

**A review of the Incidence and Prevalence of Learning
Disability and Effective Health Care in East Sussex**

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Learning Disabilities in East Sussex

Executive Summary

Learning Disability data collection is poor. It is not possible to establish exact incidence or prevalence of learning disability because of differences in classification and incomplete coding at NHS service provision level. Data is available on the numbers of people known to adult social care and children's services, but these do not reflect the true prevalence of learning disability. Prevalence is age specific for a variety of reasons, including changes in patterns of mortality, and the effect of gender and ethnicity.

Because of increased longevity amongst people with learning disability and an increase in the numbers of older people in the general population we expect to see numbers of older people with learning disability increasing at both a national and local level. Another unpredictable factor that will influence population growth is increased migration to the South East. Using population estimates we might anticipate a local increase of 10% in numbers of service users by 2011, measured from a 2001 baseline.

Information about children is contradictory. Numbers of children and young people are predicted to drop in the ESCC area to 2026. The rise in numbers of young people aged 10 – 19 locally seen over the last five years will gradually drop back from 2011 onwards. To counteract this, there is anecdotal evidence that young people with more severe and complex needs survive longer into childhood and young adulthood.

The numbers of children with statements of special education need in the area over the last seven years has been fairly steady, with a slight downward trend. The areas of definitive growth are the numbers of children with a diagnosis of Autistic Spectrum Disorder, and a new category (since 2004) of profound and multiple learning disabilities. If there is a real growth in need in the local population of children, the question arises about the numbers of children being assessed but not receiving a service.

Health service data about numbers of people with learning disability and levels of activity is very poor. Primary Care registers are promising and will increase access to services including screening. Child health records are incomplete, as are death certification and hospital episode statistics (HES). Accurate HES data is important as it could be used to monitor access and outcomes for the many conditions that people with learning disabilities are most susceptible too, including gastro-intestinal cancers, diabetes, and epilepsy.

Learning Disabilities in East Sussex

Evidence of effective health care and other interventions

The evidence base for most interventions is weak with the exception of work on challenging behaviour, supported employment and some pharmacological interventions. There is much evidence to suggest that overall health status of people with learning disabilities is poor and that this is exacerbated by poor access to health care services.

The areas where local attention should be focused include:

- Monitoring health improvement outcomes from health action planning (from QOF data), with particular reference to common health problems (Appendix 1 of literature review)
- Improve uptake of cervical screening and mammography
- Improved information sharing between agencies
- Increase service user evaluation of health care
- Staff training in learning disability – from medical and nursing school to continuing professional development for health professionals
- Planning services for older people with learning disabilities, including planning for old age for people with Downs from age 40, and from age 50 for others
- Improved retirement and bereavement counseling
- Investigate local palliative care services
- Mental health - access to services and in particular monitoring the relationship between schizophrenia and bowel cancer
- Transitions planning: improved information to service users, parents and carers

Learning Disabilities in East Sussex

Introduction

Learning disability (LD) is a descriptive diagnosis or concept, not a disease or illness, and it does not infer a particular aetiology. Social functioning is an integral part of the diagnosis.

Classification of intellectual disability is a complex and confused area. There is still little agreement on terms or classes. An international system of classification has existed since 1980 (and was reviewed in 1995), the ICDH-2, but this is not widely used for data recording. This confusion may be partly responsible for the difficulties in establishing the prevalence of learning disability.

Prevalence in adults, older people and children

The reported prevalence of LD of any variety varies substantially across studies. The WHO estimates prevalence in industrialised countries to be around 3%. The Department of Health estimate varies in different documents between 3.5 per 1000 and 4.3 per 1000 for severe learning disability (SLD) and 2.5% for mild learning disability (MLD).

One study¹ gives the prevalence rate in Western countries for 'severe mental retardation' (IQ < 50) as 3 – 4 per 1000 population. This study estimates prevalence of 'moderate mental retardation' (IQ > 50 < 70) at 30 per 1000. Using this measure, a typical District of 250,000 would have 750-1000 people with severe mental retardation. 25 – 40 of these would have severe behavioural problems. This estimated prevalence is based on a 1995 review of population studies carried out between 1960 and 1981, and the studies focused predominantly on young adults and teenage children. A 1985 review estimated age specific ratios of 5 per 1000 as not uncommon for older children and young adults².

According to the Institute of Neurology, Neuroscience and Psychiatry at Newcastle University, statistically the prevalence of people with IQ < 70 should be 2.5 % (2 standard deviations from the mean). This is however the prevalence of mild intellectual impairment, rather than mild learning disability. In reality the prevalence of MLD is 1 – 2% due to:

- Higher mortality amongst the most severely disabled
- Diagnostic changes over time – more people are being diagnosed now as LD

¹ Roelvelde N, Zielhuis GA, Gabreel F The Prevalence of Mental Retardation: a critical review of recent literature. *Developmental Medicine & Child Neurology* 1997; 39 (2): 125-32

² Fryers, T : Handicap due to Intellectual Impairment. Oxford Textbook of Public Health Vol. 4 OUP 1985

Learning Disabilities in East Sussex

- The role of functioning – those with an IQ < 70 but who function normally socially would not be classified as LD³.

Similarly, there is evidence that prevalence of severe learning disability is age dependent, because of a combination of lack of diagnosis in early years, a higher than average mortality rate for older people with SLD, flaws in registers and different research methodologies in different studies.

The male to female ratio of SLD indicates 20% excess in males. There is an excess of 1.4 – 1.8: 1 males: females for mild learning disabilities. There appears to be a positive association between mild learning disability and lower socio-economic group, which may be accounted for by poor environmental & social factors, less access to health care and exposure to toxins.

To summarise, there can be no single measure of prevalence.

Evidence of trend

It is thought that incidence and prevalence of LD increased up the mid-1960's, with decreases into the 1980's albeit to a level that was still twice that of the 1960's. A complex series of changes have impacted on rates, some increasing incidence and prevalence and some decreasing. These changes include

- An overall decrease in the numbers of children since the late 1960's
- The impact of oral contraception on conceptions in older women
- Antenatal screening for Downs, amniocentesis, & selective termination
- Availability of neonatal care & subsequent decrease in mortality
- New technologies – anti-convulsants and advances in surgery
- Immunisation programmes decreasing encephalitis, encephalopathies, and rubella associated prenatal damage

UK birth cohorts are therefore of differing size, meaning that as each cohort ages their age specific prevalence varies. Currently individuals in the largest cohort are probably in their early to mid-forties.

Given the above, an exact picture of trend is difficult. Emersen and Hatton⁴ however have estimated the increasing numbers of adults

³ IQ is an easily quantifiable way of classifying learning disability but there are problems with it. IQ varies during development, and IQ does not capture social functioning, motor and verbal skills, or individual strengths and skills.

⁴ Pressures on Learning Disability Services: The Case for Review: produced for ADSS October 2005

Learning Disabilities in East Sussex

with learning disabilities to 2021. Nationally they predict a 22 % increase on the 2001 baseline figure in numbers known to services, and a 22% increase in true prevalence of LD (including Asperger's syndrome), adjusted for increasing survival, increasing ethnic diversity⁵ and decreasing mortality⁶.

