingham)

In Birmingham, the Carers Partnership Board has strategic oversight of the Council's Carers Commissioning strategy including the city-centre Carers Centre. The Carer Centre provides details of services offered; training, employment advice, information on short breaks, carers rights, benefits and health checks. There is a supporting Carers Network web site. Feedback from carers demonstrates a consensus that a more coherent approach to registration and identification for health issues in people with learning disabilities, and better information would help carers maintain their own health.

Advocacy

There are a number of independent advocacy services managed by charities with funding from private and public partners. A review of the websites of Birmingham Learning Disability Partnership Board[113] and of the National Forum for People with Learning Difficulties[114] indicates that there are at least 5 advocacy organisations dedicated to support People with learning disability. In addition, there are several other advocacy charities supporting people with disabilities in general and are listed as supporting also People with learning disability. Apart from charities, Social Workers and Connexions PA also offer advocacy support.

Of the five advocacy organisations dedicated to People with learning disability, four were under contract with BCC until June 2010[115].

A review of advocacy services (BCC:2010b) highlighted the following issues:

- Current and future demand outstrips the available offer
- Lack of specific health advocacy services
- Need for city wide transition advocacy
- Need to meet increasing demand from the BME population
- Need to provide advocacy training to volunteers and paid staff
- Need to train carers and People with learning disability to conduct self-advocacy whenever possible, especially in important but not critical areas.
- Need to shift from crisis management to early prevention
- Short Breaks

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[113] http://www.tellusmore.org/
[114] http://www.nationalforum.co.uk/view.asp?id=0
[115] BCC (2010), p. 32.

In May 2007 the department for education and skills (DES) launched the programme Aiming High for Disabled Children (as part of the Every Child Matters reform). This programme proposed a transformation of disabled children's services and a substantial overhaul of short break provision. There is now a duty on local authorities to provide short breaks for disabled children, which will become statutory by April 2011.

Short breaks are intended to have positive benefits for both children and families and carers. During 2008/9, Birmingham PCTs allocated funds to provide the infrastructure and clinical support to enable short breaks to take place. Birmingham will be able to access additional funds as commitments have been made in 2007 Aiming High for Disabled Children, the 2008 Children's plan, and the 2009 Child Health Strategy.

Aiming High for Disabled Children set out the expectations for the short break service. Among other things, it specifies that a short breaks service must ensure that children and young people on the autism spectrum are not disadvantaged in accessing short breaks. The extra funding is likely to enable the short breaks service to be preventative and supportive rather than based on crisis intervention.

A joint strategy between Birmingham City Council and the three PCTs (Birmingham City Council and Birmingham PCTs:2009) has outlined the key areas for investment to deliver the statutory full service offer for short breaks by 2011. In preparing the full service offer, a dataset combining information from various sources including school records, Children in Need records, the Disability Register, data from Children's Centres and Pre-school Liaison Groups has been established.

This combined dataset suggests that out of the City's child population of 285,812[116] there are around 47,826 children who receive some form of support relating to their specific or educational needs. Around 15,500 of these have significant or enduring needs and are in receipt of specialist or targeted provision.

The priority groups, as determined in February 2009, for short breaks can be found in Table 37. The total number of children with a priority need for short breaks has been estimated at 1,078.

Primary disability	**Secondary disability**	**Age range**				
		0-4	**5-9**	**10-14**	**15-19**	**Total**
ASD	BESD/SLD	163	316	273	221	973
PMLD	ASD	1	3	2	2	8

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[116] 2008 estimations

Primary disability	Secondary disability	Age range				
		0-4	5-9	10-14	15-19	Total
SLD	ASD	4	20	37	36	97
Total		168	339	312	259	1,078

Table 37 Priority groups for short breaks by age band (Source: AHDC Short breaks Strategy Birmingham)

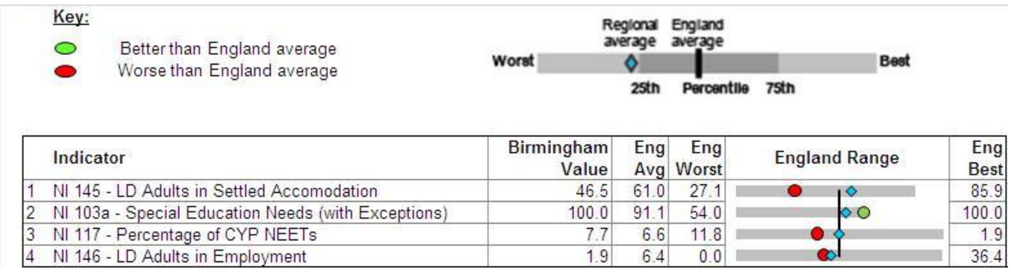
- **ASD**: Autistic Spectrum Disorder
- **BESD**: Behavioural, Emotional and Social Difficulties
- **SLD**: Severe Learning Difficulty
- **MLD**: Mild Learning Difficulty
- **PMLD**: Profound and Multiple Learning Difficulties

Equal and active citizenship

This chapter discusses the current state of provision of services by public agencies in Birmingham that promote equal and active citizenship for people with learning disability. A detailed analysis of service records is provided in chapter Error! Reference source not found.. In this chapter four areas of services are reviewed: Housing, Education, Employment, and Transport.

These service areas are discussed in terms of how they support people with learning disability. However there are not always statistics available on provision of service to individuals with learning disability. In some cases statistics on service to people with disabilities are provided instead as proxy for the current situation.

Figure 38 below provides an overview of the National Indicators discussed later in the chapter.



	Indicator	Birmingham Value	Eng Avg	Eng Worst	England Range	Eng Best
1	NI 145 - LD Adults in Settled Accomodation	46.5	61.0	27.1	🔴 ◆	85.9
2	NI 103a - Special Education Needs (with Exceptions)	100.0	91.1	54.0	◆ 🟢	100.0
3	NI 117 - Percentage of CYP NEETs	7.7	6.6	11.8	🔴 ◆	1.9
4	NI 146 - LD Adults in Employment	1.9	6.4	0.0	🔴◆	36.4

Figure 38 National Indicators for Birmingham in 2008/2009 (Source: Audit Commission)

The charts provide a mixed picture, where services to adults do not seem to maintain the higher level of provision which is available to children. This dichotomy will be discussed in the following four sections.

Housing

The majority of adults with mild / moderate learning disabilities live with a parent or other relative[117]. Adults with more severe learning disabilities are more likely to be in supported living or residential care homes.

National Indicator 145 (NI 145) is the percentage of adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) in settled accommodation[118] at the time of their assessment or latest review. Fewer adults live in settled accommodation (46.5 % in

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[117] Emerson et Al (2005) p. 27.

[118] It is worth noting that people in not settled accommodation may include long term sheltered settings such as registered care and nursing homes and long term health care units. De facto settled accommodation includes any stable long term residential arrangement.

Birmingham versus 57.5% in the West Midlands or 65.2% in England) (Figure 39).

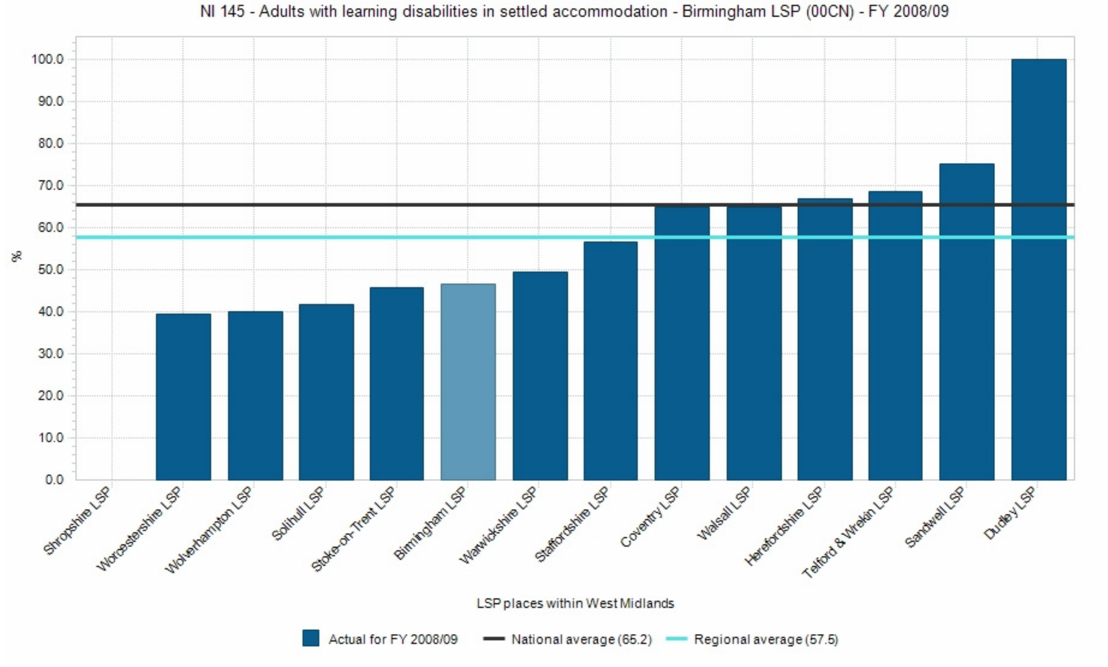

Figure 39 Percentage of adults with learning disability in settled accommodation (Source: Places Analysis Tool, ASCAR 2008/8009, PHIT)

A recent report from BCC (BCC:2010b) indicates that the demand for settled accommodation will need to be met by community based services. An on-going closure programme means that by the end of FY 2010/11 all long stay residential homes will be closed and the people with learning disability moved to community based services[119] (to be provided by a preferred list of providers currently under review).

The report also highlights the need for a structured pathway to independent living from either a family or a residential home. Current reviews have identified a need for a flexible set of housing packages that can deal with different level and type of needs. However providers have not yet been identified and it is recognised that the Adults and Communities Directorate needs to work with potential providers (private and third sector) to develop these packages (BCC:2010b).

Child and adult education

There are 13 special schools in Birmingham that deal with children with learning disability. In 2009, 1927 children attended these schools. The

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[119] BCC (2010b) P. 22. This move aims to reduce the number of people with learning disability not in settled accommodation (See note **Error! Bookmark not defined.**).

remaining children with learning disability were taught within main-stream schools[120].

Children's education in state and specialist schools.

In Birmingham the vast majority of disabled young people in mainstream schools with learning disabilities are supported to access work experience within a work setting.

Most young people in special schools do have support to access work experience but this can sometimes be dependent upon the complexity of their disability. There is still also a fine line between the distinction of actual work experience and work related experience.

There are no NI statistics on the proportion of children with learning disability over the total receiving SEN. However there are 2008 figures for the proportion of children in secondary school with SEN due to learning difficulties on a national (England) basis[121]. This data indicates that 44.3% of SEN children in the 13-18 age range had learning disability.

This information, in association with statistic NI 103b on the number of children with SEN may be used as a proxy to show the relative position of Birmingham compared to regional and national performance.

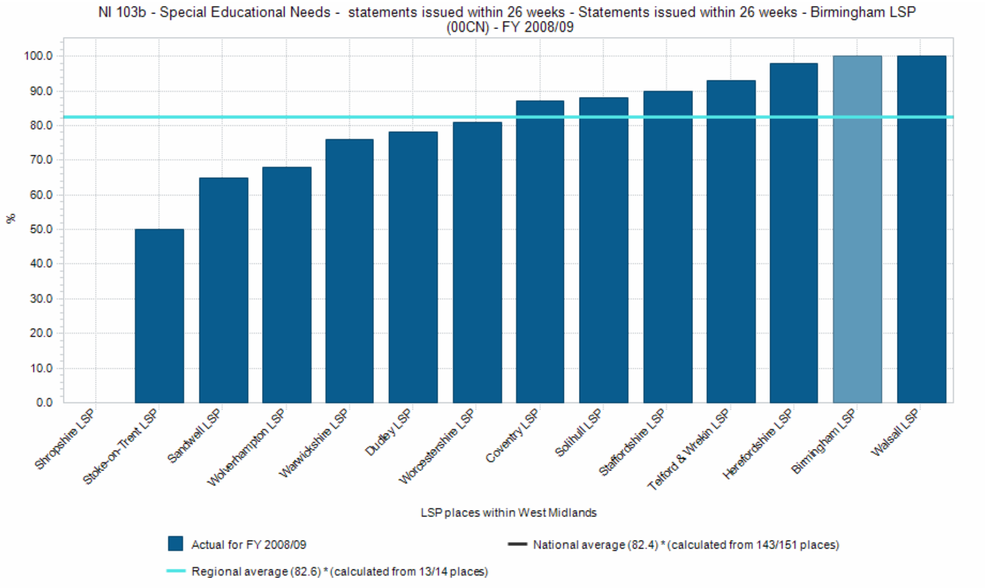

Figure 40 Percentage of SEN children (Source: Places Analysis Tool, ASCAR 2008/8009, PHIT)

Figure 40 shows that Birmingham performs very well in national and regional terms, so that young people with learning disability in Birmingham have a

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[120] Data provided by BCC in 2009.
[121] DCSF (2008), Table 9.

reasonably good prospect of a positive transition to adulthood, as far as the provision of suitable education is concerned.

