

LEICESTERSHIRE
together

LEICESTERSHIRE JOINT STRATEGIC NEEDS ASSESSMENT



LEARNING DISABILITIES

SEPTEMBER 2009

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1.2 INTRODUCTION

The term learning disabilities is a 'label' used to describe a range of different 'intellectual disabilities' which a person has acquired either from birth or in childhood. This means that the person has a permanent condition which can affect their ability to learn new things and cope with day to day life on their own. This chapter focuses on the health and social care needs of people with learning disabilities and their parents, families and carers in Leicestershire.

There are different levels of learning disabilities from mild, moderate, severe and profound which generally describes the varying degrees of help and support that a person might need. The broad spectrum of people with learning disabilities cover conditions such as; downs syndrome, profound and multiple learning disabilities with complex needs, autistic spectrum conditions, behaviour that is challenging, sensory and hearing impairment and mental ill health as well as many other conditions.

Legal and Policy Context

The Legal and policy context for people with learning disabilities is enshrined by the white papers Valuing People (2001), Valuing People Now (2009), the Carers Strategy (2008), the Human Rights Act (1998) and the Disability Discrimination Act (1995). The key principles laid down are that people with learning disabilities have Legal and Civil Rights, the right to be supported to live independently if they need it, the right to have a choice of services and the right to be included in their communities. In addition, this should include all people with learning disabilities especially those groups who are often least heard. 'Personalisation', 'Having a life', 'Housing' and 'People as citizens' are also key themes in terms of the empowerment and support for people with learning disabilities. In addition, carers play a vital role in the lives of people with learning disabilities and should be recognised and supported and seen as expert care partners.

Valuing People (2001) states that many people with learning disabilities need additional support and services throughout their lives and so they seem to have a longer and more intensive involvement with public services than the vast majority of other people. As a result, it is important to look at this population in detail.

1.2 DEMOGRAPHY

1.2.1 Data sources

Two sources of data have been used to explore the demographic profile of people with learning disabilities living in Leicestershire. The first data source is a local Learning Disabilities (learning disability) Register. The learning disability register collates epidemiological information regarding people with learning disabilities in Leicestershire. The register is created and maintained by the University of Leicester, Leicestershire and Rutland Health Care NHS Trust and three Local Authority Social Services Departments (The Unitary Authority of Leicester City, Leicestershire and Rutland). The register was set up in 1987 to provide a sampling frame for research to assist future service planning and delivery. This source provides information on real cases of

people with a learning disability who have ever been in contact with local adult services. Notification to the register is a continual process. Referrers to the register include residential care, private, voluntary, and statutory support services, as well as providers of further education, among others. When this sample is discussed reference will be made to 'known' people with learning disabilities.

The second source of data is provided by the Institute of Public Care (IPC) for the Care Services Efficiency Delivery Programme (CSED). Estimated prevalence rates and service projections are provided for adults (18-64), detailed on the PANSI.org website (Projecting adult needs and service projections) and for older people (65+) on the POPPI.org website (Projecting Older People Projection Information System). This source provides information on the number of people who in theory have a learning disability (i.e. some reduced learning capacity) but it is recognised that most have not traditionally used support services as adults. When such data are discussed reference will be made to 'estimated' people with learning disabilities.

1.2.2 Locality specific prevalence

It is estimated that 9828 adults (18-64) and 2231 older people (65+) in Leicestershire have a learning disability. There are currently 1858 known adults with learning disabilities (20-69) and 85 older people with learning disabilities (70+) living in Leicestershire (learning disability Register). Although the groups (known versus estimated) are not comparable it should be noted that there is a large discrepancy in the numbers of known and estimated people with learning disabilities. This will relate to the fact that only those who come to the attention of service providers are referred to the learning disability register. It is likely therefore that there are a large number of people with learning disabilities who are not known to service providers and are therefore not known to the learning disability register.

Table 1: Numbers of adults with learning disabilities in Leicestershire

Data source	Data type	Numbers with learning disabilities
Adults		
learning disability Register (aged 20-69)	Cases reported	1858
PANSI (aged 18-64)	Estimate	9828
Older people		
learning disability Register (aged 70+)	Cases reported	85
PANSI (aged 65+)	Estimate	2231

Table 2 shows that in Leicestershire (2009) there were 1,943 known people with learning disabilities (19 plus). Charnwood has the greatest number of people with learning disabilities (586) and Melton has the least (143). The percentage prevalence is broadly similar according to locality. However Table 2 which details the estimated numbers of people with learning disabilities based on a 2.3% prevalence rate, shows that Charnwood (3,210 people) has the highest estimated numbers of adults with learning disabilities followed by Hinckley and Bosworth (1,973 people), reflecting local population sizes.

Table 2: Number of known people with learning disabilities – Leicestershire

Area	People with learning disabilities	Total population	Percentage prevalence
Charnwood	586	134,600	0.4
North West Leicestershire	312	71,600	0.4
Hinckley and Bosworth	309	84,300	0.4
Harborough	225	64,300	0.3
Blaby	200	73,800	0.3
Oadby and Wigston	168	44,700	0.4
Melton	143	39,000	0.4
Leicestershire	1,943	512,300	-

Source: learning disability Register

Table 3: Estimated number of people with learning disabilities (aged 18+) – Leicestershire

Area	People with learning disabilities	Total population	Percentage prevalence
Charnwood	3,210	134,600	2.4
Hinckley and Bosworth	1,973	84,300	2.3
Blaby	1,729	73,800	2.3
North West Leicestershire	1,676	71,600	2.3
Harborough	1,499	64,300	2.3
Oadby and Wigston	1,050	44,700	2.3
Melton	910	39,000	2.3
Leicestershire	12,047	512,300	-

Source: PANSI & POPPI

Age

The greatest proportion of known people with learning disabilities are aged between 20 and 29 in all localities excluding Blaby where it is 30-39. See Table 4 for further details. The distribution of age across all Leicestershire localities for known people with learning disabilities is relatively consistent, peaking in all localities (excluding Blaby) in the 20-29 age group and declining from that point onwards. See Table 4 for further details. The age of known people with learning disabilities in Melton is more consistent across the 20-59 age groups than other localities. The needs of a wider age group will therefore need to be catered for in Melton when providing support services.