The increase in numbers is considered to be most significant in the older people age groups. As the population of older people in the country increases, so do the numbers of people known to services, as well as the true prevalence of learning disability. This is evident in the following table, taken from Emerson & Hatton's work for the Association of Directors of Social Services (2005).

Table 1 Estimated Percentage Increase in Numbers from 2001 (national)

Known to services	2011		2021	
	Unadjusted	Adjusted	Unadjusted	Adjusted
20 – 59	4%	7%	4%	8%
60 – 79	20%	36%	41%	59%
80+	21%	58%	35%	95%
Total	6%	12%	9%	22%
True Prevalence	2011		2021	
	Unadjusted	Adjusted	Unadjusted	Adjusted
20 – 59	4%	8%	3%	9%
60 – 79	19%	41%	37%	62%
80+	16%	56%	37%	95%
Total	7%	16%	11%	22%

There is anecdotal evidence to suggest marked increases in the rates of survival into adulthood of children with severe and complex disabilities. There are few data to substantiate these claims.

Emerson & Hatton estimate an increase of 5% in children known to services and 7% in true prevalence, in the 15 – 19 age group, to 2011. This estimate is taken from studies of one local authority case register only and it is not clear to what extent this register is representative of other areas.

⁵ Significantly higher prevalence of learning disability is reported amongst South Asian, black and other minority ethnic groups where the demographic profile is skewed towards younger age groups due to past patterns of migration (Emerson & Hatton: ADSS October 2005)

⁶ Emerson & Hatton's work is largely based on local case registers in Leicestershire, where there are higher numbers of south Asian population than in the ESCC area. This may affect their estimate of prevalence as their figures reflect a growing ethnic minority population which may not be appropriate for the ESCC population.

Learning Disabilities in East Sussex

Applying estimates to ESSC population

Figure One Interim Population Projections for Residents of East Sussex⁷

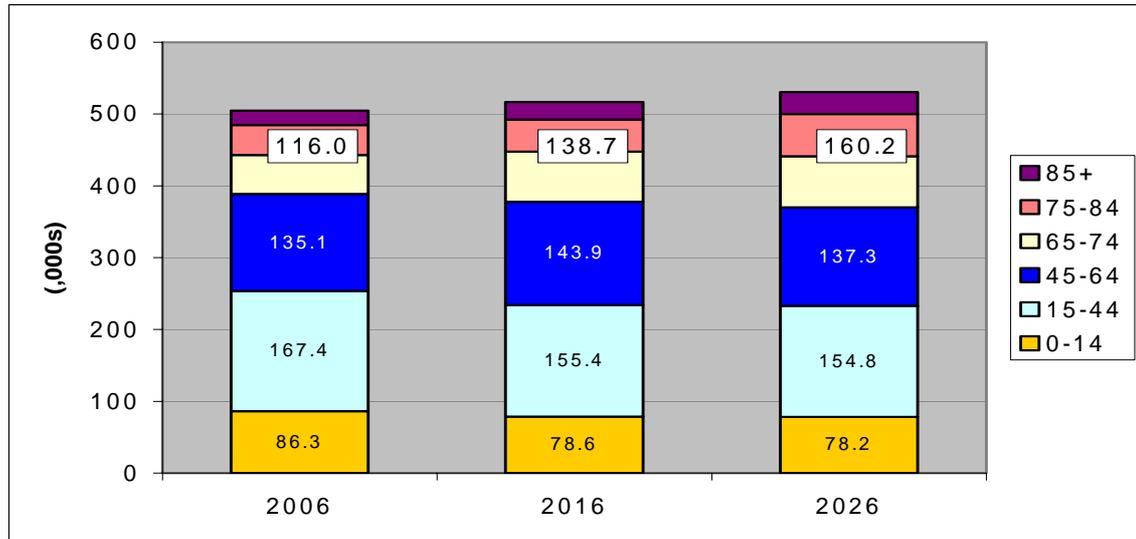


Table 2 Predicted population change 2001 – 2026 (in numbers)

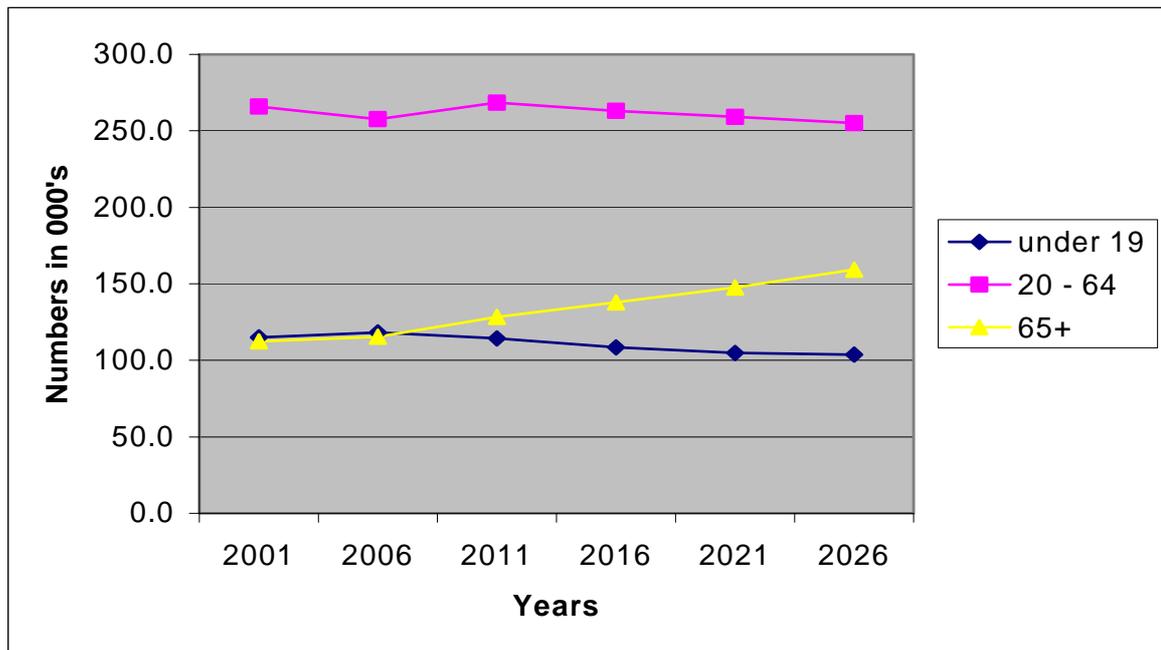
Actual change, 2001 - 2026						
PERSONS	2001-06	2006-11	2011-16	2016-21	2021-26	2001-26
0-4	-739	-1,786	-894	200	565	-2,654
5-9	-1,656	-924	-1,955	-840	462	-4,913
10-14	1,071	-1,806	-1,072	-1,921	-611	-4,339
15-19	4,692	893	-1,952	-1,043	-1,733	857
20-24	852	3,925	548	-1,919	-717	2,689
25-29	-4,363	163	3,603	616	-1,531	-1,512
30-34	-4,973	-4,742	-98	3,671	1,003	-5,139
35-39	-861	-5,184	-4,944	-36	4,012	-7,013
40-44	3,179	-1,038	-5,339	-4,873	232	-7,839
45-49	3,202	3,000	-1,154	-5,268	-4,633	-4,853
50-54	-3,747	3,027	2,841	-1,114	-5,026	-4,019
55-59	4,434	-3,699	2,860	2,823	-923	5,495
60-64	5,258	4,337	-3,589	2,823	2,916	11,745
65-69	979	5,076	4,180	-3,315	2,883	9,803
70-74	270	1,235	4,855	4,052	-2,877	7,535
75-79	-727	785	1,479	4,603	3,872	10,012
80-84	350	-66	1,189	1,672	4,233	7,378
85+	2,301	1,877	1,731	2,707	3,651	12,267
All ages	9,522	5,073	2,289	2,838	5,778	25,500

Despite an overall increase in population, the numbers of people in younger age groups are predicted to fall or rise only very slightly. The increase seen in the 10 – 14 age group over the last 5 years is predicted to fall slowly over the next 20 years, as is the 15 – 19 year age group, albeit from 2011 onwards. The numbers of people in the working age adult population will also decline, up to the ages of 55 – 59, and older age groups are predicted to increase. Figure 2 demonstrates population change in a line graph format.