Other services for young people with learning disability

Connexions Birmingham allocates named Personal Advisors to all learning institutions. In addition to generic advisers, the service has six specialist LDD Champions based in each area delivery team. LDD Champions mentor individual Connexions staff and identify and respond to local area training needs.

Tracking information about outcomes after college is an area of weakness as no one agency has the specific duty to collect data and the numbers of students involved is so large.

National information[122] based on Connexions records indicated that in June 2005 75.3% of 16 to 19 years old with learning disability were in education, employment or training, while 12.7% belonged to the NEET category.

An indirect source of comparison may be provided by statistic NI 117, showing the proportion of all YP not in education, employment or training (NEET).

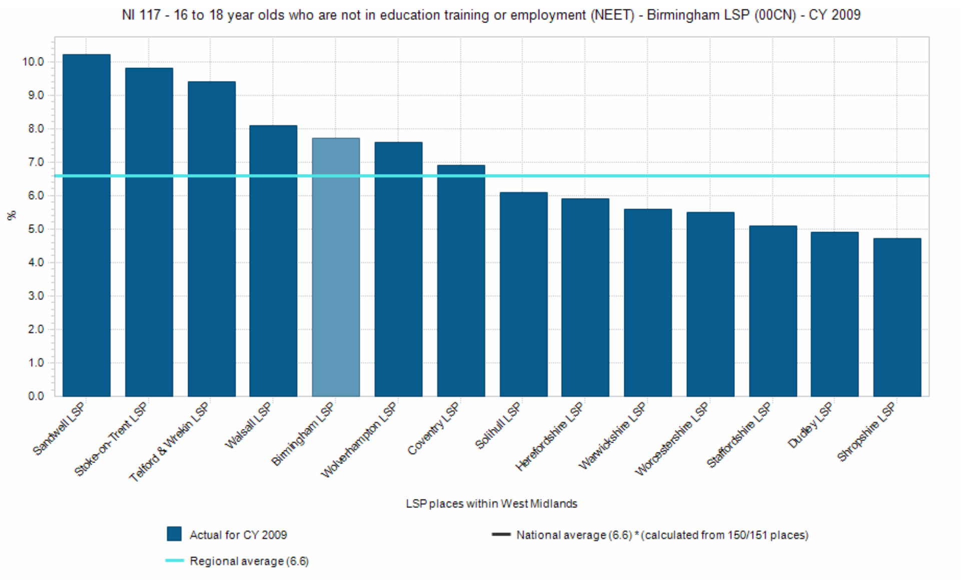

Figure 41 Percentage of 16 to 18 years old NEET (Source: Places Analysis Tool, ASCAR 2008/8009, PHIT)

Figure 41 shows that Birmingham registered a higher rate of NEET compared to national and regional figures. Within this context, young people with learning disability not actually registered with any adult services may find very difficult to hold either jobs or receive some form of training and education.

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[122] Hatton et Al (2005) p. 19. England data.

Paid and voluntary employment

There is no recent detailed data on the employment figures. National (England and Wales) evidence from the 2003/04 survey on learning disability[123] indicated that only 23% of people with learning disability had a job (17% paid and 6% unpaid).

It is very difficult to obtain an exact figure of the number of disabled young people aged 18-25 supported into employment, as there is more than one employment service in Birmingham. Some are incorporated within the local authority, others are stand-alone services and all collect information individually and differently and operate to different agendas and have differing funding streams.

Information specific to learning disability (LD) cannot be extracted from Job Centre Plus data as the category ‘disability’ covers LD, Physical Disability (PD) including visual impairment, Mental Health (MH) and learning difficulties such as dyslexia and this information is not broken down into separate categories.

It must also be remarked that the National Indicator statistic 146 (individual with learning disability aged 18 – 69 in employment) has only limited value, as it is based on the records of known people with learning disability to social services, thus reflecting only a small fraction of the total adult population with learning disability.

In general, people with learning disability in Birmingham may receive support through three agencies: Forward4Work, managed by DES, and two charities, Mencap and Rathbone. There is no available data for the services of these last two agencies. It is worth noting however that unlike Forward4Work (managed by DES) they are not bound to registration criteria, and therefore they are likely to provide their service to people with learning disability with mild and moderate LD.

Services for DES people with learning disability

In Birmingham there are a range of employment focussed services that seek to prepare people for work and remove barriers to employment. The Ability Plus identifies vacancies within the organisation that can be ring fenced for someone with a disability.

The transformation of adult day centres had also led to a number of work related enterprises developing. There are also a range of organisations that support young people once employment is secured.

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[123] Emerson et Al (2005), p.47.

Our main source of information is represented by the Disability Employment Service, who manage a variety of training and employment services for disabled young people aged 15 to 19 (but also older). Table 38 in the next page shows the trend of DES intake of Adults with learning disability in the past few years.

Fiscal Year	Female	Male	All
2005/06	16	64	80
2006/07	28	99	127
2007/08	61	188	249
2008/09	56	191	247
2009/10	29	104	133

Table 38 Adult people with learning disability registered per each Fiscal Year (Source: DES Updated records to 02/08/2010)

To date there are 384 adult people with learning disability[124] in Birmingham who are provided training, recruitment or support while being employed. The services come in a variety of formats, but they are essentially related to four types: Outsourced training, in house Training, Recruitment and support to working people to retain and develop their jobs.

Table 39 shows the breakdown of the volume of services for active People with learning disability by gender, ethnicity and service type.

Service Type	White			BME			Total
	Female	Male	All	Female	Male	All	
In House Training	45	82	127	25	47	72	199
Outsourced Training	5	5	10	0	6	6	16
Employment	11	60	71	1	19	20	91
Recruitment	32	120	152	11	40	51	203

Table 39 Service volume delivered by type of service, gender and ethnicity (Source: DES Updated records to 02/08/2010)

At present the majority of support activities are training and recruitment services. It has been noted (PHIT:2010a) that in the past few years a considerable number of school leavers have been offered placements in

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[124] DES records updated to August 2010. Active people are defined by records with “start of project” field filled in and “end of project” field empty, as indicated by DES database manager.

training colleges, so that the figures related to training services may not be indicative of the true extent of the demand for training and education, which is a sought after option by parents (PHIT: 2010a).

National indicators

The National Indicator 146 (NI 146) is the percentage of adults aged 18-64 with learning disabilities that are known to ‘Councils with Adult Social Services Responsibilities’ (CASSRs) to be employed:

1. working full-time as an employee or self-employed (16 or more hours per week);
2. working as an employee or self-employed (5 to 15 hours per week);
3. working as an employee or self-employed (1 to 4 hours per week).

Categories 1-3 above are combined to report on the employment rate for this group. This statistic is based on data provided by DES (PHIT:2010a). The percentage of adults aged 18-64 with learning disabilities that find employment is 1.5 % in Birmingham versus 2.9% in the West Midlands or 6.8% in England (Figure 42).

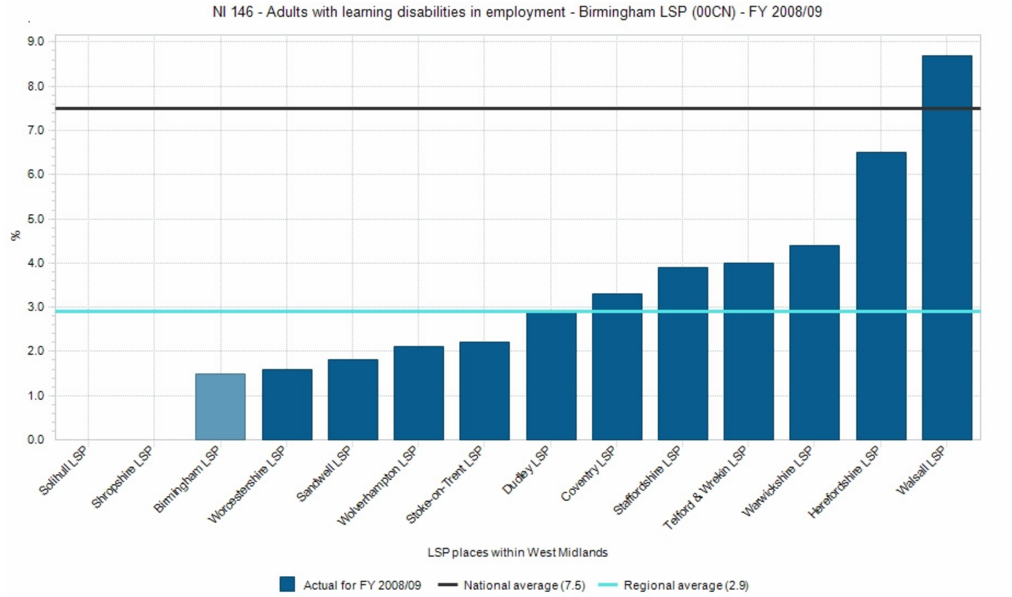

Figure 42 Percentage of adults aged 18-64 with learning disabilities in employment (Source: PAT Analysis Tool, ASCAR 2008/2009, PHIT)

Transport

In Birmingham a review of Travel Training has been completed, leaflets about travel training have been provided to families through school and the feedback from parents/carers and schools has been very positive. Birmingham Learning Disability Partnership Board has a Transport Policy linked to the Travel

Training Team, but this is only applicable once a young person with learning disability reaches the age of 18.

Centro[125], the West Midlands Integrated Transport Authority, promotes and develops public transport across the region. Free bus passes are issued to eligible disabled passengers (to be used on the whole UK bus system and if issued in Birmingham this also includes local trains and the metro).

They can approve requests very quickly for higher mobility Disability Living Allowance candidates and the more complex cases (which may require additional information by a General Practitioner (GP) can take longer. There are currently (September 2010) 14,360 people in Birmingham with active concessionary (free) passes on the grounds of a disability.

Blue Badges are issued to people with severe mobility problems and gives the individual (or the person driving the individual) permission to use dedicated parking bays and/or free on-street parking.

Between FY 2006/07 to FY 2008/09 41,157 blue badges were issued in Birmingham. The breakdown by ward shows that the rate of blue badges concession was higher than places like Herefordshire and Stoke-on-Trent but lower than places like Dudley, Sandwell or Staffordshire.

Unfortunately there is no available data on the breakdown by disability type. Therefore any estimate of the level of mobility support granted to people with learning disability would not be reliable. De facto Blue Badges concessions would be restricted to the carers of those people with learning disability who have specific neurological conditions limiting mobility (such as cerebral palsy).

With regards to concessionary bus passes, it is difficult to estimate the numbers of people with learning disability who have received these concessions which tend, again, to be linked to specific mobility issues.

Mobility allowance is paid to the client with learning disability for their sole use and they are allowed to name two drivers (a third can be requested). Drivers using vehicles for other uses are not insured. Mobility scheme offers one year free road tax.

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[125] Taken directly from the Centro website. www.centro.org.uk

Service User, Carer and Stakeholder Views

There is a body of evidence to suggest that any improvements to services for people with learning disability need to better differentiate between mild, moderate, severe and multiple conditions. These groups often have different life experiences and have different living and caring arrangements. This chapter seeks to summarise this, coming from published literature, professional, stakeholder, user and carer views.

The analysis has highlighted a number of specific challenges for the population with learning disability in Birmingham. Subsequent analysis and commissioner discussions are encouraged to:

- Ensure the process of transition from birth to childhood and then to adulthood is smooth and tailored to the family circumstances and the individuals' needs
- Design improved systems for crisis management, delayed transfer of care, and reduce the length of time to assess and provide services that address current challenges
- Improve the number of health checks and ensure earlier preventive medical interventions are in place, that are person and family centric
- Focus special attention on the increased numbers of People with learning disability with challenging behaviours and consider the impact this has on safeguarding, criminal and prison populations.