Table 4: Number of people with Learning Disabilities – according to age (known)

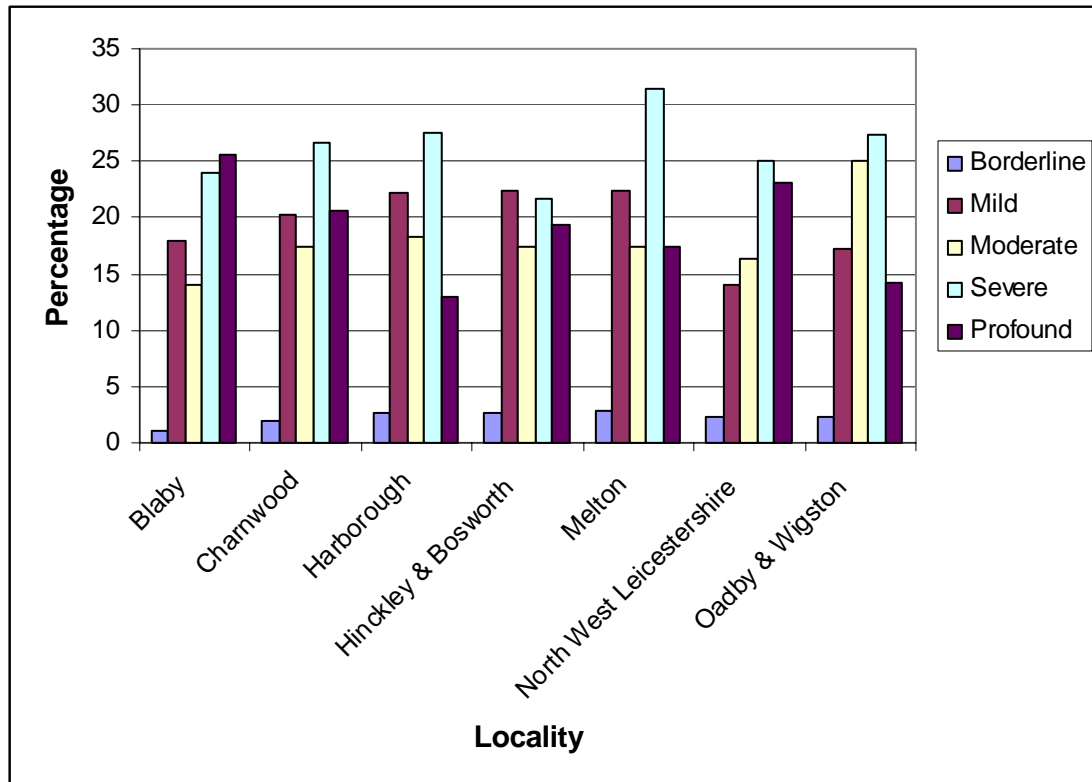
Area	20-29 (%)	30-39 (%)	40-49 (%)	50-59 (%)	60-69 (%)	70-79 (%)	80+ (%)	Total (%)
Blaby	64 (21.8)	50 (25.0)	32 (16.0)	24 (12.0)	15 (7.5)	6 (3.0)	1 (0.5)	200 (100.0)
Charnwood	128 (24.4)	139 (23.7)	133 (22.7)	93 (15.9)	56 (9.6)	26 (4.4)	2 (0.3)	586 (100.0)
Harborough	55 (32.0)	47 (20.9)	39 (17.3)	44 (19.6)	26 (11.6)	12 (5.3)	1 (0.4)	225 (100.0)
Hinckley & Bosworth	99 (25.2)	64 (20.7)	64 (20.7)	40 (12.9)	22 (7.1)	8 (2.6)	3 (1.0)	309 (100.0)
Melton	36 (30.1)	35 (24.5)	32 (22.4)	29 (20.3)	8 (5.6)	3 (2.1)	-	143 (100.0)
North West Leicestershire	94 (29.8)	70 (22.4)	69 (22.1)	41 (13.1)	21 (6.7)	7 (2.2)	2 (0.6)	312 (100.0)
Oadby & Wigston	50 (27.1)	30 (17.9)	38 (22.6)	23 (13.7)	11 (6.5)	12 (7.1)	2 (1.2)	168 (100.0)
Total	526 (27.1)	435 (22.4)	407 (20.9)	294 (15.1)	159 (8.2)	74 (3.8)	11 (0.6)	1943 (100.0)

Source: learning disability Register

Disability severity

The majority of known people with learning disabilities, in all localities excluding Blaby and Hinckley and Bosworth, have severe disabilities. However the learning disability Register represents those known to services with more severe disabilities and is not representative of everyone estimated to have a learning disability, including a high proportion with mild disabilities. See Figure 1 for further details.

Figure 1: Severity of learning disability according to locality (known)



Source: learning disability Register – using the WHO-ICD 10 definition of severity

Comparisons between known and estimated numbers of people with learning disabilities with moderate to severe disabilities (including profound disabilities) show that there are broadly similar proportions in each Leicestershire locality. See Table 5 and Table 6 for further details. Please note this is not a direct comparison, as the learning disability Register includes people with learning disabilities aged 19 and over whereas PANSI/POPPI data includes those aged 18 and over. It may be the case that there are adults with learning disabilities with moderate to severe disability in Blaby who are not receiving statutory support, and are therefore not listed on the learning disability Register. If this is the case then there may be a large number of people with learning disabilities who, with changing needs as they age, may require statutory support in the future.