⁷ Source: E Sussex County Council, March 2006, using Chelmer populations

Learning Disabilities in East Sussex

Figure 2 Trends in East Sussex population to 2026



Given the difficulties of establishing age specific prevalence rates discussed above, the following table should be interpreted with caution. Age specific prevalence rates estimated in 1990⁸ for 1990, 1995 & 1998 have been applied to current and future ESCC population figures to 2016. These rates do not include age-specific mortality rates or information on (im) migration to/from the area.

Table 3 Estimates of age specific prevalence for severe intellectual impairment⁹

Age	Prevalence/1000 population			ESCC populations ¹⁰			Estimated Numbers		
	01/01/1990	01/01/1995	01/01/1998	2006	2011	2016	2006	2011	2016
0 – 4	2.5	2	1.75	25700	23900	23000			
5 – 9	3	2.25	2	28000	27000	25000			
10 – 14	4	2.75	2.25	32400	30600	29500			
15 – 19	4.5	3.5	3	32300	33200	31200	81	66	55
20 - 24	5	4	3.75	21500	25300	25800	65	57	52
25 - 29	4.5	4.5	4.25	18300	18400	22000	73	51	50
30 – 34	4	4	4.5	24700	19900	19700	111	67	59
35 – 39	3.5	3.75	4	33400	28200	23200	167	101	87
40 – 44	3	3.25	3.5	36500	35400	30100	164	159	128
45 – 54	2.5	2.75	3	66000	72000	73800	264	277	310
55 – 64	2	2.25	2.5	68700	69300	68600	223	225	257
65 – 74	1	1.25	2	54050	60300	69400	148	178	260
75+	NK	1	1.25	61600	64200	68600			
Total				503000	508000	510000	1296	1181	1258

⁸ From Fryers – see Footnote 2

⁹ All population figures have been rounded up to the nearest 100. Totals are an approximation.

¹⁰ Using Chelmer 2006 population projections, ESCC

Learning Disabilities in East Sussex

As an alternative to the above, local prevalence rates have been calculated for 2011 and 2021 using Emerson and Hatton's estimates¹¹. These rates were estimated to include recent evidence of the impact of changes in mortality on people with learning disabilities, using the 2000-2003 Sheffield Case Register, as well as evidence that certain minority ethnic groups have higher rates of learning disability. Emerson & Hatton present estimates in terms of administrative prevalence (numbers known to services) and true prevalence (total numbers in the community). These could be used as a proxy for severe learning disability and either mild learning disability or mild intellectual impairment.

Table 4 True Prevalence – estimates applied to ESCC population

Age Band	2001 Pop	2001 Rate (%)	2001 No.	2011 Pop	2011 Rate (%)	2011 No.	2021 Pop	2021 rate (%)	2021 No.
15-19	27,600	2.69	742	33,200	2.77	919	30,200	2.67	806
20-24	20,500	2.6	533	25,300	2.69	680	23,900	2.71	648
25-29	22,600	2.42	547	18,400	2.49	458	22,600	2.49	563
30-34	29,600	2.42	716	19,900	2.49	495	23,500	2.49	584
35-39	34,200	2.4	821	28,200	2.45	691	23,200	2.46	571
40-44	33,300	2.42	806	35,400	2.45	867	25,200	2.47	622
45-49	31,100	2.26	703	37,300	2.28	850	30,900	2.31	714
50-54	35,500	2.13	756	34,800	2.37	824	36,500	2.39	872
55-59	31,800	2.1	668	32,500	2.33	757	38,200	2.32	886
60-64	27,200	1.98	539	36,800	2.20	809	36,000	2.22	799
65-69	26,800	1.81	485	32,900	2.01	661	33,700	2.01	678
70-74	26,000	1.73	450	27,500	2.34	643	36,400	2.33	848
75-79	23,500	1.52	357	23,500	2.07	486	29,600	2.08	616
80+	36,100	1.44	520	40,600	1.89	767	48000	1.93	924
Total	405,800	2.02	8,643	426500	2.37	9907	438000	2.36%	10131

Table 5 Administrative Prevalence estimates applied to ESCC population

Age Band	2001 Pop	2001 Rate (%)	2001 No.	2011 pop	2011 Rate (%)	2011 No.	2021 pop	2021 rate	2021 No.
15-19	27,600	0.68	188	33200	0.68	226	30200	0.68	205
20-24	20,500	0.61	125	25300	0.60	152	23900	0.61	146
25-29	22,600	0.53	120	18400	0.53	98	22600	0.53	120
30-34	29,600	0.53	157	19900	0.54	107	23500	0.54	127
35-39	34,200	0.6	205	28200	0.61	172	23200	0.61	142
40-44	33,300	0.62	206	35400	0.62	219	25300	0.63	159
45-49	31,100	0.56	174	37300	0.56	209	30900	0.57	176
50-54	35,500	0.44	156	34800	0.48	167	36500	0.49	179
55-59	31,800	0.5	159	32500	0.55	179	38200	0.55	210
60-64	27,200	0.39	106	36800	0.43	158	36000	0.43	155
65-69	26,800	0.32	86	32900	0.36	118	33700	0.36	121
70-74	26,000	0.25	65	27500	0.34	94	36400	0.34	124
75-79	23,500	0.16	38	23500	0.23	54	29600	0.23	68
80-84	36,100	0.14	51	40600	0.18	73	48000	0.18	86
Total	405,800	0.48	1836	426500	0.50	2026	438000	0.49	2018

¹¹ Taken from Estimating Future Need/Demand for supports for adults with learning disabilities in England, Emerson and Hatton, Institute for Health Research, Lancaster UK 2/6/2004

Learning Disabilities in East Sussex

The estimates in Table 5 appear to be an overestimate of about 70% for 2001, compared to actual 2001 figures of 1145 people known to adult social care. If however we use these figures, they predict a growth in numbers known to services to 2011 of about 10%.

The following table, using overall rather than age specific prevalence estimates, suggests the numbers of people including children with learning disabilities, by condition. Again, caution is advised, and these are likely to be overestimates.