In the following sections there will be a description of best practices in the delivery of services. Following that the patterns of distribution of Adult services and the feedback gathered in the past from People with learning disability and their carers is discussed in detail. A final section will consider current estimates and projection of the population with learning disability and the implication for the planning of service to the community with learning disability.

Current perspectives on services delivery

The delivery of learning disability services differs for people at different stages of life; hence there is need to comprehensively investigate the required and suitable services that learning disabled people at each stage of their lives will need. The relevance of planning for the transition pathway for people with learning disabilities cannot be over-estimated.

Many people with learning disabilities, depending on the severity of their condition, require continuing access to a combination of support services in order to enjoy a stable and good quality of life in adulthood. As expected, a transition change to adulthood is a new dimension of life and establishes a new set of needs.

This new experience could either be positive in which case there are lots of new opportunities with adequate support services to facilitate their growth and development or it may be negative and a time full of worry especially when young people move from those who they are familiar with in a well secured accommodation where life is at its best to a lonely and unfamiliar environment or better put ‘into the unknown’.

Thus, to enhance effective growth and development and prevent the consequences of failing to plan for learning disabled people, researchers in the field have been investigating and developing care pathway models to facilitate this transition. In this section we have revised the model proposed in one review of best practices (Gordon et al.:2010) which suggested a transition pathway and services which are fit for the learning disabled people at different stages of their lives.

Besides this source, transition pathways for younger people between age 13 and 25 were also reviewed from the Birmingham City Council[126]. Essentially, this will highlight services required and offered to the younger people under the scope of the analysis.

Models for services delivery

Childhood

The childhood stage marks the beginning of a transition planning. This is an important time to prepare the young people with learning disability on what they need to know including their rights as they grow from childhood to adulthood. Transition planning starts by encouraging them to dream big about the future, and should be followed by proper planning on how to achieve and sustain their successes.

As the emphasis is on strategic prevention (Department of Health, 2009), proper planning prevents poor performance. Key stakeholders, who might be involved in transition planning include but are not limited to teachers, Special Educational Needs Co-coordinators (SENCOs), Personal Advisers, Parents and Guidance and other people like health staff and social workers. Secondary school teachers especially have significant roles to play in the transition period and currently according to Birmingham City Council1 there are over 50 secondary schools that have received this training and more are already scheduled to do so.

It was also recorded that staff from other agencies, including Connexions, Personal Advisors who work alongside schools on transition, are also trained in the Transition Pathway process. To enhance and ensure successful transition, it is thus important that the following should be taken into consideration while making the transition planning especially for the young people with a learning disability.

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[126] http://www.birmingham.gov.uk/transition

Further learning engagement at home
Ensure the provision of well-structured daytime activities after leaving school. These areas of engagement could be in further education (lessons and training at home) to fully inform them about their rights and everything else they need to know including some information they may not be comfortable to ask their teachers in school like sexuality awareness.

Health care services
Continuous specialist health care coupled with other essential supports such as social care services should be readily available

Accommodation services
Housing provision needs to be put in place to ensure healthy, stable and good quality of life. Some may still want to stay in the family house while others may be interested in living independent lives but in either case, full support must be given.

Leisure
Enjoyable leisure opportunities during the evening times and on weekends should be organised to integrate them with other people as this will promote their sense of belonging.

Entitlements/benefits
The benefits and other disability-related entitlements also need to be arranged on time especially at the early stage of their lives with appropriate authority and planned in such an efficient manner to ensure that all People with learning disability optimally and gainfully utilise the available funds for their personal growth and development.

Education on rights and career options
Essentially, this group of people should be fully supported and allowed to make important decisions about their future when it matters most. Likewise, during this transition time, key stakeholders should be involved in the planning to educate people with learning disabilities about their rights, choices of careers options, etc., to fully enable them to achieve successful transition and meet challenges in the future.

Adolescents and the younger adult
People at this stage of their lives required the following services as a measure of enhancing their personal growth and development and more importantly preventing any form of social inequality, discrimination and harassment.

Independent living support services
At this stage of life, many people with learning disabilities will prefer to be supported to live independently, thus one of the key services which must be prioritised for them is accommodation. Specialists in the field of social care have also identified direct payments as one of the main ways to encourage

independence and enable people to take control of their lives. Likewise, community equipment and adaptations play a vital role in enabling disabled people of all ages, to maintain their health and independence and to prevent inappropriate hospital admissions. Therefore, effective provision of community equipment services also has a beneficial impact on local health and social care economies.

Employment

To enhance personal growth and promote equality among the whole population, People with learning disability who are willing to get a paid job should be encouraged and supported. Although it depends on the severity of their conditions, many people with learning disabilities are not employable because they are too fragile, vulnerable and prone to risk of pre-mature deaths. Besides, they may not be able to undertake the huge daily workloads which require physical, emotional and mental wellness among others. Employment is also a key factor to encourage independence especially during these age brackets. It can help providers of services to save lots of money and also in turn make those employed financially better off.

Healthy lifestyles

Health Action Plans are a means of improving someone’s healthy living and lifestyles and should be developed for all people with learning disabilities and be reviewed regularly and more importantly prepared in consultation with the users. This helps people to get support and services that suitably meet their needs. The advantages are significant. It helps them become healthier and reduces health inequalities.

Organised health checks

Likewise, a system of organised health checks should be arranged periodically. The reality is that people with learning disabilities have greater health needs than the general population and as such these needs must be prioritised during the planning stage. It is therefore suggested that the following should be incorporated to enhance better services:

Promote and ensure that every person with learning disabilities has access to regular health screening where appropriate in order to continually identify suitable services to meet their needs

Improving communication links across services may potentially be useful in generating more accurate information about the number of persons with learning disability

Following a timely and appropriate referral to other community service providers such as specialist learning disability teams, local authority support, the voluntary sector and other primary care services, it is important to develop effective partnership across agencies to promote good health, treat any cause of ill health and prevent further deterioration. Besides, it will also help to provide useful information for planning purposes.

Adulthood

Adults with learning disability have been found to benefit from the following services.

Active involvement in social activities

Typically, people with learning disabilities have had limited opportunities to socialise, which only serves to exclude them from pursuing social and leisure activities that most people enjoy. However, we must call for a change to improve services and support that will empower people with learning disabilities to acquire the skills and opportunities that will lead to a more active social life and the chance to build new friendships and relationships.

Social networking and friendship

This is similar to the point mentioned above. Social networking is wider. Services and support should be given to help them socialise and engage in activities in their local communities, and, if possible, also beyond the local level. If given the opportunity, they should be encouraged to participate in media activities and networking.

Some people with learning disabilities may have the chance to socialise within their day centre settings. Others may only have friends that are paid to be with them, such as carers. However, in these cases, activities can be limited, with little opportunity to develop personal interests and learn new skills. This in turn impacts on the ability to acquire new skills needed to improve employment opportunities, thus improving the chance to live more independently.

Local councils may also provide specialist services designed to help foster new friendships, provide new activities, the chance to learn new skills and meet people that they might not otherwise have the chance to be friend.

Building new hopes, dreams and aspirations

It has been recognised that social opportunities for people with learning disability are restricted and can remove them even further from mixing with people of all abilities but it should not limit the extent they can aspire to be great. They should be challenged to dream big, build new hopes and aspirations like other people.

Self-care

To date, there have been moves to build upon self-directed support or self-advocacy; giving learning disabled people the opportunity to have more control over the services they receive. For instance, direct payments facilitate those with learning disabilities to access the finances that will open up more socialising opportunities for them.

Ageing and end-of-life stage

This is the last stage in the transition planning. It is essential to continue providing the required services for people with learning disability through their end of life and most importantly to check and ensure that they have been given choices.

Lifestyle support
Virtually, everyone in this category has retired from active work and there is need to organise retirement supports and other activities that will elongate their lives. A good example of lifestyle support that can be rendered is day-centre activities where both younger and the older people can relax and enjoy leisure activities and learn together. There could also be specialised activities at the senior citizen's centres; day centres etc. for the learning disabled adults and other supports for participation in the community.

Maintenance and strengthening of social networks
It is essential that each individual network is well mapped and planned accordingly to ensure people live up to their life expectations and dreams.

Promotion of health and healthy lifestyle
Similar to the provision of specialised health care services for younger People with learning disability, it is advisable to extend these services to adulthood. Suitable physical activities should be organised for the adults such as gentle exercise to combat weight problems etc.

Local voice, involvement and engagement

In Birmingham a range of mechanisms are used to capture views on services such as visits, annual satisfaction surveys, committee/forum/user meetings, compliments and complaints, telephone reviews, compliance with national care standards and audits.

In addition to the national drivers and local developments, more specific engagement takes place to consult on proposed changes and gain insight about the users' perception and satisfaction with services. The way this has been done over the last few years is summarised below.

Young people

Disabled young people are represented through direct events and activities that involve participation and consultation events. In February 2009 the Young Champions were formed, a group of young disabled people who meet twice monthly to support hearing the voices of young disabled people (BCC:2010a).

One hundred young people have completed the Bringing Everyone Together Online Survey which covers a range of questions around disability (BCC:2009b). This online survey is being carried out again using different questions created by the Young Champions.

A further 89 young people were involved in consultation around Short Breaks through questionnaires and focus groups. Another 16 people are members on the Young People Panel for the Youth Opportunities Fund with £88K awarded to 42 youth projects. Ten young people have been part of the Me2 Accreditation Framework through Sutton College and four young people have been involved in the development of revised children's guide for residential homes (BCC:2009b).

A focus group exercise was carried out with 40 young people across eight different groups[127]. The groups included young people at East Birmingham College, refugee and asylum seeking children in care, homeless young people, disabled young people, young people who are care leavers with a wide range of backgrounds and needs as well as some young people with additional learning needs. The main lessons drawn from the exercise were that:

- Their hopes and aspirations are high.
- They want to be able to do the same things as everyone else.
- They want to be economically active.
- They want inclusion in the community, a safe place to live reasonably close to an important person in their life.
- There are many examples of poor communication, poor preparation and planning across all agencies.

Parents and carers

The views of parents and carers were sought in a variety of settings and events. Four events were held using existing networks[128]. Over 160 parent carers contributed to the process. In addition, up to 100 foster carers/professionals were involved. Some parent/carers are directly involved in strategy planning groups including the Learning Disability Partnership Board – Transition Group and the Disabled Children and Young Persons Board. In summary, their views focused on:

Choice at age 11: is it real or imaginary?

The need for improved communication, preparation and planning.

Attitudes and advice of staff from all agencies are experienced as inconsistent. Information, advice and guidance services are experienced as poor, partial and sometimes contradictory.

Examples of poor communication, poor preparation and planning across all agencies.

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[127] Birmingham City Council, Sep 2008 p.9.
[128] Birmingham City Council, Sep 2008 p.9.

Another consultation exercise was carried out in connection with the joint commissioning strategy for services for people with learning disabilities 2006-2011 and beyond project. There was wide consultation to get an extensive range of views and gauge levels of support for the proposals. Over 360 responses were received and collated and analysed[129].

The findings suggested that “Staff, carers and people with learning disabilities were generally supportive, with high levels of sign up to the intentions linked to health and greater choice over places to live and how to be supported. Reservations were evident from those involved with people with severe learning disability about independent living.

There were notable concerns with commissioning intentions linked to what people do with their time, the availability of day centres and support for carers. Changes to day services attracted the highest level of comment, particularly from respondents involved with people with severe learning disability.

Comments focussed on making appropriate, supported employment more available, minimising closure of day centres and increasing the availability of short breaks for carers. Many people have expressed a wish to live more independently with or close to friends and to have a more varied set of day activities that may include attendance at a day centre. There is a strong wish expressed by carers to have more certainty, equity and flexibility with regard to short breaks”.

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[129] BCC and Eastern and North NHS PCT, Joint Commissioning Strategy for Services for People with learning disabilities, (2006) p. 15.

Appendix A: Further Analyses of Service Data

BCC service analysis

BIU service records

This section aims to show the client characteristics associated with the LD client receiving services using statistically robust models for the personal data produced by the Birmingham City Council Business Information Unit (BCC BIU). Essentially, the analysis covers seven main services which are accommodation, day care, direct payments, home care, appointment and receivership, adaptation and equipments. Each of these services was analysed separately with the key characteristics such as age, gender, ethnicity, FACS and area of residency. The findings are subsequently presented.