Table 5: Numbers of known adults with moderate to severe disability – according to locality

Order	Locality	Frequency	% of total
1	Charnwood	379	30.9
2	North West Leicestershire	201	16.4
3	Hinckley & Bosworth	181	14.8
4	Harborough	132	10.8
5	Blaby	127	10.4
6	Oadby & Wigston	112	9.1
7	Melton	95	7.7
-	Grand Total	1227	100.1

Source: learning disability Register

Nb: All totals do not equate to 100.0% due to rounding error

Table 6: Estimated numbers of adults with moderate to severe disability – according to locality

Order	Locality	Frequency	% of total
1	Charnwood	683	26.8
2	Hinckley & Bosworth	416	16.4
3	Blaby	364	14.3
4	North West Leicestershire	354	13.9
5	Harborough	316	12.4
6	Oadby & Wigston	220	8.6
7	Melton	191	7.5
-	Grand Total	2544	99.9

Source: POPPI/PANSI

Nb: All totals do not equate to 100.0% due to rounding error

Ethnicity

In terms of the ethnicity of known people with learning disabilities in Leicestershire South West Leicestershire has an increased number of adults with learning disabilities from an Asian background (7.3%) and from a Black and African background (1.1%) compared to Leicestershire, 3.5% and 1.1 respectively. Similarly, Market Harborough has a greater proportion of people with learning disabilities from a Chinese background (1.1%) than Leicestershire overall (0.1%). See Table 7 for further details. Ensuring that the cultural needs of Asian and Black and African people with learning disabilities in South West Leicestershire, and likewise Chinese people with learning disabilities in Market Harborough, are met is essential to prevent inequalities. The ethnicity breakdown of the estimated 12059 people with learning disabilities in Leicestershire (aged 18+) is not currently given on PANSI/POPPI.

Table 7: Ethnicity of known people with learning disabilities according to locality

Ethnicity	Blaby	Charnwood	Harborough	Hinckley & Bosworth	Melton	North West Leicestershire	Oadby & Wigston	Total
Asian	9 (12.0)	40 (53.3)	3 (4.0)	-	-	2 (2.7)	21 (28.0)	75 (100.0)
Black - African	3 (37.5)	2 (25.0)	1 (12.5)	-	1 (12.5)	-	1 (12.5)	8 (100.0)
Chinese	-	-	2 (100.0)	-	-	-	-	2 (100.0)
Mixed race	0 (0.0)	9 (47.4)	1 (5.3)	4 (21.1)	0 (0.0)	4 (21.1)	1 (5.3)	19 (100.0)
White	164 (9.9)	493 (29.7)	191 (11.5)	272 (16.4)	135 (8.1)	275 (16.6)	131 (7.9)	1661 (100.0)
Other	1 (25.0)	2 (50.0)	-	-	-	-	1 (25.0)	4 (100.0)
Not known	23 (13.2)	40 (23.3)	27 (15.5)	33 (19.0)	7 (4.0)	31 (17.8)	13 (7.5)	174 (100.0)
Grand Total	200 (10.3)	586 (30.2)	225 (11.6)	309 (15.9)	143 (7.4)	312 (16.1)	168 (8.6)	1943 (100.0)

Nb: All totals do not equate to 100.0% due to rounding error

Source: learning disability Register

Accommodation

The majority of known people with learning disabilities in Leicestershire live with their parents (35.3%) followed by residential home (21.0%). See Table 8 for further details. POPPI/PANSI data regarding accommodation is not available.

Table 8: Accommodation type of those with known learning disabilities

Accommodation type	Frequency	Percentage
Parents	685	35.3
Residential home	409	21.0
Staffed home/hostel	61	3.1
Alone	94	4.8
Housing Association accommodation	70	3.6
With spouse	42	2.1
Foster/family placement/guardian	36	1.9
Unstaffed home	24	1.2
NHS Staffed Group Home	18	0.9
Other	253	13.0
Not known	251	12.9
Total	1943	100.0

Source: learning disability Register

Downs syndrome

The estimated numbers of those with downs syndrome in Leicestershire is given below. It is estimated that 5.9 per 10,000 general population will have downs syndrome. When this is applied to Leicestershire population data Charnwood has the greatest estimated numbers (68 people), due to its large population size, followed by Hinckley and Bosworth (41 people). The numbers of known people with downs syndrome is not available.

Table 9: Numbers with downs syndrome according to locality

Locality	Frequency	Percentage
Charnwood	68	27.1
Hinckley & Bosworth	41	16.3
Blaby	36	14.3
North West Leicestershire	35	13.9
Harborough	31	12.4
Oadby & Wigston	21	8.4
Melton	19	7.6
Grand Total	251	100.0

Autistic spectrum disorder

It is estimated that 39 per 10,000 of the general population will have autistic spectrum disorder. Table 10 details how many people with learning disability in each locality this would equate too.

Table 10: Autistic spectrum disorder (18-64) according to locality

Locality	Frequency	Percentage
Charnwood	1095	27.1
Hinckley & Bosworth	662	16.4
Blaby	577	14.3
North West Leicestershire	566	14.0
Harborough	501	12.4
Oadby & Wigston	340	8.4
Melton	304	7.5
Grand Total	4045	100.1

Nb: The total percentage does not equate to 100.0 due to rounding error

1.2.2 Projected prevalence

The numbers of people with learning disabilities in Leicestershire is due to increase in the future. This is due to a number of factors including:

- A growth in the numbers of young people with complex and multiple learning disabilities surviving adulthood¹.
- An increase in the proportion of younger people from a South Asian minority ethnic community².
- Reduced mortality among older people with learning disabilities.