Table 6 Estimating Numbers by condition in ESCC Area ¹²

<i>Condition</i>	Prevalence using ESCC Chelmer	
	2006 503000	2011 508000
<u>Mild intellectual impairment</u> IQ < 70, prevalence 2.75%	13832	13970
<u>Mild learning disabilities</u> Prevalence 1 – 2 %	5030 - 10060	5080 – 10160
<u>Severe intellectual impairment</u> IQ < 50 and others with co-existing conditions, prevalence 0.3 – 0.4%	1509 - 2012	1524 - 2032
<u>Down's syndrome</u> Prevalence 30% of SLD 10% given up at birth, 10% full time or part time care during childhood	663	670
<u>Challenging behaviours</u> Point prevalence of significant challenge	100	102
<i>Challenging behaviours</i> – point prevalence of those who may present difficulties to carers or risk to themselves	503	508
<u>Autistic spectrum disorder</u> Whole spectrum	4577	4622
<u>ASD IQ < 70</u>		
Classical (Kanner's) autism	251	254
Other spectrum disorders	754	762
<u>ASD IQ < 70</u>		
Asperger's syndrome	1810	1828
Other spectrum disorders	1759	1777
<u>Epilepsy</u> Severe learning disability and epilepsy	271 - 363	274 - 366
<u>Epilepsy</u> Profound learning disability and epilepsy	110 - 150	111 - 152
<u>Cerebral palsy and LD</u>	462 - 684	467 - 691

¹² Source of estimates Health Care Needs Assessment Learning Disability Version 3 2002

Learning Disabilities in East Sussex

Table 7 Other estimates of prevalence amongst adults with LD

Condition or illness	Estimated prevalence
Psychiatric illness among adults <i>Not clear whether rate increases with severity of intellectual disability</i>	10 – 39%
Psychiatric morbidity in adults aged 65 and over	69.5%
Psychiatric morbidity amongst adults aged 50 and over, excluding dementia	11.4%
Schizophrenia	1.3% - 3.7%
Affective disorders including depressive illness and mania	1.2% - 6%
Anxiety related neurotic disorders	16.4%
ADHD	15%
Alzheimer's neuropathology, over 65 (not Down's)	31% - 78.5% ¹³
Autistic Disorder in adults	7.7 - 9/10,000

Numbers known to services

This is referred to in the literature as either the ascertained prevalence or the administrative prevalence.

There has been a 15% growth in numbers of service users since the 2000-1 period. There were a total of 1345 service users known to services during 2005-6. The majority (800 plus) received professional support and approximately half received residential care and/or day care.

¹³ Data to this point from Health Evidence Reviews (Wales) 1999

Learning Disabilities in East Sussex

Social Care

Figure 3 Adult social care clients in receipt of learning disability services 2001-2, 2003-4 and 2005-6 by age

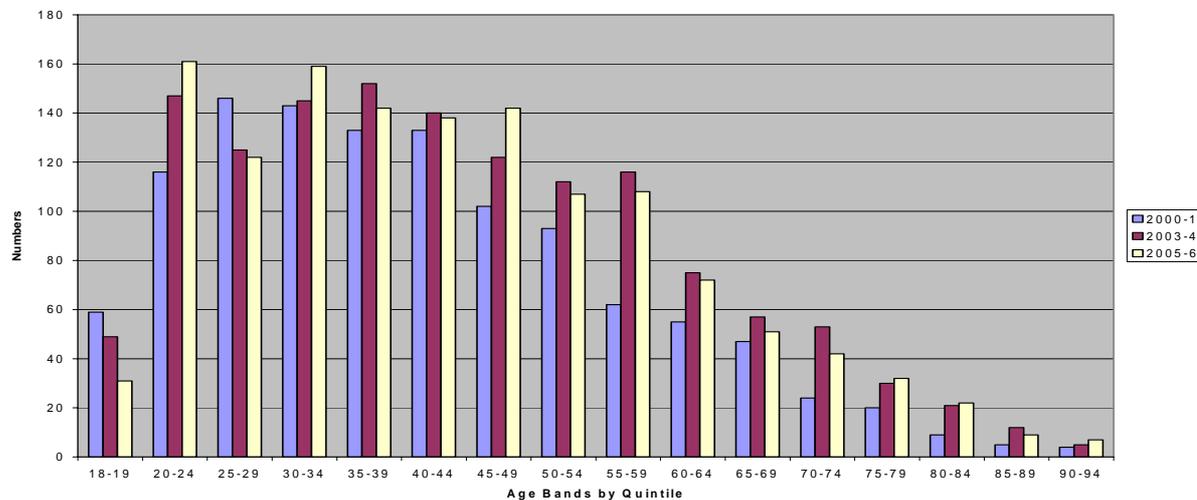


Table 8 Referrals Assessments and Packages of Care 01/01/05 – 31/03/06 – total numbers clients by type of provision, ESCC

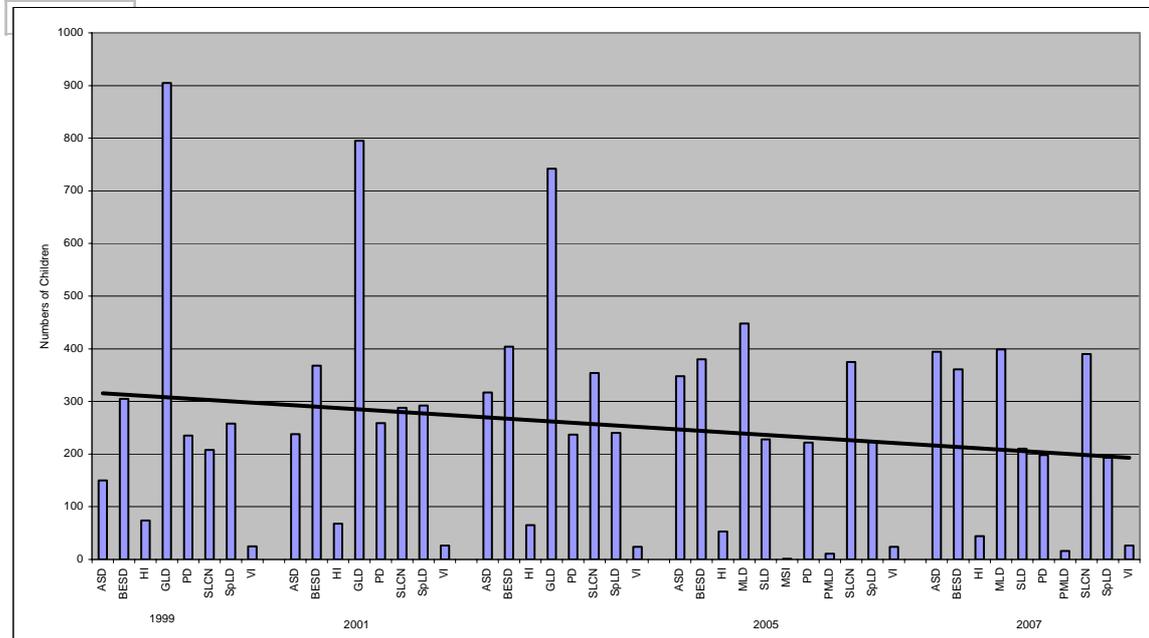
Type of Service	18 –64	65 – 74	75+	Total
Assessment	81	3	4	88
Review	805	49	16	870
Service during period	1151	163*		1314
Service on last day of period	695	33	15	743

* Information provided for 65+ age group only

Learning Disabilities in East Sussex

Children's Services

Figure 4 Number of Children with Statements of Educational Need ESCC by Category 1999 - 2007¹⁴



The figures show surprising consistency over the last 8 years, with an increase in stated children with a diagnosis of autistic spectrum disorder the only evident increase – over 160% from 1999 – 2007. As ASD is a very broad diagnosis, an indication of the severity of ASD in these children will assist in the estimate of need for future services for adults from these figures. The numbers of children in the category general learning disability (split into mild and severe from 2004) appear to be on a downward trend. The category of profound and multiple learning disabilities has seen an increase in numbers since 2005, the first year of use. Although this is a 50% increase, the numbers are very small, rising from 11 to 16 children. The overall increase in numbers of children with statements seen between 1999 and 2003 has begun to drop back since that date.