Accommodation services

Approximately a third of the BCC BIU people are recorded as receiving accommodation services. The proportion of male and female people receiving accommodation services is similar. Within those receiving any services from BCC BIU, accommodation is provided to a greater proportion of people in the older groups than younger people.

With regards to ethnicity, a smaller proportion of Asian or British Asian people than of other ethnic groups received accommodation. In other ethnic groups a similar proportion in each received accommodation services. There are several possible reasons for this. The analysis only considers applicants who receive any service and thus cannot make any comment on whether applicants from any ethnic groups are less likely to be given the service. Also there are a number of factors which may influence whether people apply for services including cultural values, beliefs, religion and/or individual preferences.

Interestingly, the findings revealed and confirmed different proportions of people in the Fair Access to Care Services (FACS) bands receiving accommodation services. A greater proportion of people in the ‘critical’ FACS band received accommodation services than in all of the other need groups.

Provision of accommodation service by residential location was not assessed as it could not be determined whether records reflected the position before provision of accommodation services or after. In the latter scenario the analysis would just highlight any differences in location of current provision of accommodation services rather than the originating location of people who receive these services.

To summarise the findings and implications, the results suggest accommodation services are provided to a higher proportion of those in the older and most severe FACS categories compared to the overall client group of BCC BIU. Accommodation services are provided to a smaller proportion of BCC BIU Asian or British Asian people than other groups. Finally, the results suggest that the proportions of males and females, known to BCC BIU and receiving accommodation is similar.

In this and in subsequent analyses, any differences in levels of provision of services in groups should not be taken to reflect increased chances of an applicant in any particular group receiving the services nor of different levels of provision to these groups within the overall population with learning disability as the data available is only for those receiving any service and not for all who apply for a service and are unsuccessful. However identified differences may indicate a need for further analysis if it is not a factor which should influence allocation of this service.

Day care services

About 29% of people of BCC BIU received day care services. A higher proportion of female than male BCC BIU people receive day care services. Of BCC BIU people in each age band, a higher proportion of those in the older year age bands received this service than younger groups. A lesser proportion of service users from outside of Birmingham than living inside Birmingham receive day care services. Across ethnic groups, a higher proportion of those in Asian or British Asian groups were in receipt of day care service compared to those in other ethnic groups.

FACS group was also associated with provision of day care services. A higher proportion of those in the ‘critical’ need FACS group were in receipt of day care services compared to those in any other FACS groups.

Direct payments

Only 6% of BCC BIU people received direct payments. A similar number of the males and females known to the BCC BIU service were in receipt of direct payments. A significantly higher proportion of people known to the service in the age band 18 to 24 were in receipt of direct payments than all the other older age groups.

A higher proportion of the Asian or Asian British people known to the service received direct payments compared to other groups. FACS group was associated with receipt of direct payments. A higher proportion of those classified with a ‘critical’ FACS needs received direct payments than those in the no FACS group. The proportion of those receiving direct payments was similar in each group with a FACS assessment.

An equal proportion of service users living inside compared to outside Birmingham receive direct payments.

To summarise, the analysis suggests that as a proportion of the people in these groups known to the service young adults (18-24), Asian and British Asians and those in the most severe FACS group are more likely to be in receipt of direct payments.

Home care

About 16% of people of BCC BIU receive home care. For home care service, a similar proportion of males and females known to the service receive home care. Provision of home care is also similar across different age groups of people.

Ethnicity of people known to BCC BIU is associated with receipt of home care. relevant and may be considered. The results show a higher proportion of the Black or Black British ethnic groups receive home care than other ethnic groups.

The relevance of FACS was also demonstrated for provision of this service. The proportion of people provided with homecare was higher in the group of critical FACS group People with learning disability than other groups.

Home care services were provided to a smaller proportion of service users living outside Birmingham than inside.

Appointee and receivership

Very few people were in receipt of appointee and receivership services, 4%. A larger proportion of older BCC BIU people receive appointee or receivership services in comparison to people in younger age groups. There was no difference in the proportion of male and female BCC people receiving this service. Ethnicity associated with receipt of this service. A larger proportion of those in the mixed ethnic group are in receipt of this service than in other ethnic groups.

The relevance of FACS was once again demonstrated. The analysis shows that in comparison to those in other FACS groups, people assessed as having ‘critical’ needs are significantly more likely to be in receipt of this service.
Adaptation services

As less than 1% of BCC BIU people received adaptation services, numbers are too low to robustly evaluate the effect of the majority of demographic factors on likelihood of provision of this service. It was noted that all who received this service were Birmingham residents. Also people in two of the younger age bands aged 25 to 44 were more likely to receive adaptations than those in older age groups.

Equipment services

Three percent (3%) of people known to Birmingham Social Services had received equipment services. All those receiving equipment lived within Birmingham. These services were delivered to a significantly greater proportion of males than females known to the service. Age is also associated with receipt of equipment services with the proportions receiving equipment services being higher in the older age groups. The proportion of people within the Asian ethnic groups receiving equipment services was significantly higher than in the other ethnic groups.

Findings summary

The outlined points below are the most noticeable findings from the analysis presented above:

The finding reveals the relevance of FACS in the provision of virtually all the services and thus it appears that people in the more severe need groups are more likely to receive services. The result shows that Social Services appear to be prioritising some of the services as literature review (Gordon et al, 2010) suggested.

Age, gender, ethnicity and residence have inconsistent relationships with the provision of services.

It is important to emphasise again that any differences in level of provision within the Birmingham Social Services population cannot be extended to the same demographic subgroups in the population with learning disability as a whole. This is as the data on which the analysis is based is only the subset of people who receive any service from Birmingham Social Services[130]. This dataset omits people who applied to Birmingham Social Services who did not receive any services (n=197) and thus no judgement can be made about the likelihood of people in any demographic group being allocated a service. It is also not clear whether all people are assessed for all services. Finally, the people applying to Social Services may not reflect the entire population of people with learning disability. Bearing these limitations in mind, the conclusions presented will prove ineffective if used in generalising policy actions for the whole population with learning disability however they may indicate areas which are worthy of further investigation within a dataset more reflective of the whole population with learning disability.

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[130] Source BCC BIU, sample size used for analysis stands at 3115 records of LD people.

A few service areas were not analysed due to low counts across the board for most of the explanatory variables (gender, ethnicity, age, etc.). For example, meal and respite care are part of the services BCC provides for people with learning disability. However, the beneficiaries of these services were too few to be subject to any statistical analysis otherwise the results will be too spurious and misleading. For instance, there were only 18 people receiving a meal service from the data set of 3115 people, just over half a percent. Likewise, only eight (8) people were receiving respite service. Classifying these numbers by demographic variables will provide no meaningful results.

There are interesting consistencies in the findings which are in line with the suggestions and recommendations from some literature reviews. For instance adaptation is one of the services recommended in an ideal model of service delivery (Gordon et al:2010), as it plays a vital role in enabling learning disabled people of all ages to maintain their health and independence and to prevent inappropriate hospital admissions. This service is recommended principally for adolescents and younger adults and the findings confirmed that these services are provided to a greater proportion of those in the age bands 25 to 44 compared to other older age groups.

Social care experts[131] have also identified direct payments as one of the main ways to encourage independence for the younger adults, our statistical analysis shows that direct payments are provided to a larger proportion of those in younger than older age groups.

Table 40 summarises the significant variables according to the services. Red stands for a significantly lower proportion of the group in question receiving the service compared to the reference group. Green stands for a significantly higher proportion of the group in question receiving the service compared to the reference group. Reference groups have been selected on the basis of largest overall user group except for age where the larger of the two extreme age bands, the youngest people, was selected. The analysis is based on only those in receipt of at least one service and therefore cannot indicate likelihood of receipt or not of services by group.

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[131] There is emerging evidence, for instance from the IBSEN evaluation of the individual budget pilots, that people with learning disabilities have a lot to gain from increased choice and control over their support arrangements. Support available to date has often been inadequate, unsuitable or unacceptable. The benefits of choice will be most effectively realised through greater integration of health and social care resources (Glendinning et Al:2008). However, perceptions about risk have sometimes compromised access to, and uptake of, options like direct payments (Carr and Robbins:2009). See also Glendinning et al (2009), and Jones et Al (2010).

Explanatory variables		Accommodation Services	Day Care	Direct Payments	Home Care	Appointee & Receivership	Adaptation Services	Equipment Services
Gender	Female	⬛	🟩	⬛	⬛	⬛	⬛	🟩
Ethnicity	Asian or Asian British	🟥	🟩	🟩	⬛	⬛	🟩	🟩
	Black or Black British	⬛	⬛	⬛	🟩	⬛	⬛	⬛
	Mixed	⬛	⬛	⬛	⬛	🟩	⬛	⬛
	Other	⬛	⬛	⬛	⬛	⬛	⬛	⬛
Age	25-34	🟩	🟩	🟥	⬛	⬛	⬛	⬛
	35-44	🟩	🟩	🟥	⬛	🟩	⬛	⬛
	45-54	🟩	🟩	🟥	⬛	🟩	⬛	🟩
	55-64	🟩	🟩	🟥	⬛	🟩	⬛	🟩
	65+	🟩	🟩	🟥	⬛	🟩	⬛	🟩
Residence	Outside Birmingham	🟩	🟥	🟥	🟥	⬛	⬛	⬛
FACS	Substantial	🟥	🟥	⬛	⬛	🟥	⬛	⬛
	Moderate	🟥	🟥	⬛	🟥	🟥	⬛	⬛
	Low	🟥	🟥	⬛	🟥	🟥	⬛	⬛
	No FACS rating	🟥	🟥	🟥	🟥	🟥	⬛	⬛

Table 40 Regression analysis of Adult and Community Care Services allocation to all known active people in FY 2008/09[132] *(Source: Logistic regression of BIU records of active people with learning disability in FY 2008/09)*

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[132] The analysis was based on logistic regression of client records derived from service records. Different services packages have been regrouped in seven types of services. Each client was flagged as receiving or not that class of service (1/0 binary variable). The binary variable was treated as outcome of five categorical factors, sex, ethnicity, age band, area of residence and FACS assessment. The logistic regression was run in *SPSS* (glm command, distribution family *binomial*, function link *logit*). Models were selected by means of stepwise backward regression. Some service were omitted due to the very few people receiving them.

Reference groups: Gender=Male, Ethnicity=White, Age=18-24, Residence=Living in Birmingham, FACS=Critical.

All service users receiving adaptation services and equipment services were resident in Birmingham.

Subgroups were merged if necessary due to low numbers.

🟩	Significantly higher proportion are users of the service compared to reference group
⬛	Similar proportion are users of the service as reference group
🟥	Significantly lower proportion are users of the service compared to reference group

DES service records

The services provided by the Disability Employment Service unit can be grouped in four types: in house training, outsourced training, employment related services and recruitment.

We have carried out regression analysis on these four services granted to People with learning disability using two datasets: one composed of people receiving services in fiscal year 2008/09, and one of People with learning disability who have been supported at one time or another up to 02/08/2010.

The first set provides an updated snapshot on the same time frame used for the BIU records. Due to the small amount of records available some limitation has been placed on the number and format of explanatory variables included in the model.
The second set provides an historical perspective, but any conclusion must be qualified by the fact that the quality of records may have varied overtime and that the policy and administrative procedures have also changed overtime.
Given the constraints on the data, time and resources available the modelling is fairly basic. It is aimed only to detect, if any, basic demographic factors that may influence the delivery of services. This is chiefly due to theoretical and practical constraints[133].

Active people during FY 2008/09

This dataset is composed of 242 records, with some people having been registered as early as in fiscal year 1982/83. The oldest reported client was born in 1944. We have analysed the influence of gender[134], ethnicity[135], birth cohort year (as proxy for age) and fiscal year of first registration (to account for patterns in provision of services)[136].

Table 41 summarise the finding of the analysis. Green cells highlight a positive effect; red ones, a negative one. Grey cells show no significant effect either

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[133] Ward information has not been included as it was out of date. Analysis on service records rather than client records has not been run as it requires a more advanced form of modelling requiring more time for data preparation and interpretation, as well as being very sensitive to data quality and the number of available records. The format chosen for the selected explanatory variable is also contingent on the number of available records.

[134] As a dummy variable by which male is the comparison groups (male = 0).