The number of adults with learning disabilities is predicted to increase in the future by 8.3% in Leicestershire. This is an increase from an estimated 9,828 adults with learning disabilities in 2008 to 10,643 adults with learning disabilities living in Leicestershire in 2025. The predicted increase of older people with learning disabilities in Leicestershire is more dramatic at 54.3%, from 2,231 people in 2008 to 3,443 in 2025. These predictions are based on prevalence base rates which are adjusted to take into account ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). As people with learning disabilities live longer there will be a need to increase the number / capacity / range of health and social care services tailored to meet this need.

Table 11: Predicted prevalence of people aged 18-64 with learning disabilities

	2008	2010	2015	2020	2025	% increase 08-25
Adults with learning disabilities (18-64)						
England	784,084	796,141	811,173	826,056	840,499	7.2
Leicestershire	9,828	9,975	10,146	10,378	10,643	8.3
Older people with learning disabilities (65+)						
England	170,841	177,286	201,075	220,192	240,833	41.0
Leicestershire	2,231	2,368	2,796	3,129	3,443	54.3

Predicted prevalence – 18-64

There is predicted to be a small increase in the numbers of people with: learning disabilities, autistic spectrum disorder, challenging behaviour and down syndrome in Leicestershire. For those aged 18-24 there is predicted to be a general decrease in the numbers of these conditions. This reflects the overall demographic changes, e.g. predicted reductions in the 18-24 population. Table 12 provides an example of the predicted prevalence of all levels of learning disabilities. For the predicted prevalence rates of the remaining conditions: autistic spectrum disorder, challenging behaviour, downs syndrome, please see Appendix 1.

Table 12: Learning disability (all levels) – Leicestershire (18-64)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 18-24	1,678	1,717	1,660	1,558	1,595
People aged 25-34	1,770	1,872	2,184	2,266	2,194
People aged 35-44	2,384	2,299	2,068	2,197	2,528
People aged 45-54	2,069	2,173	2,362	2,286	2,085
People aged 55-64	1,926	1,914	1,872	2,071	2,241
Total population aged 18-64	9,828	9,975	10,146	10,378	10,643

Source: www.pansi.org.uk

Table 13, given below, provides a further breakdown of the projected prevalence of moderate or severe learning disabilities (ages 18-64) according to locality. For those aged 18-64 Charnwood has the greatest predicted increase in the numbers of learning disabilities people (moderate to severe disability), whilst Blaby has the least.

Table 13: Learning disability according to locality (moderate or severe) – 18-64

Area	2008	2010	2015	2020	2025	% change 08-25
Charnwood	613	630	654	674	704	14.8
North West Leicestershire	312	318	325	338	352	12.8
Harborough	276	279	283	289	297	7.6
Hinckley & Bosworth	365	369	372	381	391	7.1
Blaby	319	319	321	325	330	3.4
Melton	167	169	168	170	172	3.0
Oadby & Wigston	190	190	189	190	194	2.1
Leicestershire	2242	2274	2312	2367	2440	8.8

Source: www.pansi.org.uk

Predicted prevalence – 65's and over

For those aged 65+ with learning difficulties the predicted increase is more dramatic (than those aged 18-64), again reflecting demographic changes (predicted increases in those aged 65+). These predictions are based on prevalence rates which are adjusted to take into account age. The predicted frequency of the number of people with learning disabilities (65+) with downs syndrome and the number of people with learning disabilities with both downs syndrome and dementia is given in Table 14.

Table 14: Learning disability (all levels) – Leicestershire (65+)

Older people with learning disabilities (65+)	2008	2010	2015	2020	2025	% increase 2008-2025
England	170,841	177,286	201,075	220,192	240,833	41.0%
Leicestershire	2,231	2,368	2,796	3,129	3,443	54.3%

Source: www.pansi.org.uk

In Leicestershire it was predicted that in 2008 302 people aged 65 and over were living with moderate or severe learning disabilities. This is predicted to increase in 2025 to 447 people. For the over 65's Harborough has the greatest predicted increase followed by North West Leicestershire. This is reflective of general changes in demographics and will be true for all conditions.

Table 15: Learning disability according to locality (moderate or severe) – 65+

Area	2008	2010	2015	2020	2025	% change 08-25
Harborough	40	44	54	60	66	65
North West Leicestershire	42	46	55	60	65	55
Melton	24	26	31	35	37	54
Hinckley & Bosworth	51	54	67	73	78	53
Charnwood	70	75	87	95	101	44
Blaby	45	48	56	60	64	42
Oadby & Wigston	30	30	33	34	36	20
Leicestershire	302	323	383	417	447	48

Source: www.pansi.org.uk

1.3 FACTORS RELATED TO LEARNING DISABILITIES

1.3.1 Co-morbidities

People with learning disabilities often have increased health needs, in comparison to the non disabled population. For example, people with learning disabilities are more likely to experience: psychiatric problems (e.g. emotional and behavioural disorders), gastrointestinal problems (e.g. swallowing problems), respiratory problems (e.g. chest infections, aspiration pneumonia), orthopaedic problems (e.g. joint contractures, osteoporosis) dermatological problems, cerebral palsy, epilepsy, sensory impairments (hearing and/or visual impairments) and obesity³.

