



Joint Strategic Needs Assessment
for
Adults with Learning Disabilities

2007/2008

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1. EXECUTIVE SUMMARY

People with learning disabilities are amongst the most vulnerable and marginalised people within Cambridgeshire. They are more likely to:

- be socially excluded,
- have poorer physical and mental health
- have difficulties in accessing health care
- be at risk from abuse
- be discriminated against
- need support to access housing, health, employment and independent living
- be at greater risk of ending up in prison

People with learning disabilities deserve to be treated as equal citizens however are often at the margins of our society. Very few have jobs, live in their own homes or have control over their lives.

The Key Messages from the assessment of need can be summarised below.

Demography

- Significant growth in population is anticipated over the next 10 to 15 years.
- A growth in the number of people with complex needs is expected, because more babies with more complex needs are surviving into adulthood and people with learning disabilities are living longer and developing additional health needs.
- Much of Cambridgeshire is rural and there are major access and transport issues for people with learning disability, as with the rest of the population.
- Small pockets of diverse population risk being overlooked.
- Travellers represent the largest single ethnic minority group in Cambridgeshire making up about one percent of the population. There is a much higher than national prevalence of learning disability in the Traveller community.
- There is a significant risk that the compounding impact of disability, health inequalities and social deprivation will affect health, wellbeing, opportunity and outcomes.
- There is a risk that people with low level needs or Autistic spectrum are unable to or have difficulty in accessing services.
- The location of people with learning disability is affected by service location, housing costs and development opportunity. As a result of cheaper housing, more people with learning disability live in Fenland.
- There is a need to look at equitable level of access and provision across the county.
- Resources in county need developing to minimise the need for out of county placements.
- Mainstream community services will need to respond to increasing numbers of people with learning disability living in their local community.

Children, Young People, and Transitions into adult life.

- If a child with learning disability is placed out of county for schooling there is risk they will not return and the transition process to adult services will be more difficult.

- Experience in childhood impacts future expectations and opportunities.
- Need for forward planning and accommodation options to be considered at an early stage
- Increased expectations from families and young people may impact on budget and opportunities.
- Access to information, person centred approaches, FE education and forward planning are key for the life chances and wellbeing of families and young people.
- New transitions protocols are underpinned by person centered planning.
- Recent development of in county FE provision is having a positive impact.

Choice and Control

- Access to good information, advocacy and person centred planning underpin choice and control and opportunities for self directed support.
- Continued access to direct payments and the implementation of self directed support will enhance individualised arrangements and develop a greater focus on self-advocacy.
- Services need to develop to better meet the individualized and cultural needs of people from diverse communities.
- Users and carers wish to influence and drive service improvements.
- Advice, training and information services need to be developed further to meet the changing needs relating to self directed support.
- Developments to increase access to individual budgets needs to ensure equity of access within budget.
- Some service users and carers may need support and advice to manage individual budgets.

Supporting Carers

- Support, information and assessment for services are vital in order to maintain carers in their role.
- Access and allocation of short breaks for carers needs to offer choice and equity.
- Carers need access to emergency support.
- Forward planning promotes both carer and user wellbeing.
- Carers, in particular older carers, may need support at times to articulate their needs.

Good Health

- People with learning disability are at significant risk of major health problems.
- People with learning disability and their carers have experienced significant health inequalities and barriers to mainstream services.
- Joint work is needed to:
 - Identify people with learning disabilities in primary care and ensure they have health action plans that are implemented and monitored.
 - Ensure equality of access.
 - Ensure health is promoted by preventive action and maximum practical self-care.
 - Develop broad appreciation, knowledge and skills related to the increasing longevity of people with learning disabilities.
- It is important to address priority risks as raised by National Patient Safety Agency. Swallowing problems is a major cause of death.

- The management of challenging behaviour through restraint and or medication is a cause for concern.
- There is a need to develop specialist capacity in mental health, challenging and offending behaviour management in county and in the community where possible.
- Specialist services need to be available equitably across the county.

Housing

- The demand for quality housing and support is increasing.
- Joint work with the housing agencies is key to:
 - Ensure access is fair and prioritized appropriately.
 - Expanding the range of housing available including rental, shared ownership and full ownership.
 - Ensuring the needs of disabled people are taken into account in future developments.
- The development of in county services is needed to enable people living out of county to move back to Cambridgeshire.
- Supporting People services need to be flexible, user focused and not accommodation based.
- People want choice about the type of accommodation, where they live and who they live with.