Given that the numbers do not show an upward trend, questions arise about the numbers of children waiting for assessment and the

¹⁴ ASD Autistic Spectrum Disorder; BESD Behaviour Emotional and Social Difficulty; SLCN Speech Language and Communication Needs; GLD General Learning Difficulty (to 2004 when pupils reassigned to MLD or SLD); MSI Multi Sensory impairment; PD Physical disability; MLD Moderate Learning Disability, SLD Severe learning disability, PMLD profound and multiple learning Disability; HI hearing impairment, VI visual impairment; SpLD Specific learning disability

Learning Disabilities in East Sussex

number assessed as not eligible for services.

Children referred to transitions panel¹⁵

Children With Statements

The number of children with statements of SLD or PMLD in Year 14 of their education has averaged 21 children per year over the last four years (**18** in 03/04, **13** in 04/05, **25** in 05/06 and **28** in 06/07).

The number of children with statements of SLD or PMLD currently between Year 13 and Year 9 of their education averages 20 children per year (**20** in Year 13, **23** in Year 12, **17** in Year 11, **20** in Year 10 and **20** in Year 9).

Learning Disability Assessment

The number of cases referred to Learning Disability Assessment who are likely to require a service from ASC, has averaged 30 cases per year for the last three years (**23** in 04/05, **31** in 05/06 and **35** in 06/07).

Referral Assessment & Packages of Care 2005/2006

The total number of LD clients aged between 20 and 24 who received a service during 2005/2006 totalled 161 people – this gives an average of 32 people per year.

Health Services

Primary Care

As of April 2006 all GP practices are required to maintain a register of people with learning disabilities registered at their practice, as part of the Quality and Outcomes Framework. At December 2006 a total of 799 individuals appear on GP Learning Disability registers in the west of the county, and 730 in the east. It is anticipated that these registers will be used to monitor health interventions, probably from April 2007 onwards. The proposed indicators are:

- Evidence of a learning disabilities health action plan
- Identification of special risks, e.g. abuse
- Evidence of invitation to cervical and mammography screening – this will include exception reporting as evidence that the issue has been discussed
- Blood pressure; body mass index and smoking status

¹⁵ Data and table from Jim White, Adult Social Care

Learning Disabilities in East Sussex

Child Health Records¹⁶

Data on birth defects is recorded in the west of the county but not in the east. The data are incomplete and possibly inaccurate, as they may not always represent a clinical diagnosis. Child Health records are held until a child is 16. Diagnosis is not always made in the first year of life and therefore number diagnosed cannot be matched to a birth cohort, and a rate cannot be calculated.

Numbers recorded for the west of the county are very small. For most diagnoses there is a maximum of one case a year. The most frequent diagnosis is Down's syndrome (ICD-10 codes Q90 – Q92), and numbers of diagnoses fluctuate from an average of one to two cases per year to a maximum of 7, in 1996.

Child health recording of birth defect is incomplete and likely to be inaccurate. We cannot match this data to information about migration and immigration into and out of the county and therefore this information is of very limited use for projections and service planning.

Specialist Trust Service Provision

Sussex Partnership Trust provides specialist services for people with learning disabilities. This includes psychology, nursing and various therapies. NHS continuing care, forensic services, a limited number of residential services – there are currently 12 tenants living in the Supported Living Service, with a further 4 receiving outreach support within their family homes - and some out of area placements are provided. There are three community teams serving the East Sussex area.

¹⁶ICD-10 Conditions searched: Q86 foetal alcohol syndrome, Q87.1 Prader-Willi, Q87.84 William's disease, Q90 – 92 Down's syndrome, Q93.5 Angelman, Q96 Turner's syndrome, Q99 Fragile X, PO4 foetal poisoning with noxious influence via placenta, P20 intrauterine hypoxia, P21 birth asphyxia, P35 foetal rubella syndrome

Learning Disabilities in East Sussex

Figure 5 Sussex Partnership Trust Patients by Age and Community Team March 2007

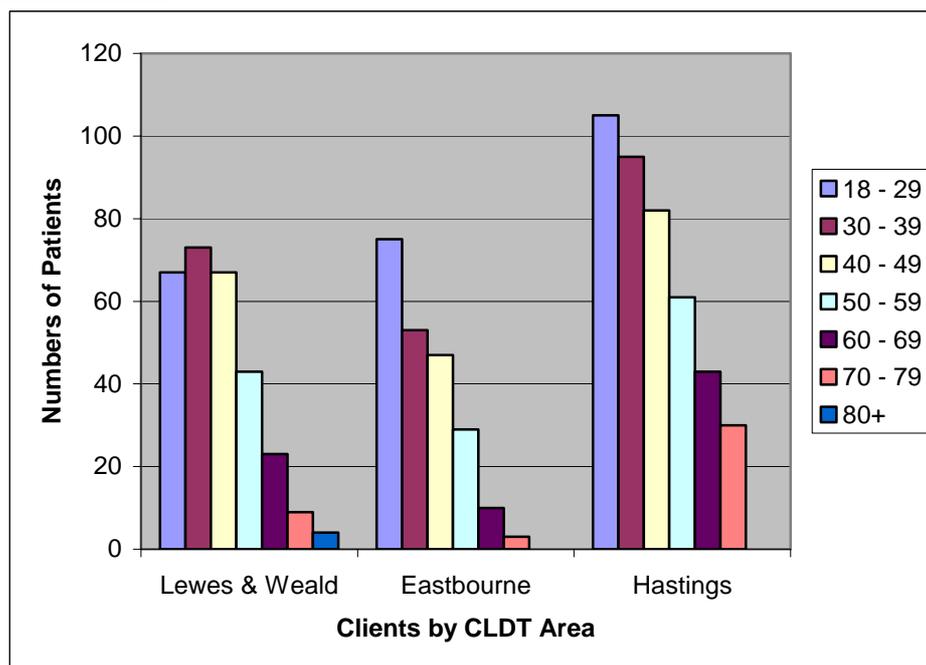


Table 9 Percentage of male patients and percentage placed by other local authorities, March 2007

Area	Lewes & Wealden	Eastbourne	Hastings
Male %	68.18	57.14	48.56
OLAs %	43.36	23.04	50.96

54% of service users in total are male. 42% overall are placed in the area and funded by other local authorities. This is to some extent balanced by the 200 – 300 service users placed by ESCC in other local authority areas. This indicates that approximately 500 – 600 service users known to adult social care are not currently known to the specialist Trust. Either their needs are met by primary care, they are waiting to be assessed, have been seen and discharged or there is significant unmet need in the community.