A health survey conducted in Wales showed that people with learning disabilities:

- Had a higher rate of psychiatric illness (32.2%) than the general population (11.2%)
- Had more illness than the general population (6% reported no illness compared with 37% of the general population)
- Had a 22.1% prevalence rate of epilepsy
- Had poor eyesight (19.1% of cases compared with 8% of the general population)
- Were overweight (22.8% were overweight and 23.6% were obese)⁶.

Obesity

People with learning disabilities are more likely to be overweight or obese than the general population placing them a greater risk of developing co-morbidities including cardiovascular disease, diabetes, osteoarthritis and various cancers⁷. For example, a Welsh study found that of 2240 adults with learning disabilities (select randomly) 22.8% were overweight and 23.6% were obese⁶. In Leicestershire it was found that of 1119 adults with learning

disabilities (aged 20 and over) 20.7% were obese and 28.0% were overweight. In those aged 25 and over 15% of men and 32% of women were obese. In comparison to the general population a lower proportion of men with learning disabilities were obese (15% compared with 19%) whereas a greater proportion of women with learning disability were obese (32% compared with 23%). However the study authors comment that the prevalence of obesity was lower than previous studies. This may have related to the fact that in the Leicestershire study the sample was not representative of people with learning disabilities with mild difficulties (in comparison to studies conducted previously), where the risk of obesity is higher⁴.

Epilepsy

A local study, utilising the learning disability Register, has examined the co-morbidities of those with intellectual disabilities. Intellectual disabilities were defined as moderate, severe or profound developmental intellectual impairments with associated adaptive behaviours problems and a likely need for long term support. The study found that of 2393 adults (aged 19 and over) with intellectual disability 26% (622 people) were diagnosed with epilepsy. There was no significant difference in the prevalence of epilepsy according to age, gender, ethnicity or living status (with family or independent living). A diagnosis of epilepsy was associated with a number of limitations, including limitations in daily living, walking, and social skills⁹. People with learning disabilities with epilepsy may need increased support from statutory and voluntary services.

1.4.2 Mortality

The mortality rates of those registered with intellectual disability on the Leicestershire learning disability Register have been examined locally. It was found that the mortality rates amongst those with intellectual disability were three times higher than the general population. The greatest difference in the mortality rates was amongst those in their twenties. Within this age group males and females had a mortality rate nine and 17 times higher than the general population, respectively⁵.

1.4.3 Physical aggression

A small proportion of people with learning disabilities show aggressive behaviour. A local study, in which interviews were conducted with 3065 adults known to the Leicestershire learning disability Register, found that 14% of adults with learning disabilities were physical aggressive towards others (as reported by their carers). Men with learning disability, those who were younger, people with more severe learning disabilities and those in institutional settings had a significantly higher prevalence of physical aggression. A higher proportion of those caring for people with learning disabilities with aggression (42%) said they were unable to cope in comparison to those caring for adults without aggression (10%)⁶. Support for carers of those with physical aggression is therefore essential.

1.4 LOCAL AND NATIONAL SERVICE/BENEFIT USE

1.4.1 Current use

New contacts

Between 2007-2008 there was a 7.5% increase (from 93 to 100) in the number of referrals from adults with learning disabilities. The number of referrals from older people with learning disabilities remains extremely small at eight referrals in 2008, although this was double the amount of the previous year. See Table 16 for further details.

Table 16: Assessments of new clients 2005 – 2008

	Frequency			% change 05/06 – 06/07	% change 06/07 – 07/08
	05/06	06/07	07/08		
18-64	80	93	100	16.3	7.5
65+	3	4	8	33.3	100.0
Total	83	97	108	16.9	11.3

Source: Leicestershire County Council referral, assessment and packages of care

Community based services

The most frequently provided community based service in 2007/2008 was community opportunities (67.9% of people with learning disabilities receiving the service) followed by professional support from health and social care workers (52.2% of people with learning disabilities receiving the service). Overall there has been few change in the proportions of people receiving services from 2006/2007 to 2007/2008, although the provision of home care has increased (from 14.6% to 20.2%) and the provision of professional support has decreased (from 52.2% to 27.9%). Please note however that the reporting of professional support may not be accurate due to varying interpretations of what constitutes professional support and therefore the recording of information. See Table 17 for further details.

Table 17: Community service use

Type of support	Age 18-64				Age 65 or over			
	2006/07		2007/08		2006/07		2007/08	
	Frequency	% of total	Frequency	% of total	Frequency	% of total	Frequency	% of total
Home care	139	14.6	198	20.2	24	29.6	36	42.4
Community opportunities (day care)	646	67.9	655	66.8	60	74.1	56	65.9
Meals	7	0.7	4	0.4	4	4.9	4	4.7
Short breaks (respite care)	142	14.9	164	16.7	4	4.9	3	3.5
Direct Payments	91	9.6	102	10.4	2	2.5	2	2.4
Professional support	497	52.2	274	27.9	31	38.3	15	17.6
Equipment / adaptations	72	7.6	82	8.4	8	9.9	18	21.2
Total Number of people receiving support	952	N/A	981	N/A	81	N/A	85	N/A

Source: Leicestershire County Council referral, assessment and packages of care

Residential/Nursing care

In terms of residential and nursing care the table below (Table 18) shows that the demand for, and the commissioning of Local Authority residential care decreased by -37% and -20% (from 2007 to 2008) for those aged 18-64 and 65+ respectively. The provision of nursing care has also decreased by 25% for 18-64 year olds and 33% for people aged 65 and over.