[135] As categorical variable using the ONS 5 categories classification, white being the comparison category, or as dummy, white being the comparison category (white = 0) and 1 being black and minority ethnic group.

[136] The latter variables have been included as banded categories ranked in order of time, i.e. lowest ranks refer to most recent cohorts/fiscal years. The reference categories refer to the lowest ranks i.e. youngest client / most recently registered.

way. Lighter colours indicate that the service and the factor are only weakly related[137].

Overall the more relevant finding is that gender and ethnicity operate in different directions with regards to the provision of training versus employment services. Female and BME people are more likely to receive training support, while they are less likely to receive employment support.

DES services	**Gender**	**Ethnicity**	**Birth Cohort**	**Intake**
In House Training	🟩	🟩	▨	▨
External Training	▨	▨	▨	▨
Recruitment	▨	▨	▨	🟩
Employment	🟥	🟥	▨	🟩

Table 41 Regression analysis of DES service allocation to all known active people in FY 2008/09[138]
(Source: Logistic regression of DES records of active People with learning disability in FY 2008/09)

This difference may be related to historical patterns, whereby only recently female and BME people have accessed DES services in greater numbers while people already in employment (mostly older and white) no longer need training.

This interpretation is indirectly supported by the fact that year of first registration (Intake) and Birth Cohort are positively related to access to recruitment and employment support. Older people are more likely to receive these types of services, while existing younger people may not yet be ready to access them.

People with learning disability supported by 02/08/2010

This dataset is composed of 851 records, with some people having been registered as early as in fiscal year 1982/83, and with the oldest people being born in 1941. Table 42 below summarises the finding of the analysis[139]. Split cells with different colours show a variable effect as the category changes.

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[137] That is, the goodness of fit of the model or the statistic test for the factors is only significant at the alpha level 0.1

[138] The analysis was based on logistic regression of client records derived from service records. Different “projects” i.e. service packages have been regrouped in four classes of services. Each client was flagged as receiving or not that class of service (1/0 binary variable). The binary variable was treated as outcome of four categorical factors, sex, ethnicity, birth cohort and fiscal year of first registration (both banded into categorical groups). The logistic regression was run in *R* (glm command, distribution family *binomial*, function link *logit*). Models were selected on goodness of fit statistics, level of information expressed (Akaike Information Criterion - AIC) and parsimoniousness (least possible number of explanatory variables. We started on saturated models (i.e. including all possible interactions) and paired the models down by considering the patterns of significance of each factors’ levels. Stepwise techniques were not used as they led sometimes to non parsimonious models with few or none significant coefficients.

[139] See note 145

DES services	Gender	Ethnicity	Birth Cohort	Intake
In House Training	🟩	🟩	🟥	🟥 ⬛
External Training	⬛	⬛	🟩 ⬛	⬛
Recruitment	⬛	⬛	🟩	🟩 ⬛
Employment	🟥	🟥	⬛	🟩

Table 42 Regression analysis of DES service allocation to all known people by 02/08/2010 (Source: Logistic regression of DES records of active People with learning disability in FY 2008/09)

As far as in house training is concerned, the results are in line with what was observed in section 0. Female and BME client are more likely to receive training services, while older people are less likely. As noted before, there is a probable generational effect that explains this discrepancy.

External training only shows a possible non-linear relationship, with older birth cohorts being initially favoured. Later cohorts do not show significant differences compared with the youngest one.

With regards to recruitment, various models have been tested and the findings indicate that older BME birth cohorts generally seem to be more likely to receive recruitment support. To an extent, the year of intake also influences positively the chance to get recruitment services, i.e. the earlier a client was registered the more likely the client is to receive a recruitment support.

The results concerning employment show that female and BME[140] people are less likely to receive support while in employment. It may be possible that for historical reasons females are still mostly taking advantage of training programmes and are not yet in paid or voluntary work, which then reduces the need of the related services allocated to female people.

Conversely, people that have been registered with DES for a longer time are more likely to receive support, which is to be expected as these people are probably already settled in employment.

Location analysis for critical people with learning disability

Figure 43 shows the people with critical needs by PCTs and where they are receiving services. HoB tPCT has the higher volume of people receiving services elsewhere.

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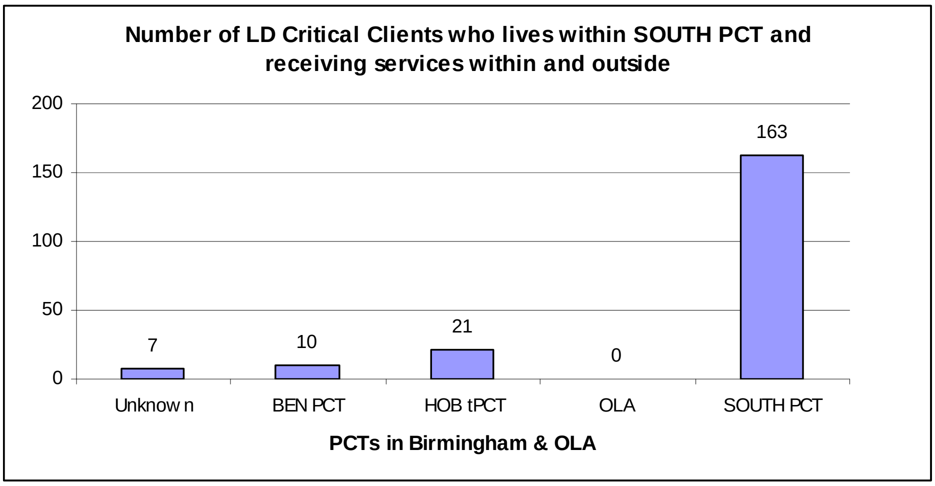
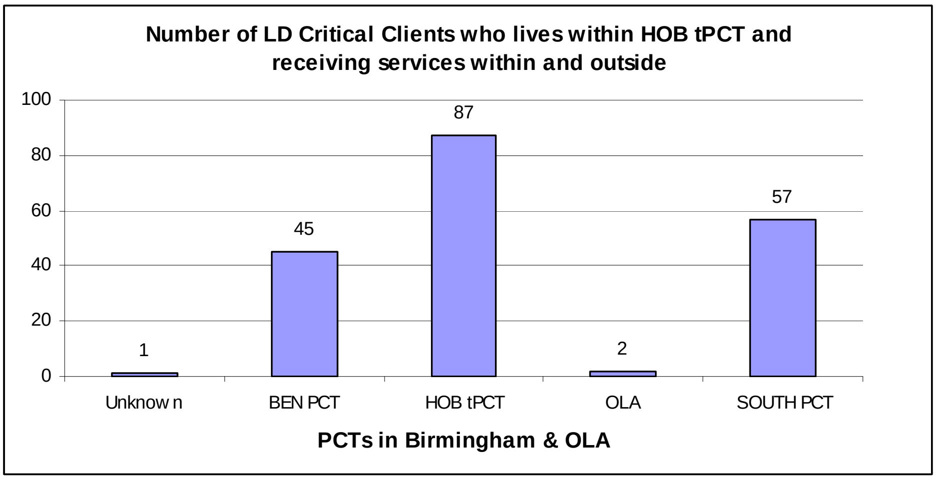
[140] The regression analysis has found a specific significant negative effect for Asian people. Also minority ethnic group have been found to be associate with a negative (albeit not significant) effect.





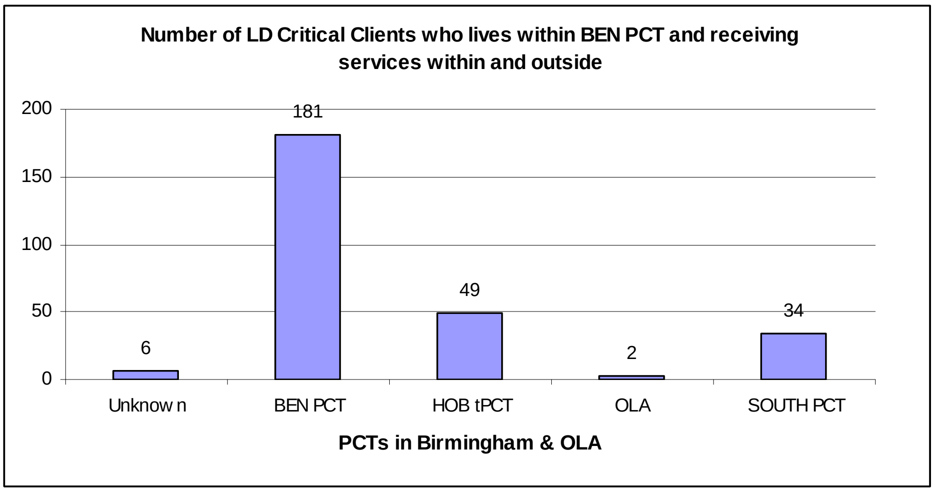


Figure 43 PCTs of residence of critical people and PCTs where they receive services (Source: BCC Business Information Unit FY 2009/10)

Table 42 shows that there are wards where services are available and the people need to travel elsewhere to receive services. It is known that people with learning disabilities can find difficulty using travel transport[141], thus it is possible that we are creating another need.

The data for the following figures has been processed to reflect changes in ward boundaries after 2004, and therefore it represents an estimate of the current situation[142]

LD Client Ward	Total	Service Centre in Ward?	People receiving services outside ward
ACOCKS GREEN	23	NO	100%
ASTON	27	NO	100%
BARTLEY GREEN	19	NO	100%
BILLESLEY	28	NO	100%
BORDESLEY GREEN	27	NO	100%
BOURNVILLE	18	YES	100%
BRANDWOOD	16	NO	100%
EDGBASTON	6	YES	100%
HALL GREEN	18	NO	100%
HANDSWORTH WOOD	14	NO	100%
HODGE HILL	14	YES	100%
KINGS NORTON	10	YES	100%
KINGSTANDING	26	NO	100%
LADYWOOD	11	YES	100%
LONGBRIDGE	14	NO	100%
LOZELLS AND EAST HANDSWORTH	34	NO	100%
NECHELLS	20	NO	100%
NORTHFIELD	19	NO	100%

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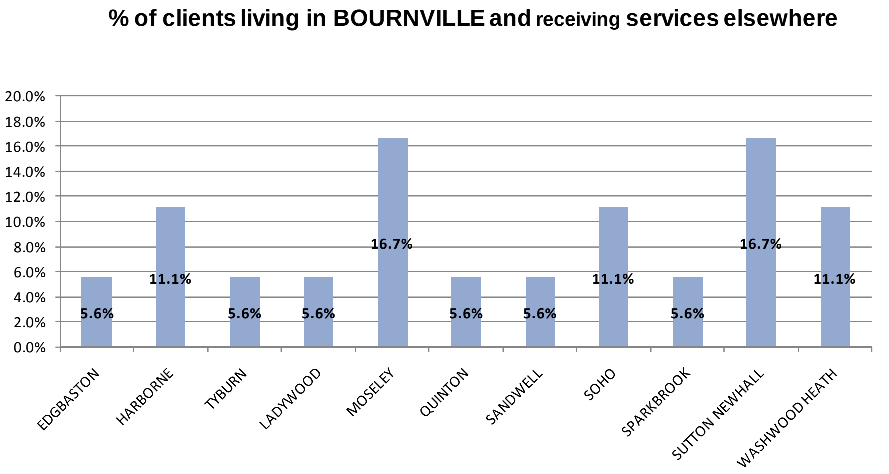
[141] About Learning Disability' website (2010).

[142] The original data has ward references still based on pre-2004 boundaries. The figures have been re-weighted in terms of the ward population, using ONS tables providing the population shifts across old and new ward boundaries. This has lead to rounding some estimate figures, so that from the count of people with learning disability has changed from 861 to 855. In the case of some wards with low counts (less than 10) figures have been rounded up to one to avoid 0 counts, by ranking estimates in ascending order and rounding up those at the top.