Hospital Episode Statistics

Hospital data available by year includes the number of admissions by length of stay, frequency of admission, age, and reason for admission for people with certain codes¹⁷ of LD with an ESCC postcode. Given the above discussion on incompleteness of data and the fact that there is no denominator for this data (as we don't know the total number of people with learning disability in the population using the hospitals), it is difficult to calculate rates and to compare this to other regions. Not everyone with a learning

¹⁷ The same ICD codes were searched as for child health records.

Learning Disabilities in East Sussex

disability is coded as such at hospital admission, and some admissions give learning disability as the reason for admission, rather than admission or contact with a hospital for a specific purpose, e.g. operation or treatment for illness. This information is not useful for service planning at present but does contain useful data about reasons for and frequency of admission and could with further work be useful as a measure of access.

Deaths in East Sussex Brighton & Hove Area

Another possible source of NHS data is death registrations. Again the completeness of recording is questionable. The only information readily available was on Down's syndrome and it may be that this is not always entered on the death certificates. Other than five cases of developmental disorder, no other conditions pertinent to learning disability were recorded on the death certificate. It is therefore not advisable to use this information to estimate numbers of people in the area, life expectancy, or to generalise about common cause of death.

Summary

The measures of prevalence are estimates and given the difficulties with definitions described above, and the likelihood of different prevalence rates for different age bands, unlikely to be very accurate. The figures given in Table 3 however are not dissimilar to the numbers of people known to and in receipt of social care services during the year 2005 – 6 (Figure 3/Table 9). Using these estimates however we do not predict growth in numbers of service users over the period 2006-2016.

However, given the pattern of demographic change (an increasing elderly population, and increased longevity), we should be planning for more older people with learning disabilities. Using the Emerson and Hatton estimates, an estimate of 10% growth to 2011 from a 2001 baseline is reasonable.

Locally we are predicting a drop in the numbers of children in the general population aged 0 – 15 but we don't know the age specific prevalence rates of learning disabilities in this age group. Increased survival of children and young people with more complex and severe learning disability may increase the prevalence and counteract the downward trend in this part of the population.

Information from service use is patchy. There are just under 1600 people on general practice learning disability registers. There are 1345 people currently in receipt of service from adult social care. 200 – 300 of these are placed outside the area. The Partnership

Learning Disabilities in East Sussex

Trust currently provides services to 919 people, 42% of whom are placed in the area by other local authorities. This indicates that between 500 – 600 people are not currently known to the Trust. Given the issues of poor health and poor access for people with learning disabilities, it is worth investigating this further.

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Health, health needs and needs

Authors, date and journal	Title	Population	Methods	Results	Discussion	Level
Bland, Hutchinson et al Journal of Learning Disabilities vol 7 (4) 323 – 344 2003	<u>Double jeopardy? Needs and services for older people who have a learning disability</u>	UK	Questionnaire survey to people over 65 in one community health trust area in England. Questionnaire completed by health staff. 94 out of possible 141 people sent survey	Most common health problems faced were psychological and behavioural difficulties, incontinence, circulation, respiration and eyesight. Few formal diagnoses of mental illness evident.	Over 70% of older adults had received regular BP checks, blood tests and eyesight tests but other screening poorly subscribed – breast, cervical or hearing. Staff not aware and need for training. Older PWLD not good at expressing need for care Overall positive levels of satisfaction for access to health care staff. This survey measured staff perceptions rather than older PWLD themselves	III
Hatzidimitriou, E & Milne A <u>Dementia</u> 2005.4: 341	<u>Planning Ahead: Meeting the needs of older people with intellectual disabilities in the United Kingdom</u>	UK	Review of policy, research and health issues	Life expectancy now 70 – 74 years. 28% of people with MLD are aged 50+ Age related problems impact at earlier chronological age. People with severe and complex needs experience age related morbidity from around	At the moment most agencies react to needs rather than co-operative pre-emptive planning. Paper makes recommendations for service planning for older people with LD – includes a strategic planning framework, person centred planning commencing age 50 or 40 for people with Down's, flexibility	Ib

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

				30 yrs.	in commissioning, attention to workforce and training for staff in generic OP services	
Holland British Journal of Psychiatry 2000 176 pp 24-31	<u>Ageing and learning disability</u>	UK	Review	Various studies indicate a convergence in terms of health and social care between PWLD and the general population as they age – e.g. less epilepsy, Lots of mental health problems in older PWLD remain undiagnosed	Health and social care need to work together to develop joint strategies. More research is needed on ageing and learning disabilities. Social aspects to be addressed include the lack of opportunity to work and therefore the lack of opportunity to retire – planning for retirement needed, help with bereavement needed, help with communication, life history etc when loss of family carer/parent	*
McGrother et al. <u>Journal Intellectual Disability Research</u> Vol. 40 Issue 2 Page 183 1996	<u>Community Care for adults with learning disability and their carers: needs and outcomes from the Leicestershire register</u>	2117 adults and 982 carers known to specialist services in Leicestershire	Cross sectional study based on an epidemiological register	Behavioural and psychological problems and epilepsy were the main disabilities for adults. Leading unmet needs reported by residential carers were for day care and other forms of residence, long term social support, respite care and housing adaptations. Depression	This is quite an old paper and therefore may not be of much relevance. Recommends keeping epidemiological registers and ‘methods’ to aid purchasing and providing for this client group.	III

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

				very common amongst carers		
Tuffrey-Wijne Palliative Medicine 2003 17, 55-62	<u>The palliative care needs of people with intellectual disabilities: a literature review</u>	UK	Systematic review	This area has not been a focus of research. There are some case studies to draw on. Many problem areas arise. The views of PWLD themselves have not so far been researched. PWLD or their carers may not recognize symptoms of terminal illness.	High pain thresholds, poor communication, lack of screening, inadequate diagnostics, lack of staff training with PWLD may all lead to deaths which could be avoidable. Understanding concepts of terminal illness and dying amongst PWLD is key. A tool for communicating need amongst PWSLD is needed. Access to cancer and palliative care services needs to be enhanced. Info on cancer and on dying in accessible formats is needed. Training of carers and staff also paramount.	Ia
Young & Chesson British Journal Learning Disability 34, 11-19 2006	<u>Obtaining views on health care from people with learning disabilities and severe mental illness</u>	Research took place within 2 12-bedded in patient md assessment and treatment units in Grampian. 6 patients interviewed	Interviews with PWSLD using analogue scales and photographs		Considerable resources and skills needed to meaningfully engage with pwsld and challenging behaviour in assessing health care. Although time consuming staff supported these efforts.	III
Young &	<u>Stakeholders</u>	Postal	Questionnaire on 7	85% identified staff	Apparent rejection of the	III