Table 18: Residential/nursing care use 2006-2008

	18-64					65+				
	Frequency			% change	% change	Frequency			% change	% change
	06	07	08	06-07	07-08	06	07	08	06-07	07-08
LA residential	44	41	26	-7%	-37%	10	10	8	0%	-20%
Independent residential	415	422	429	2%	2%	62	65	65	5%	0%
Nursing	17	12	9	-29%	-25%	5	3	2	-40%	-33%
Total	476	475	464	0%	-2%	77	78	75	1%	-4%

Nb: the year 06 refer to financial year 05/06, 07 refers to financial year 06/07, 08 refers to financial year 07/08

Source: Leicestershire County Council referral, assessment and packages of care

Direct Payments

There has been a steady increase year on year in the uptake of direct payments for adults with learning disabilities (18-64). Between April 2006 and October 2007 there was a 109% increase in the numbers receiving direct payments. See Table 19 for further details.

Table 19: Numbers of service users receiving direct payment

Learning Disability	Apr-06	Oct-06	Apr-07	Oct-07	Apr-08	Oct-08	% Increase Oct-06 to Oct-07	% Increase Oct-07 to Oct-08
Aged 18-64	55	62	75	91	101	115	46.8%	26.4%

Source: Leicestershire County Council referral, assessment and packages of care

Service projections

The table below details the predicted numbers of people with learning disabilities helped to live at home or in residential or nursing care in the future. These figures are calculated by applying the current number of people receiving support (to help them live at home or in residential and nursing care) to population projections. These projections assume that there are no changes to existing models of provision (e.g. decommissioning of residential / nursing care services and commissioning of more community based services, both of which are national expectations).

Table 20: Projections of provision for adults with learning disabilities (18-64 years)

Leicestershire	2008	2010	2015	2020	2025	% change from 08-25
Helped to live at home	972	985	1,001	1,023	1,048	7.8
Residential and nursing care	479	485	493	504	516	7.7

1.6 SERVICE USERS PERSPECTIVES

The views, wishes and future needs of people with learning disabilities and their parents, families and carers have been ascertained via a number of consultation exercises. For example, people with learning disabilities and their families/carers have been consulted regarding the development of the Short Break Strategy, the Day Services Modernisation Strategy and the Housing and Supported Living Strategy.

Short break strategy

As part of this consultation people with learning disabilities detailed their preferences for day services in the future. The preferences (in order of preference) were to have:

1. Self directed support/ individualised budgets to go on holiday with family members
2. Access to more community opportunity options (e.g. day services)
3. Monies to purchase services and/or support via direct payments
4. A befriender
5. Access to supported holidays with their friends
6. Access to more emergency short breaks
7. The opportunity to go on holiday on their own
8. A buildings based short breaks service
9. Access to a sitting service
10. More adult placement schemes

However, the preferences (in order of preference) of parents and family carers of adults with learning disabilities were to have:

1. More emergency residential short breaks provision
2. Shared holiday breaks with their family member with a disability
3. More community opportunities
4. More direct payments
5. More short breaks in a residential home
6. More holiday breaks for their family member with a learning disability
7. More holiday breaks for their family member and their friends if they wanted to go
8. More monies from the independent living fund
9. More residential short breaks in the Independent sector
10. More homebased sitting and activities services.

Day services modernisation programme

The wishes of adults with learning disabilities their parents, families and carers in relation to day services were to:

- Make day services even smaller
- Have more volunteers
- Work with support workers to have free admission to community facilities
- Have a range of activities to choose from, have more evening activities and a relaxation room
- Have more opportunities for volunteering, work, training
- Have access to more funding and monies to purchase things they want to do

The wishes of parents, families and carers were as follows:

- To have more services or community activities at the weekends and evenings
- To have more paid work and voluntary work
- To have more integrated community activities
- To have the right kind of support in the community that balances promoting people's independence and safeguarding them
- For all community opportunities (e.g. day services) to have the same standards of service
- To have a single review rather than many different reviews
- To have smaller day services
- For organisations to work together
- For adults with learning disabilities to have opportunities for real work or employment

Housing and supported living strategies

A survey examining the housing and support needs of people with learning disabilities registered on the Leicestershire learning disability Register was completed in 2004. A total of 507 forms were returned. The results from the

survey highlighted a number of needs that related to improvements that could be made to support agencies. Respondents identified a need for agencies to:

- Work closely with people with learning disabilities, their carers and service providers to increase awareness about the range of housing and support services that could be accessed or developed.
- Work with providers of care homes to enable their residents to be more aware of other housing and support options that could be considered for the future.
- Provide easily available information by locality on housing options, support and care services for people with learning disabilities, their carers and supporters.
- Develop a range of day services that enable people with learning disabilities to gain independent living skills that can form part of the support services required as mentioned in the survey results.

1.7 VALUE FOR MONEY

The unit costs presented below (Table 21) relate to the year 2007/08 [this can be updated in the backend of July for 2008/09] and are taken from the statutory return PSSEX1. The unit costs for residential or nursing care are calculated by taking the total gross cost of the activity (to the Adult Social Care Service) during the year and dividing this by the number of weeks where the bed is occupied. The unit costs of home care are calculated by dividing the total gross cost by the number of people in receipt of the service (as of the 31st March 2008). Day care unit costs and meal costs are calculated by dividing the gross costs by the average number of sessions per week and number of meals per week respectively.

When Leicestershire Local Authority is compared with the East Midlands Authorities it is evident that out of the seven authorities Leicestershire has the Fourth most expensive for residential/nursing care. The unit costs for home care in Leicestershire are the cheapest in the East Midlands. In terms of direct payments, the average amount given to Leicestershire residents is the second lowest in the region. See Table 22 for further details.