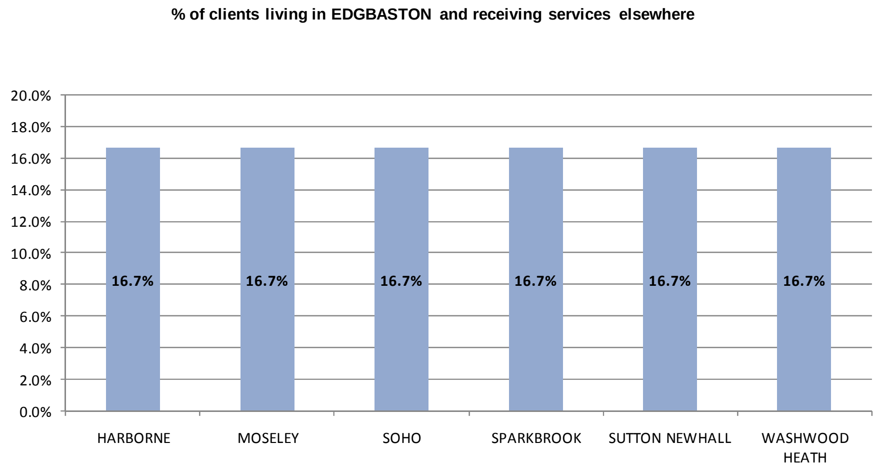
LD Client Ward	Total	Service Centre in Ward?	People receiving services outside ward
OSCOTT	11	NO	100%
PERRY BARR	11	NO	100%
SELLY OAK	14	NO	100%
SHARD END	14	YES	100%
SHELDON	14	NO	100%
SOUTH YARDLEY	42	NO	100%
SPRINGFIELD	34	NO	100%
STECHFORD AND YARDLEY NORTH	20	NO	100%
STOCKLAND GREEN	37	YES	100%
SUTTON FOUR OAKS	7	NO	100%
SUTTON TRINITY	35	NO	100%
SUTTON VESEY	14	NO	100%
TYBURN	27	NO	100%
WEOLEY	23	YES	100%

Table 43 People with learning disability by wards and services access (Source: BCC Business Information Unit FY 2009/10)

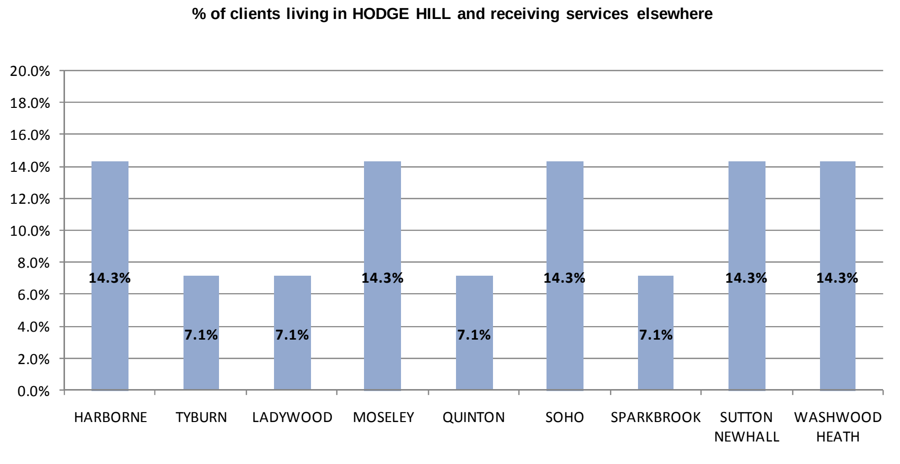
Figure 0.2 below shows those wards where there is a service centre and that 100% of the people go elsewhere to receive services. Again, this raises the question about the location of the services for critical people and the satisfaction of their primary needs. Bournville, Edgbaston, Hodge Hill, Kings Norton, Ladywood, Shard End, Stockland Green and Weoley are among those wards. It is worth noting also that one ward (Tyburn) has 96% of its people (26 out of 27) served outside its boundaries.



% of clients living in BOURNVILLE and receiving services elsewhere



% of clients living in EDGBASTON and receiving services elsewhere



% of clients living in HODGE HILL and receiving services elsewhere

Figure 44 People that need to go elsewhere to receive services (Source: BCC Business Information Unit FY 2009/10)

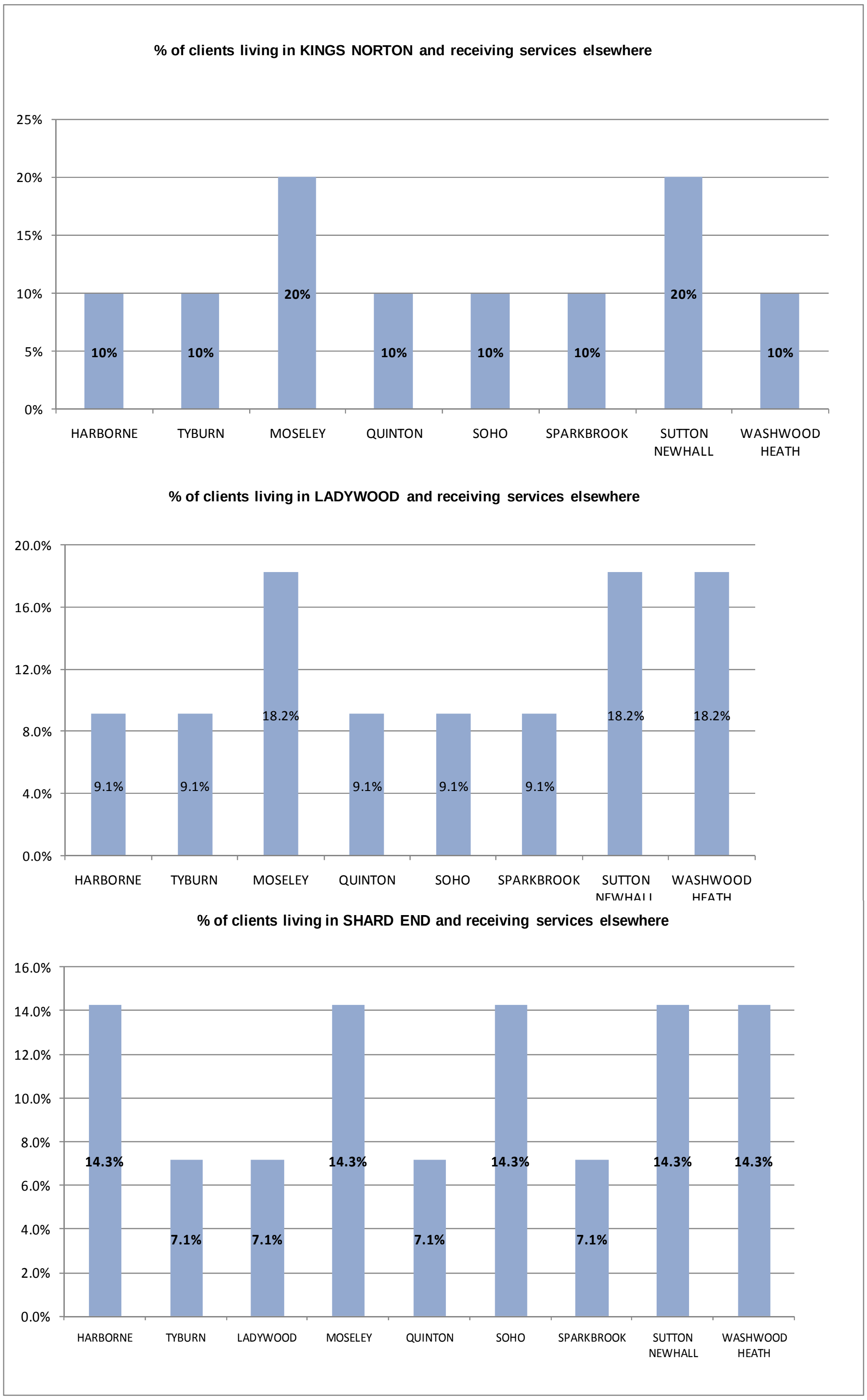


Figure 45 People that need to go elsewhere to receive services (Source: BCC Business Information Unit FY 2009/10)

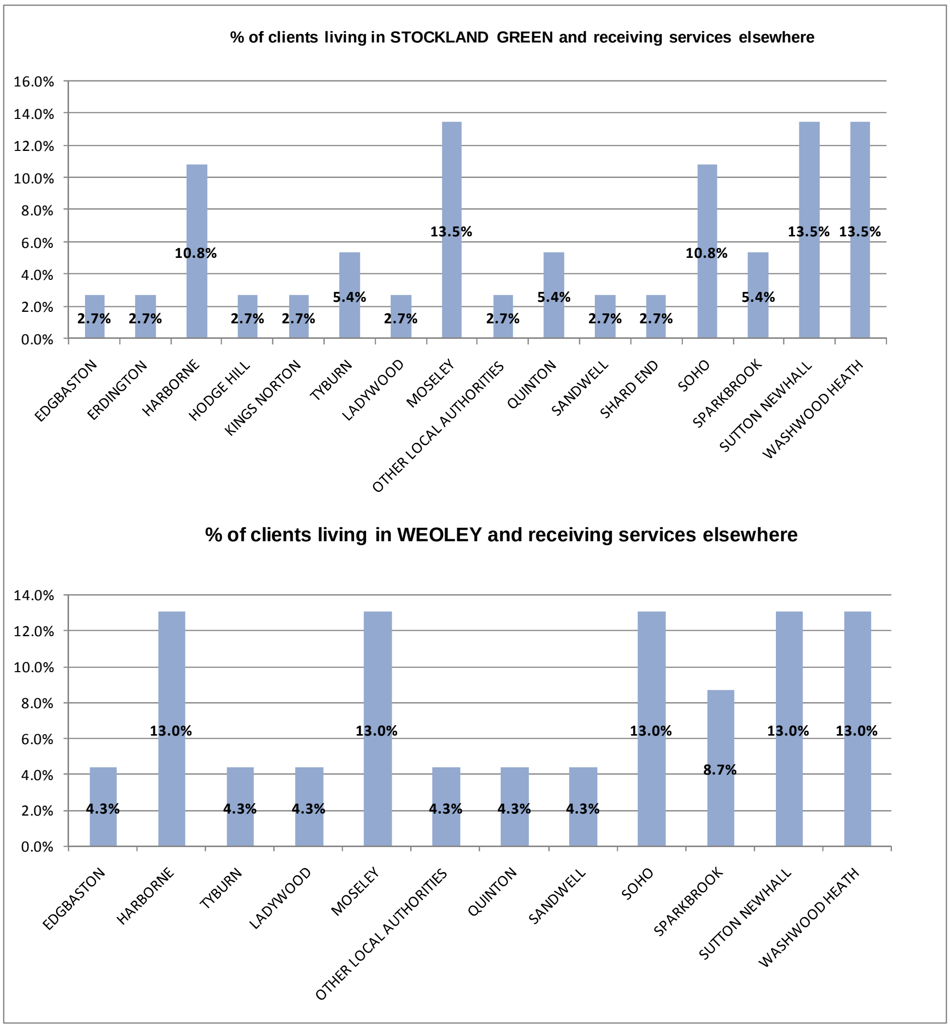


Figure 46 People that need to go elsewhere to receive services (Source: BCC Business Information Unit FY 2009/10)

A different type of analysis is illustrated in Figure 47. The location of the Day Care centres has been mapped against the geographical distance from Birmingham postcodes. Assuming an even distribution of the People with learning disability of these centres (932 individuals) in the city, the map provides an approximate measure of the ease of access by People with learning disability to the centres.