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Chesson Health and Social Care in the Community 14 (1) 17 – 25 2006	<u>views on measuring outcomes for people with learning disabilities</u>	questionnaire survey sent to 94 stakeholders in Scotland. 77% response rate. Statutory and voluntary sectors	main topic areas – approaches to service evaluation, views of outcome measures, appropriateness of measures and desired future measures of evaluating health outcomes	appraisal as main method of evaluation 32% reported specific outcome measures used, mostly standardized or published tools. Outcome measures were not seen as impractical or detrimental. Goal setting with users and individualized methods were preferred. Complexity of outcome measures highlighted.	medical model raises the issues of effective evidence health care to a group known to suffer health inequalities. A social worker stated that PWLD are not ill – but a health worker pointed out the poor access to health care PWLD frequently have. The need for and importance of well- designed health outcome measures that have universal credibility is urgent.	
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Access, services (quality of, improvement,) and commissioning

Authors, date and journal	Title	Population	Methods	Results	Discussion	
Adams et al 2006 34, 68- 76 British Journal of Learning Disabilities	<u>Individual planning: an exploration of the link between quality of plan and quality of life</u>	UK	Comparison of two groups of people in residential care. All participants had a plan therefore no control group. Goal rating score was applied to divide	Very small numbers do don't think data is reliable Inter-rater reliability was 100% for assessing goals Half of the staff involved had had training on producing individual	This study found few relationships between having a good individual plan and outcomes in terms of quality of life. Could be poor implementation of the plans? There was a trend towards people with higher quality plans spending more time in meaningful activity	11b

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

			people into 2 groups – one with a higher quality plan & one without 36 people took part	plans but no significant difference in quality of plan seen.	V small study in one geographical setting – what is applicability to other areas?	
Alborz A et al <u>J Health Services Research Policy</u> Vol 10 No. 3 2005	<u>Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence</u>	UK population	Systematic review of theory, evidence and gaps in knowledge Research on databases, mailshot to researchers and a consultation exercise	Lack of rigorous research in this area Significant gaps in evidence base 3 rd parties can both empower or obstruct access to health care Communication problems, rigid procedures and lack of interpersonal skills amongst health professionals a number of innovations were identified	Innovations include: Communication aid e.g. hearing loops Prompt card to support GPs health check programmes Walk in clinics A substantial amount of literature on unmet health need was reviewed indicating 72% - 94% of PLD have an unmet need. Poor bodily awareness and depressed pain responses may be some of the reasons why. Carers may help identify ill health but may also decide no action is needed Shortage in provision of MH services was evident Signs and notices in health care settings inadequate Comms. aids such as loops needed Interpreters needed for non-English speaking BME communities	Ia

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Concannon, L British Journal of Learning Disabilities 2006 34, 200-2005	<u>Inclusion or control?</u> <u>Commissioning and contracting services for people with learning disabilities</u>	UK	Review of policy	Paper examines commissioning and contracting services – is there a real shift in power from service provider to service user? Focuses on direct payments	Rather than have needs met creatively people continue to be slot into services. Collaborative working between care managers, contractors, commissioners and advocates is needed to successfully develop direct payments. Current success rates are very low	*
L Hannon <u>Nursing Standard</u> 17, 46, 39-42 2003	<u>Secondary Care for people with learning disabilities</u>	Description of project studying this field in UK and comparing to Canada	Study trip, literature review	Problems with access to secondary care Hospital liaison nurse role works Pre admission assessments and extra info useful Acute services staff lack disability awareness People with LD need to develop skills to be more actively involved in planning, developing and evaluating services	Develop a care pathway for hospital admissions including core principles Highlight additional needs at an early stage Active working links between acute and community ld service Hospital liaison nurse in post Disability awareness training for staff Explore current communication systems in hospital User friendly information Ask service users to be involved in designing the system	*
Hogg, J <u>J R Soc Medicine</u> 2001; 94: 333-336	<u>Essential healthcare for people with learning disabilities: barriers and opportunities</u>	UK	Review	Consultation rates lower in primary care though higher in specialist care Communication difficulties Challenging behaviour during consultations.		*

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

				Little medical education in this field, either undergrad or post grad		
Kruschwitz, Musgrave et al Informatics in Primary Care 2006 14; 175-181	<u>Integrating data for learning disability service providers: are the barriers and solutions technical or organisational</u>	UK	Review of policy and service scenarios	Paper proposes 2 scenarios: need for data at population level for planning and need for data at care management level for individual service planning. Identifies issues with data management – multiple agencies, multiple data sources within agencies, data not kept up to date, confidentiality issues, lack of common coding and terminology and duplication of recording, legislative barriers on data sharing.	Recommends application of new web technologies as solution to data sharing. Fear of change may be behind reluctance to move forward rather than data protection issues. Benefits of patient confidentiality need to be weighed up against the costs of creating barriers. LD services have the scope to be early innovators in this field	*
Lindsey M Advances in Psychiatric Treatment (2002) Vol. 8 pp 138-148	<u>Comprehensive health care services for people with learning disabilities</u>	UK	Review	Lists health issues and service issues	Requirements Equal access to health services Sufficient support to enable access Disability awareness training as integral part of staff training Access to specialist services for those with complex needs	*

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

					Community learning disability teams working closely with primary care teams Systems for individualised health plans Partnerships between agencies for co-ordinated service planning and delivery	
Martin M British Journal of Learning Disability Vol. 27 1999	<u>A comparative review of primary health care models for people with learning disabilities: towards the provision of seamless health care</u>	UK	Review	Discusses various models	No one model necessarily the best. Various aspects of different types prove positive. The model that uses a facilitator improves access only where the primary care team are fully engaged and persuaded to participate. The CLDN led model requires that the nurse and primary health care team know each other well. The GP led model is clinically effective with good clinical audit, but consultations need time and this model would be enhanced if the user were more involved. Health promotion is an integral part of any model	*
Melville et al J Intellectual Disability Research Vol. 50 Part 1 pp 11-17	<u>The outcomes of an intervention study to reduce the barriers experienced by</u>	All practice nurses working the greater Glasgow area	A three-group pre and post intervention study. The intervention was designed to test the hypothesis	1 group received training pack and had training event, 1 group received pack only. 1 group no intervention. Training intervention group	Training pack had positive outcome on staff No long term outcomes measured – measured at 3 months only Nurses not randomised to groups – self motivation may have produced	11a

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Jan 2006	<u>people with intellectual disabilities accessing primary health care services</u>		that increasing knowledge of professionals would increase ability of people with LD to access appropriate services	reported positive impact 81% felt more able to meet needs of clients 66% reported changes to clinical practice	good results Positive impact on lives of clients should also be measured	
Melville et al J Intellectual Disability Vo. 49 Part 3 pp 190-198 March 2005	<u>Enhancing Primary health services for adults with intellectual disabilities</u>	All practices in greater Glasgow area	Purpose designed questionnaire to measure nurses attitudes, knowledge, training needs and self-efficacy in their work with people with LD	69% (n = 292) participated. 25% reported a growing workload with PWLD. 8% had received training in comms with PWLD. A knowledge gap was identified 86% reported specific difficulties during consultations. 68% did not modify duration of consultations. Viewed LD to be a high priority area for future.	Nurses had positive attitudes and high self-efficacy scores in their work with people with LD. They need to be targeted in other areas for specific training in this area	III
Morgan, Ahmed & Kerr British Journal of Psychiatry 2000 176,	<u>Health care provision for people with a learning disability</u>	South Glamorgan Health Authority area (Wales)	A record linking study of secondary care contacts of 434,000 between 1991 and 1997	The distribution of PWLD correlated significantly with social deprivation. The presence of a LD hospital affected care	Overall patients with LD are not excessive users of psychiatric services in terms of numbers of admissions or length of stay. LD patients tend to use more medical beds than other patients but have	III