Table 21: Costs of Leicestershire service for adults with learning disabilities

2007/2008		
Client group and service	Units of indicator	Cost (£)
Residential and nursing care for adults with learning disabilities		
Residential and nursing care for adults with learning disabilities	Per person per week	£879
Nursing care for adults with learning disabilities	Per person per week	£645
Residential care for adults with learning disabilities	Per person per week	£884
Home care		
Adults with learning disabilities receiving home care	Per person per week	£67
Direct payments		
Adults with learning disabilities receiving direct payments	Per person per week	£143
Day care		
Adults with learning disabilities receiving day care	Per day care session	£41.8
Adults with learning disabilities receiving day care	Per person per week	£353

Source: PSS EX1. Return for 2007-08 version 1 – summary of East Midlands Local Authority activity.

Table 22: Learning disability service costs – East Midlands Local Authority comparison

Per person per week	Residential/ nursing care	Home care	Direct payments	Day care
	£'s			
Derbyshire	600	594	182	327
Leicestershire	879	67	143	353
Nottinghamshire	1110	575	259	349
Derby UA	917	278	148	291
Leicester UA	848	108	131	146
Rutland UA	516	-	-	313
Nottingham UA	933	198	176	372

Source: PSS EX1. Return for 2007-08 version 1 – summary of East Midlands Local Authority activity.

1.8 KEY MESSAGES

- According to the Leicestershire Learning Disabilities Register there are 1,943 adults (aged 19 and over) with learning disabilities in Leicestershire.
- Between 2008 and 2012 there are an estimated 243 people with learning disabilities coming through transitions which will have financial and resource implications for the ASCS in terms of planning ahead to meet this projected need.
- In Leicestershire in 2008 there were 4,048 people estimated to have an Autistic Spectrum Conditions. In 2008, 103 people with a learning disability and an Autistic Spectrum Condition were being supported by health and social care services. Although a small proportion of those with an Autistic Spectrum Condition will not be classed as learning disabled, the number supported by health and social care services is relatively low compared to the estimated number. Such a gap highlights that more must be done to identify and meet the needs of adults with Autistic Spectrum Conditions,, including those with Aspergers Syndrome.
- Charnwood has the greatest estimated number of people with learning disabilities and Melton has the least, probably due to its greater affluence and smaller population. The percentage prevalence is broadly similar according to each locality.
- Each area of Leicestershire is similar in terms of the ages of people with Learning Disabilities, with the majority of adults with learning disabilities being aged 20-59.
- Although a small percentage of the total number of people with learning disabilities in Leicestershire are aged 70+, in general people with learning disabilities, including those with profound and more complex needs (as with all older people) are living longer and are therefore requiring increasingly higher cost support services for longer into their old age, which has significant financial and resource implications in terms of future planning.
- The total number of people with a learning disability in Leicestershire is predicted to increase by 8.3% between 2008-2025. Although a large proportion will not require formal support, the increase in numbers has a financial and resource implications for the future planning of health and social care services.
- Preventative support - due to the increased risk of people with learning disabilities developing co-morbidities there is a need to ensure preventative services such as screening programmes and healthy eating programmes are available to this group of people. Furthermore, due to the

estimated large number of people with learning disabilities living in Leicestershire unsupported by statutory services, ensuring that preventative programmes are easily accessible and that health needs are detected early is not only important for people themselves, but also a cost effective approach.

1.9 FUTURE SERVICE AREAS

Preventative services

Due to the increased risk of people with learning disabilities developing co-morbidities there is a need to ensure preventative services (such as screening and healthy eating programmes) are available to this group. Due to the estimated large number of people with learning disabilities living in Leicestershire unsupported by statutory services, it is essential that preventative programmes are easily accessible and that health needs are detected early.

Personalisation of services

The introduction of the personalisation agenda aims to promote choice, control and independence. This will be achieved throughout the provision of social care support, using assessment, individual budget allocation, support planning, and individual and strategic commissioning of services and support. In order to ensure this process is accessible to people with learning disabilities, care will need to be taken in the development of information, tools, resources, support planning and brokerage services. It is an expectation of the white paper *Valuing People Now* that all the work to develop systems of self-directed support involves people with learning disabilities in the design, development, planning and delivery of support.

Person centred planning

Ensuring that people with learning disabilities are supported to develop a person centred plan is a key policy objective for 2009-10 in *Valuing People Now*. This is a key expectation when considering:

- Self-directed support.
- The development of housing and support opportunities.
- Daytime, evening and weekend activities.

The value of person centred planning is also emphasised as being particularly effective for people with high support needs. All providers need to ensure that people who choose to have a person centred plan are supported to develop one. Consideration also needs to be given to ensuring greater access to person centred support planning for all people with learning disabilities, not only those attending day services. Systems need to be established through which information from person centred support plans can be aggregated to inform service planning, design, development and delivery and utilised to inform commissioning priorities.

Community opportunities

Nationally there has been a greater emphasis on provision of individualised and flexible services. The aim of such services are to support people in developing their capacity to do what they want; help people develop social skills and the capacity to form friendships and relationships with a wider range of people; enable people to develop skills and enhance their employability; help communities welcome people with learning disabilities.⁷ Locally a day services modernisation programme continues to develop small local activities and opportunities for people, where possible meeting in places shared with the local community. To support this, greater use needs to be made of public transport, including travel training to enable people to develop the skills to travel independently.

A clear plan is needed to ensure that all people with learning disabilities who want to work have access to the support required. Currently, JobCentre Plus does not provide the focussed and sustained support needed for this group of people. Work is also necessary with employers, raising their awareness, challenging their misconceptions and promoting the benefits of employing people with learning disabilities. This all needs to be supported by strong welfare rights support, to overcome the benefits concerns and potential financial costs of working over 3.5 hours per week. Opportunities for social enterprises, based on the unique skills and abilities of people with learning disabilities should be developed to provide real employment in a supportive setting.