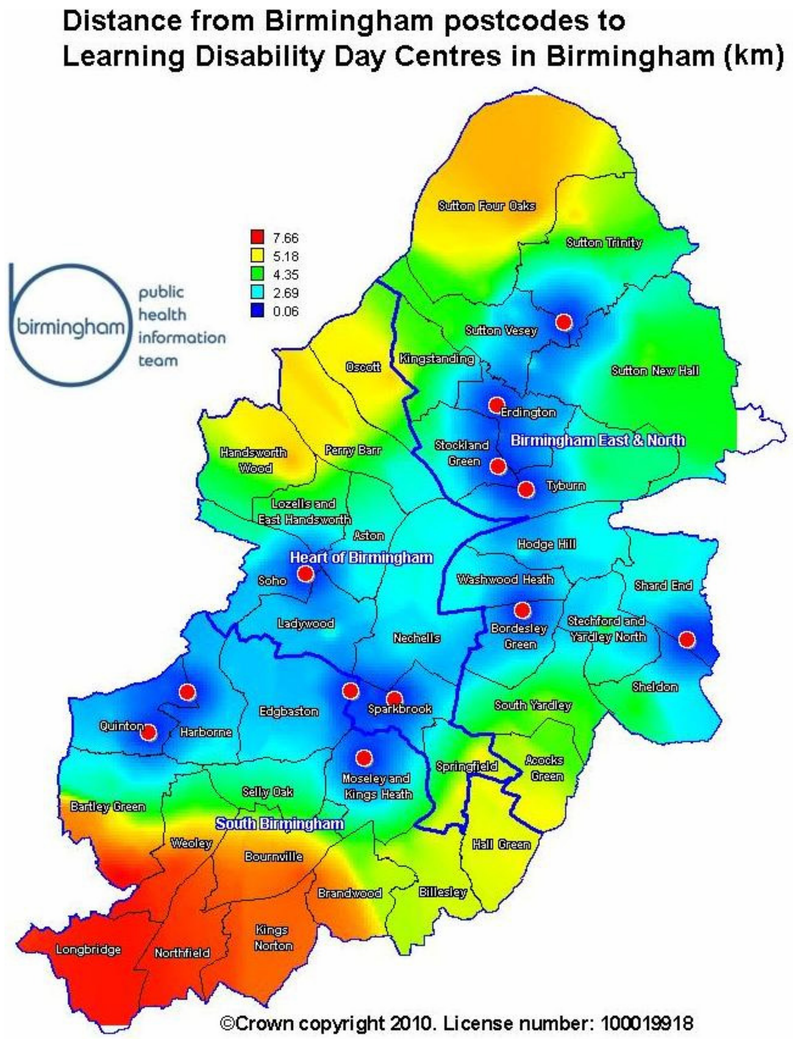


Figure 47 Distance of Learning Disability Day Centres from generic Birmingham addresses (Source: BIU, PHIT)

It has not been possible to relate directly the distance of client with learning disability addresses from the centres, nor overlay information concerning public transport facilities. With this caveat, it would be worthwhile checking whether:

The southern wards of Birmingham are adequately served by the cluster of Day centres in Quinton, Edgbaston and Moseley Kings Heath;

The clusters of Day Centres (Quinton, Mosley Kings Heath-Sparkbrook-Edgbaston, and Erdington-Stockland Green-Tyburn) are reflective of the actual distribution and needs of the people.

Appendix B: Implications of population projections and estimates

Local health partnerships have become steadily more alarmed over the last few years about spending pressures of learning disability services on health and social care budgets.

Concern was shared by the Local Government Association and led to a series of reports, and policy responses, highlighting the urgency and severity of the challenge and the need to review the current funding profile.

However the studies carried out so far have not been able to provide a coherent and detailed figure of the actual population of people with learning disability in Birmingham. The reason mostly lies in the current administrative and legal framework, which in practice is not able to capture the true extent of the population with learning disability – let alone its needs.

The following sections will discuss the current estimates and indicate some of the information bottlenecks that need to be tackled to enable the planning of services for the population with learning disability.

Population Size

The summary of the projections of the adult with learning disability population in Birmingham provides a wide spectrum of values (See Table 44). However, given the consistency of prevalence rates in the school population as indicated by SEN records in Birmingham[143], the PANSI projection provides the most reliable set of aggregate figures for current and projected estimates for the Birmingham adult with learning disability population.

Source	Population Size	Prevalence	Forecast Year	Published
JCBLD[144]	24,736	n/a	2006	2005
PANSI[145]	18,451	2.39%	2009	2009
ICD-10[146]	17,829	2.24%	2009	2010
BCC 2001[147]	5,973	n/a	2011	2001

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[143] See section **Error! Reference source not found.**.
[144] Adjusted population 18+. See note **Error! Bookmark not defined.**.
[145] See **Error! Reference source not found.** .
[146] See note **Error! Bookmark not defined.**. This estimate does not take into account people with learning disability from critical neurological conditions such as Down syndrome, Cerebral Palsy, severe form of Autism and genetic defects.

Table 44 Comparison of adult with learning disability population estimates for Birmingham. (Source: PANSI, BCC, Report Estimates)

Against this background it is useful to consider the value of the current administrative figure as a source of information on People with learning disability with more complex and severe forms of learning disability (See Table 45).

Source	Numerator	Year of Reference
BIU and DES Records	3,884[148]	2009-2010
RAP and DES Records	3,290[149]	2009
GP LD QOF Register	3,643[150]	2009
DWP	3,500[151]	2009

Table 45 Known adult with learning disability people recorded in BCC service databases (Source: Various)

The numbers recorded show a discrepancy of hundreds of individuals between Welfare and Health databases on one side and the local authority ones on the other. If the estimate based on RAP and DES records is taken and compared to the QOF figures, there are potentially 353 individuals (assuming no overlaps) that are not known as active people of BCC adult service agencies. If DES People with learning disability are excluded, the gap could raise to about 600 individuals.

If the comparison is restricted to the RAP returns (3,044), it is still reasonable to assume that up to an approximate 450 individuals (again assuming no overlaps) deemed to be eligible for DLA benefit are not at present known as people by the Adult and Communities Directorate.

A similar situation exists between the BCC databases. There are two specific examples. One concern is the lack of overlap between DES and Adult and Community Care records. The other is the inconsistency between SEN and Transition Unit records and the available figures in the BIU records.

DES and BIU

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[147] See **Error! Reference source not found.**.

[148] See **Error! Reference source not found.**. This figure assumes that all people that have been served by DES are still alive and active although they may not use DES services.

[149] This figure is the sum of the RAP returns for people with learning disability (3,044) and the DES records of active people (246) in 2008/09. This is a conservative estimate of people with learning disability that were definitively known to be alive and receiving services from BCC agencies.

[150] Adjusted figures reflecting current administrative boundaries in Birmingham.

[151] Estimate rounded to the nearest hundred of 5% population sample of DWP records.

The combined BIU records do not provide a registration date by which annual intake figures may be compared. However it is possible to make an indirect comparison between agencies' figures by looking at the size of the respective birth cohorts.

Birth Cohort	BIU	DES	DES & BIU
1985	74	38	1
1986	84	63	5
1987	88	61	7
1988	72	56	3
1989	42	29	3
1990	23	25	1
Total	383	272	20

Table 46 Birth Cohorts of BIU and DES records (Source: BCC BIU and DES records)

Table 46 shows that over the last 6 years only very small numbers of people with learning disability seem to appear both on the DES and on the combined BIU records[152].

It follows that there are potentially 272 individuals with learning disability associated to other disabilities – typically sight, hearing and mobility impairments – that are not known as people by the Adult and Communities Directorate databases if only in terms of the 'Low' FACS category people[153].

BIU and Transition Unit (TU) records.

TU has been referring approximately 80 young people (YP) with learning disability a year to Adult and Communities Directorate attention for the past 5 fiscal years. They were aged 17 to 18, and hence they were born between 1987 and 1993.

In addition to these children, TU has been referring an approximate 80 YP with learning disability aged 19 to 25 over the past 4 fiscal years. These mostly come from specialist schools. These people with learning disability were born between 1981 and 1991.

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[152] The records were matched against DOB, gender, ONS 16 ethnicity categories and wards of residence. The sets used for comparison were known DES client to August 2010 and active BIU people with learning disability to 31/03/2009.

[153] DES unit manager also pointed out that of the 200 plus records she had recently sent to BIU for the compilation of the NI 146 statistic, only few appear on the Adult and Community Care records (PHIT:2010a).

All CYP referred by TU were defined as having substantial to critical needs. Those in the YP category were also generally unable to undertake job training given the severity of their learning disability condition (PHIT:2010b).

Therefore at least an approximate 815 people with learning disability were referred by the TU to the Adult and Community Care service between FY2006/07 to 2009/10 referring to birth cohorts 1981 to 1993. Currently available BIU records shows that in effect there are only 718 existing people born between 1981 and 1991, with a possible gap of 97 individuals.

A simulation (Table 47) suggests that there is an inconsistency of numbers as far the youngest people with learning disability are concerned. The simulation considers the TU referrals in terms of birth cohorts. It is assumed that for each fiscal year the distribution across year of birth is even[154].

Birth Cohort	BIU & DES	BIU	DES	TU	TU Children	TU Young People
1989	68	42	26	54	29	25
1990	47	23	24	81	67	14
1991	6	6	0	93	90	3

Table 47 Birth Cohorts of BIU and DES records (Source: BCC BIU, DES and Children Unit (TU) records)

Table 47 shows that while the figures are consistent up to birth cohort 1989 this is no longer the case from 1990 onwards. This discrepancy does not necessarily point to ‘missing’ individuals.

However it highlights the structural weakness of the monitoring structure actually in place in Birmingham. In fact the examples mentioned above indicate that each interface between current databases (SEN, TU, DES, BIU) necessarily leads to a monitoring gap across the entire learning disability population and also within the group with critical and substantial needs.

This gap cannot be remedied with an ad-hoc solution. In fact it is not possible in practice to track a given client with learning disability from childhood through adulthood and old age because the adult care system is geared up from the perspective of the FACS Need Assessment process, which necessarily excludes the vast majority of individuals with learning disability – unlike the SEN process[155].

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[154] For example, in fiscal year 2009/10 children with LD referred by TU may be born between 1991 and 1993, as some are 18 years old during 2009 and some were 17 years old in 2010, with possible corresponding birth years 1991 to 1993. So of 80 people with learning disability 23 are assumed to be born in 1991, 24 in 1992 and 23 in 1993. A similar procedure was followed for YP figures. Figures for FY 2010/2011 are not included which would rise further the TU figures for all three years.

[155] Leaving aside confidentiality and data protection issues, which, makes impossible a timely assessment of data.

Furthermore even if the analysis is restricted to those who ‘fit’ the FACS protocol, the dispersion of data between multiple sources makes very difficult an accurate analysis of the learning disability population profile and of its needs, except by commissioning each time a collation of data which is time consuming and adds to the current workload of the Information Analysts of the BCC and PCTs.

In essence there are three bottlenecks in the existing collection system:

Registration of individuals with learning disability has to be linked to the condition and not to current needs. A needs based definition is necessarily static and misses the fact that individual circumstances may deteriorate and lead to a state of dependence that could have been otherwise prevented.

If a need based definition is to be retained in compliance with existing legislation, then the definition of need must transcend the FACS scheme (based on risk) and be extended to the right to a minimum threshold, that is registration and regular contacts by social care or voluntary sector agencies[156]. Reviewing existing self-reporting channels would also help in ensuring that current practices are learning disability ‘friendly’ and meets current needs.

The registration and monitoring function for people with learning disability must be decoupled (but not separated) from the existing service provision function.

The provision of service is necessarily unable to serve monitoring and forecasting. It collects only data on people indirectly and only in function of the service and not the served. It is restricted to those individuals with learning disability who meet threshold of need – again linked in effect to services. It is also activated only once a service has been requested – as already noted - that is only once a negative situation has arisen.

This makes prevention in fact impossible. In short, unless the two functions are separated and managed through different systems it will be very difficult to provide actionable and updatable projections of the learning disability population and its needs.

Registration of individuals with learning disability should be informed by a variety of sources and not restricted to a single source (Be it Health Care, Social Care or central Government welfare provision).

Only with a unified view of individuals with learning disability is it possible to assess current and likely future needs, including the creation of risk profiles that may prevent and delay the need for more intensive – and expensive –

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[156] Naturally only on voluntary basis.

social care interventions. Current moves in BCC to a single client with disabilities database are useful but not sufficient.

Appendix C: Rationale for recommendations

The evidence suggests that there are many other potential learning disabled people that are not yet visible to services, a proportion of which would meet the criteria for assistance. There are also a rising number of learning disabled people aged 60 or over likely to require services. This has implications across planning, monitoring, estimation, transition, service provision and especially health. Some of the recommendations we have made for commissioners are linked to these issues, and we discuss here the rationale for the five key recommendations which will address these themes in some greater detail than in the Executive Summary.

Data collection and management

The first recommendation within this theme is to consider the rationale for is to develop better way of recording, defining and tracking people with learning disability. A joint disability register where people with learning disability are appropriately flagged is a possible solution. Further information pertinent to this rationale is available above at the end of Appendix B.

At present the information collected about the learning disabled population (particularly with regard to their health status) suffers from dispersion across agencies, uneven quality, different level of coverage, and lack of comparable definition of learning disability status.

The joint register should draw data from GP surgeries QOF registers, NHS trusts and Birmingham County Council databases. However, because of current criteria of registration of identification, the register's main source should be the Statement of Educational Needs (SEN) databases, as most children with a relevant disability will be identified and assessed at some stage during the school cycle.