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

37-41				uptake. Former institution residents generated many times more admissions per 1000 patients than community residents	lower uptake of surgery – perhaps because of lower use of obstetrics and gynae. services. Patients in institutional care tend to experience more morbidity but this is not reflected in hospital usage – is a degree of acute medical care provided in residential settings? Psychiatric care also influenced by institutional factor – high rates of admission to psychiatric units for those recently discharged from residential care. Former institution residents generated 212 admissions/1000 cf. 18/1000 general population.	
Pritchard & Roy British J Learning Disabilities 34 88-93 2006	<u>Reversing the export of people with learning disabilities and complex health needs</u>	All authorities in an English region 13 commissioning authorities with a population of 5.3 million	Survey and interviews about clients placed out of area	External placements are commonplace and expensive. The population was predominately young and male requiring long term funding. Offending behaviour and extremely disturbed behaviour due to autism or mental health need common.	Given high cost local services need to be developed. To reconfigure services commissioners need to know the needs of adolescents entering adult services – data is often poor. Suggest a joint database (ASC and children’s and health, re needs)	III
Pointu & Cole British	<u>An education programme for</u>	Uk self-selected	Reports on a nurse led education	Epilepsy amongst LD most difficult to treat –	This study evaluates increased knowledge of staff but does not	III

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Journal of Learning Disabilities 33, 39-43 2005	<u>social care staff: improving the health of people who have a learning disability and epilepsy</u>	professionals. 1500 social care staff have completed the programme	programme on epilepsy awareness for PWLD, training provided for social care staff	PWLD with epilepsy being placed in community had led to deterioration in some individual's health status	evaluate outcomes for PWLD i.e. reduction in hospital admissions or numbers of episodes of seizures. Suggests a protocol and action plan for staff.	
Powrie, E Nursing and Health Care Management Issues 2003	<u>Primary Health Care Provision for adults with a learning disability</u>	UK – Scotland	Survey of all (n = 199) practice nurses employed by Grampian Health Board 107 eligible responses received	70% of respondents unsure whether health needs of PWLD were being met 36% thought that additional health screening would benefit PWLD practice nurses described ethical dilemmas, people not attending for appointments, management of regular medication eg for asthma. The process of consent and decision making was also problematic	Findings suggest that primary care teams would benefit from closer working relationships with learning disability specialists. Suggests that the factors necessary for providing health care to PWLD lie beyond the primary care teams	III
Ruddick L British Journal of Health	<u>Health of people with intellectual disabilities: a</u>	UK population	Literature review – policy and practice Not a systematic review	3 areas reviewed (1) Overview of political context (2) examine literature on quality of	(1) Unclear in policy who is to take responsibility for health (2) growing body of literature on how to work with people with LD in assess quality	*

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Psychology Nov 2005 10, pg.559	<u>review of factors influencing access to health care</u>			life which is main outcome measure (3) explore individual and care staff related factors which influence how health needs of people are recognized and acted upon	of life. This should be used to assess residential and social care. SF36 has been adapted for use as one of the few measures of health related outcomes. (3) There is a growing literature on gaining reliable and consistent self-report answers. Staff reactions to health problems need to be researched. There should also be a focus on staff training and support to facilitate access to appropriate interventions.	
White, Edwards and Townsend White Current Opinion in Psychiatry 19: 502 2006	<u>Stress and burnout amongst professional carers of people with intellectual disability: another health inequity</u>	UK	Review		Life in the community has rendered carers more clearly vulnerable to stress and burnout for a variety of complex reasons. Lack of support and lack of role definition are particular problems	*

Transitions

Authors, date and journal	Title	Population	Methods	Results	Discussion	Level
Hudson, B Disability and Society	<u>Making and Missing Connections</u>	3 localities in England during 2003 and 2004	1 st round: 50 semi structured interviews with social services	Transitions characterised by discontinuity. Transition has not reached top of agenda for	Whole systems should begin at the level of the individual, not at the birds eye level.	III

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Vol. 21 No.1 January 2006 pp47-60			managers and professionals in adults and children's services, and 14 young people. 2 nd round 18 managers and 9 service users or parents	LDPB's. No clear targets laid down for transitions (nationally). All young people will have been known to some of the transition partners for a long time, which should facilitate planning but this is not the case. Planning short term and reactive. . Lack of demographic and financial information	Where are the individuals who have the closest proximity to the problems and what resources do they have to address them? Isolate the one or two critical points with closest proximity and identify what needs to happen.	
Kerr, G <u>Journal Intellectual Disabilities</u> 2001, 5: 157	<u>Assessing the needs of learning disabled young people with additional disabilities</u>	1998-9 cohort of 12 - 16 year olds in Manchester young people with SLD and AD 58 people identified	Agreed case definition. 15 minute structured interview with an informant with access to yp's case notes using validated definitions and a scale previously used in the same area in 1977	Prevalence of SLD and AD estimated 1.9/1000 (1.4 – 2.4 C.I.'s) Increase in disabled young people in S Asian population since previous estimates	Service improvement requires attention to 2 interface areas: (1) transition to adult services and (2) multi agency co-ordination Individual assessment important for people with severe and complex needs (given small numbers) Suggestion for 4 planning groups to work on the interface issues: 1/non ambulant/vulnerable 2/ poor self help, mobile, no severe behaviour problems 3/ poor self help, mobile, severe behaviour problems 4/ severe behaviour problems,	III

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

<p>Tarleton & Ward British J Learning Disabilities 30 70-76 2005</p>	<p><u>Changes and Choices: finding out what information young people with learning disabilities, their parents and supporters need at transition</u></p>	<p>Somerset – young people in transitions team and their supporters</p>	<p>Young people were trained in research methods and undertook focus groups with yp with learning disabilities in E & Wales. Parallel focus groups with parents and supporters were run at the same time</p>	<p>All three groups wanted information about getting a job and going to college. All wanted information about the transition process in general. Slight difference of emphasis in each group.</p>	<p>mobile, good self help skills</p> <p>Parents not clear that transitions process at school should cover more aspects of a young person’s life than just education. Felt left out of the process and not enough information. PWLD did not understand the word transition. Supporters and parents views about transition process can often differ and be in contradiction with each other. Supporters concentrate of empowering the young person, and control, parents focus on the fact that young people do not have control and may feel the need to obtain permission to make their choices. Recommendations about what information is needed and how to give it are included.</p>	<p>III</p>
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Levels of Evidence

I evidence from systematic review or meta analysis of RCTs

1b Evidence from at least one RCT

Ila evidence from at least one controlled study without randomisation

Literature Review to support a Learning Disability Joint Commissioning Strategy for East Sussex

Ib Evidence from at least one other type of quasi experimental stuffy

III evidence from non experimental descriptive studies, such as comparative studies, correlation studies and case control studies

IV evidence from expert committee reports or opinions and or clinical experience of respected authorities

* non systematic review, selected review or policy review