Advocacy services

One way for people to have more choice and control is for people to be able to speak up for themselves or have support to speak up if they find this difficult. The learning disability service needs to ensure that there are a range of advocacy services that are as accessible as possible, and raise the awareness of the benefits of advocacy that will deliver positive outcomes for people.

Supporting carers

Valuing People Now and the national carers' strategy⁸ highlight the importance of providing carers with accurate, timely information, in order to support decision making, choice and control. The emergency respite service should be widely promoted to ensure it is as effective as possible. The national Valuing Families forum have stated that identifying and meeting the needs of older carers and carers from Black and Minority Ethnic communities are priorities for 2009-10, along with people with learning disabilities who are carers.

Settled accommodation and support

National information has shown that local authorities using a greater proportion of available funding on residential and nursing care, as opposed to supported living, spend more and achieve less good outcomes.⁹

Leicestershire has a high proportion of people in residential care. A clear plan is required to make the shift towards supported living, including working with

people with learning disabilities and their families to increase their awareness of housing and support choices, and development work with support providers, district councils and housing associations to increase capacity.

Transitions

Young People with learning disabilities and their parents, families and carers often find the transition into adulthood very stressful and difficult. The need for continuity of support and care for the young person and their parents, families and carers is essential as well as their need for moving into education, training, and employment opportunities. In Leicestershire we estimate that between 2008 and 2012 there are approximately 243 (source: Data from County Wide Transitions Team) people with learning disabilities coming through transitions from children's services to adults services, which will have financial and resource implications for Adult Social Care Services in terms of planning ahead to meet this projected need. We also estimate that of these approximately sixty people are likely to have an autistic spectrum disorder and less than 10% of people coming through transitions will have profound and multiple learning disabilities and complex needs.

Autistic Spectrum Conditions

People with autistic spectrum conditions are often the least heard and most vulnerable people with a disability in our society. They have poor access to health and social care, education and employment opportunities, housing and transport. In addition, they are increasingly more likely to suffer from mental ill health. They have a spectrum of conditions which are mainly around communication, social interaction and behaviour which can often be repetitive and challenging. The autistic spectrum covers people with Autism, Asperger's Syndrome and people with Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS). In Leicestershire in 2008, there were approximately 4,048 people estimated to have an Autistic Spectrum Condition. Not all of these people will have had a learning disability but there were approximately 103 people with a learning disability who also had an autistic spectrum condition. The numbers of people with autistic spectrum conditions are likely to increase and identified early as medical knowledge, diagnosis and our understanding of autistic spectrum conditions increases. We need to better understand the numbers of people with an autistic spectrum condition coming through transitions so that we can better plan services for the future.

People with profound and multiple learning disabilities and complex needs

People with profound and multiple learning disabilities and complex needs are again some of the most excluded and disadvantaged people in our society. They are likely to have complex health and social care needs. These range from physical and mental health problems to problems with mobility, epilepsy, vision and hearing impairment, communication, continence, nutrition, hydration and weight problems as well as dysphagia and other types of respiratory problems. As more and more children and young people with profound and multiple learning disabilities and complex needs are surviving into adulthood the need to understand the exact numbers projected to come

into adult services and their specific needs will be crucial in order to better understand and plan for services for these vulnerable people in the future.

Downs syndrome and dementia

Due to advances in medical knowledge, technology and health and social care there has been a reduction in the mortality rates for people with learning disabilities and as more and more people with learning disabilities are living longer they are at an increased risk of developing dementia. The prevalence rate of people with Downs Syndrome is 16% in Leicestershire. Melton has the highest (21%) and North West Leicestershire has the lowest (11.9%). Most people with Downs Syndrome in Leicestershire are in the 35 to 44 years of age (61) followed by the 45 to 54 years of age (56) and then the 55 to 64 years of age (53). The lowest number of people with Downs Syndrome is in the 18 to 24 years of age (39). This tends to confirm that people with Downs Syndrome are living longer and their likelihood of suffering from dementia is likely to increase.

1.10 References

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Appendix 1: Predicted prevalence of learning disability and related conditions - adults 18-64 (Source: www.pansi.com)

Learning disability – moderate or severe (18-64)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 18-24	384	394	384	363	377
People aged 25-34	380	402	469	487	472
People aged 35-44	598	577	520	552	636
People aged 45-54	465	489	531	513	470
People aged 55-64	417	413	406	451	485
Total population aged 18-64	2,244	2,275	2,310	2,366	2,439

Autistic spectrum disorder (18-64)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 18-24	617	632	613	577	593
People aged 25-34	711	752	877	910	881
People aged 35-44	975	939	842	892	1,023
People aged 45-54	894	937	1,012	973	883
People aged 55-64	851	846	825	911	986
Total population aged 18-64	4,048	4,106	4,169	4,263	4,366

Challenging behaviours - Leicestershire (18-64)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 18-24	15	15	15	14	14
People aged 25-34	17	18	21	22	21
People aged 35-44	23	23	20	21	25
People aged 45-54	21	22	24	23	21
People aged 55-64	20	20	20	22	24
Total population aged 18-64	97	99	100	102	105

Downs syndrome – Leicestershire (18-64)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 18-24	39	40	38	36	37
People aged 25-34	44	47	55	57	55
People aged 35-44	61	59	53	56	64
People aged 45-54	56	59	63	61	55
People aged 55-64	53	53	52	57	62
Total population aged 18-64	253	257	261	266	273

Appendix 2: Predicted prevalence of learning disability and related conditions - older people 64+

Downs syndrome – Leicestershire (65+)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 65 and over	4	4	5	5	6

Downs syndrome and dementia – Leicestershire (65+)

	Leicestershire				
	2008	2010	2015	2020	2025
People aged 65 and over	1	1	1	1	2