Because SEN status is awarded to children with learning disability from mild to moderate conditions this database is the default choice of feed for any adults with learning disability register. In this context, the planned Child disability register should be considered as a precursor and main feed for the adult disability (and hence learning disability) register.

The latest Overview and Scrutiny Report on People with Learning Disability in Birmingham (BCC:2010b) identifies a requirement for a centralised Brokerage service, whereby a dedicated office will maintain a unified view of the needs of People with learning disability, people and providers and deliver information on services and People with learning disability status to all concerned parties.

It should be considered whether the proposed Central Disability Register becomes the main tool of the Brokerage service and placed under the responsibility of this office. Brokerage services may then be provided to all learning disabled people in Birmingham in order to achieve economies of scale and greater efficiency.

Planning Process

The second recommendation is to examine the planning process in order to achieve a flexible delivery mechanism (type and volume wise).

The greatest (and not quantified) potential risk is the progressive emergence of a demand for social services from people with learning disability with mild and moderate level of disabilities, who nevertheless will require support later in life as their carers become too frail to support them or die.

At present there is no available data that can predict reliably the potential flow of people from this latter group. Therefore – at least on an interim basis – resources buffers[157] should be put in place to deal with unforeseen demand increases.
These buffers should also be able to be re-allocated across the board if they were not required in any given year. As the information on the learning disability population improves, these buffers can be minimised to deal with a smaller degree of uncertainty in the demand for services. It is important to note that Birmingham Social Services in its latest report on the needs of people with learning disability in Birmingham (BCC:2010b) recognise the need for a greater flexibility in the provision of service of people with learning disability. The increasing commissioning-led management of the budget in Learning Disabilities provision goes some way already towards this.

Transition Phases

The third recommendation is to support these improvement areas particularly as child to adult transition is critical for learning disabled people. A well supported transition to adulthood can promote self-reliance of people with learning disability and thus reduce the need for later interventions both in terms of health care and demand for support services. It will also reduce the demands on carers, thus reducing the potential demands for support from social services.

As life expectancy and the ability to live independently increase for all individuals with learning disability, more transition phases must be considered, such as:

Transition to and from secondary care following hospital admissions, and possibly moves into tertiary care.

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[157] Such as emergency funds and built-in slack in resource planning.

Transition into old age. The transition from a family context where a person with learning disability lives with their parents to one where the carer (carers) are no longer able to support their child with learning disability, to a sheltered environment where family relatives may no longer be able to stay on contact.

In general, any transition phase ought to be seen as a critical phase in the life cycle of people with learning disability and one that can suddenly lead to traumatic events, unless properly designed procedures and appropriate training for all health and social care workers involved in this phase are put in place [158].

Health prevention

The fourth recommendation is to examine the opportunity to further develop preventive health checks, apart from current HAP provisions, particularly as they relate to known co-morbidities of learning disabilities and the ethnic profile of Birmingham.
If framed within a personalisation agenda, this activity may lead to reduced demand for more intensive and individualised services. Furthermore, given the greater than expect rate of hospital admission related injuries, accidents and poisoning, it is advisable to conduct a separate and specific study on the level of risk of injury/self-harm that people with learning disability may endure in Birmingham[159].

Registration Criteria

Finally, evidence from general SEN records show how detection of learning disability can be delayed quite late depending on severity of condition. Also, the analysis of the number of registered People with learning disability known to agencies indicates that there is a vast number of people with learning disability who are not necessarily identified formally as such because their need requirements (at present) are below current threshold for notification.

In fact, at present the registration must imply a certain level of need: if the needs are light and are met via family support then some people with learning disability are virtually undetected until a crisis occurs, e.g. development of a health condition and/or inability of family to support a person with learning disability beyond a certain age.

Therefore the fifth recommendation is that the registration process must be either decoupled from needs and be based on clinical diagnosis (allowing for border line cases), or the definition of needs should be widened considerably, to enable the registration of people with learning disability who have minimal support requirements.

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[158] As discussed in sections **Error! Reference source not found.** and **Error! Reference source not found.**.

[159] See the case discussed in section **Error! Reference source not found.**.

This does not mean that the ‘Valuing People’ and ‘Valuing People Now’ recommendation of assessing people on needs should be reviewed: however, from a process management point of view, the emphasis on needs implies that many adults are not in contact with social services because their present needs do not meet currently set thresholds.

Mortality rate and epidemiological studies

A key activity of the disability register must be supporting a detailed analysis of the epidemiology of learning disability and the mortality rate for individuals with learning disability. It is only on this basis that accurate predictions on the number of people with learning disability can be produced.

What must be borne in mind is there are several conditions associated with learning disability. Each condition has a different epidemiological background and leads to different health and social pathways.

For example, as noted in chapter 0, conditions associated with severe and profound and multiple learning disability demand complex services – generally including health secondary care interventions - and are generally associated with a shorter life expectancy. Mental retardation instead does not necessarily lead to serious co-morbidities or short life expectancy. However there is a far greater risk of harm and involvement in antisocial behaviour.

A general register where people with learning disability can be followed up will enable support services to formulate appropriate predictive models to plan the appropriate support service for each group of people with learning disability and perhaps – at least for certain circumstances – start considering prevention policies.

An operational example

At a very basic level, a prime example is represented by the vast majority of people with learning disability who are not at present eligible for services under the FACS framework. Their level of risk is probably low most of the time. However a change of family circumstances, such as an illness and/or death of a family carer may suddenly turn their risk profile for the worse.

It is worth bearing in mind that in England the age profile of carers is very much skewed towards the over 65s. In fact 49% of all carers known to services (not just of those looking after people with learning disability) are aged 65 and over[160].

A general register with a regular monitoring function would enable forecast of this situation well in advance. Such prevision does not require sophisticated

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[160] DH (2010) “Personal Social Services Survey of Adult Carers in England - 2009-10”, p. 5.

analytical procedures, as age and state of health of a carer is information that can be routinely collected.

The prediction will also enable the delivery of a service package – whatever the cost - that will head off far more expensive intervention, this time within the FACS framework. A general register will also enable identification of a fairly distinct transition process that does not seem to be discussed at present, one which is related to carers and not the individual with learning disability: the transition from living with family relatives as main carers to one where parents or relatives may no longer be available and where move to a sheltered accommodation may be required.

Appendix D: Cluster analysis of FACS status of BIU people with learning disability.

The charts show the results of cluster analysis.

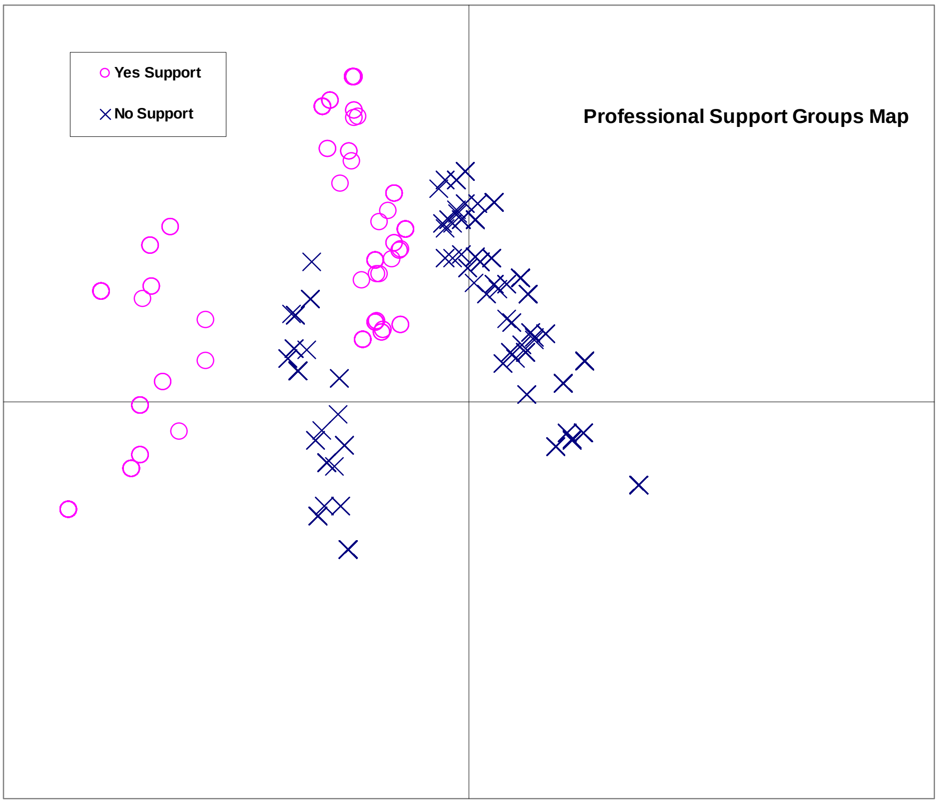

Figure 48 People with learning disability clusters by combinations of Adult Care Services delivered (Source: BCC Business Information Unit FY 2008/09)

The shapes of the clusters are indicative of further clustering hidden by the bi-dimensional display. Additional cluster analysis run separately for the two groups of People with learning disability shows (see Figure 49) that people not receiving professional support are clustered in two groups.

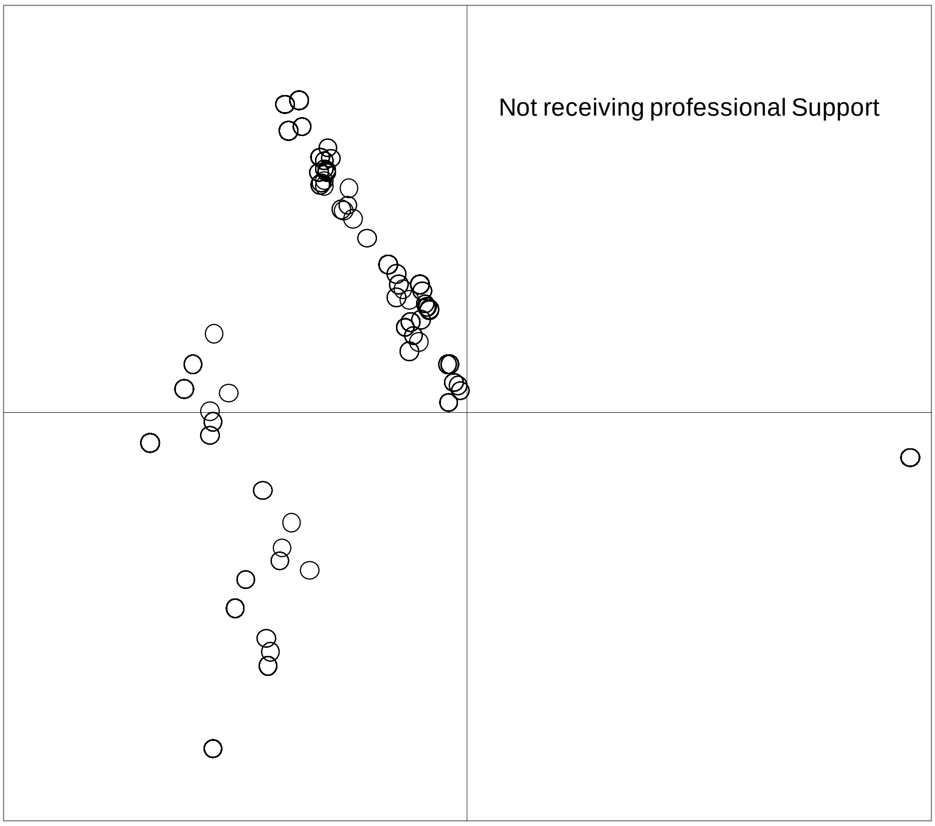

Figure 49 People with learning disability clusters by combinations of Adult Care Services delivered[161] *(Source: BCC Business Information Unit FY 2008/09)*

These two groupings are not clearly associated to either demographics or FACS classification, but they suggest the existence of two relatively homogeneous clusters of people, according to two unidentified parameters. In any case the two groups (not receiving professional support) together are mostly white (91%) and older than 65 (64%).

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[161] N = 3,115. Map coordinates generated by R Package function ‘cmdscale’. ‘cmdscale’ is a Multi-Dimensional Scaling compression function. The function does not provide confidence intervals as this is a technique that does not factor in the randomness of the data. Some of the services illustrated in the table have been aggregated (i.e. all form of accommodation; rarely provided services aggregate in ‘other’ category). The distances have been calculated with a specific algorithm (Binary method) for binary variables to reflect the format of the data available.

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