Fulfilling lives

- People with learning disabilities want the same range of opportunities as their non disabled counterparts.
- There has been an over reliance on building based services. Access to community facilities and opportunities needs development. The recommendations from the Day Services Review will address some issues.
- Joint work with the third sector, leisure services, voluntary and community groups is needed to develop a fuller range of user led opportunities.
- There is good access to training and adult education across the county through social training enterprises.
- Inclusion is affected by area of residence, finances, access to transport and staff or informal carer support.

Moving into Employment

- People want the right to paid employment but need the information, support, training and opportunity to achieve their goals.
- People with learning disabilities experience significant barriers in accessing paid work and numbers in paid employment are low.
- A range of ways of enabling people to prepare for and gain paid employment is needed.
- Work is also needed with employers, including statutory organisations to promote access to work experience opportunities and paid employment

Quality

- Person centred reviews and regular monitoring of services are important in maintaining and developing quality services.

- People with learning disabilities are vulnerable to abuse or bullying.
- Joint work with Cambridgeshire Police must continue to ensure protection of vulnerable adults is maintained and to tackle hate crime.
- Managing risk is important, but should be balanced against choice and independence.
- Independent Mental Capacity Advocacy services in line with new guidance will seek to maintain individual's rights.
- Access to preventative services for adults with learning disabilities who may not need an assessed health or social care service will maintain people's independence and well being.
- Guidance and training for appointees will increase skills in administering welfare benefits on behalf of people unable to manage their finances.

Workforce and planning

- A well trained and equipped workforce is vital to meet need.
- Recruitment and retention continues to be an issue.
- Independent sector staff have access to a comprehensive training programme.
- Workforce development needs to evolve and should include an appreciation of
 - Changing roles.
 - The development of individualized budgets.
 - The availability of assistive technology.
- The importance of Diversity Equality Training and raising awareness for the wider workforce about the needs of people with learning disability.
- Training is also needed by family carers and care staff appointed using individual budgets

Partnership

- Adult Support Services and Children's Services need to work to improve the capacity of parents with learning disabilities to raise their children and plan their families
- Services will be sought within generic older people's services where this is more appropriate for older people with learning disabilities.

Next Steps

- The JSNA will inform the Joint Strategic Plan for people with learning disabilities
- It should also influence the PCT and the County Council 's strategies and commissioning plans including the Local Area Agreement.
- It will be made available on both CC and PCT websites.
- An easy read version has been produced.
- The data will be updated yearly.
- The JSNA will be revised in the light of new developments and guidance; changing needs and priorities and ongoing consultation.

2. INTRODUCTION

2.1 Purpose

The Cambridgeshire Joint Strategic Needs Assessment (JSNA) for Adults with Learning Disabilities will describe:

- What we know about the needs of people with learning disabilities
- What we think their future needs are likely to be.

The JSNA will identify and support commissioning and planning priorities.

An Easy read summary is available.

The analysis of data and needs to date has included the views of people with learning disabilities and their families. This has included views identified through Cambridgeshire's User Parliament and carer consultation activities.

2.2 Definitions

2.2.1 Learning Disability

The Department of Health definition describes learning disability as “a state of arrested or incomplete development of mind that includes significant impairment of intelligence and social functioning”. This definition includes people with mild, moderate and severe / profound learning disabilities and generally refers to those who have acquired learning difficulties at or before birth or at an early age. Disability is not categorical but occurs on a continuum.

According to the widely used operational definition of ‘significant impairment of intelligence’, some 2-2.5% of the population have tested IQ scores below 70. Of these, most have mild learning disabilities. Figures obtained from studies screening entire populations have estimated that around 25-30 people per 1000 of the population have mild learning disabilities, of whom about 10 per 1000 will be known to services (N Roeleveld et al. 1997) The Health of the Nation's strategy for people with learning disability indicated a prevalence rate for people severe learning disabilities of between 3 to 4 per 1000 of the population. Amongst both people with mild and severe learning disabilities, there are slightly more men than women.

However diagnosis of learning disability is not an exact science, whilst it is generally accepted that around 2% of the general population is likely to have some form of learning disability this figure includes people with mild disabilities who largely do not require specialist health or social care support.

LAC (92) 15 Social care for adults with learning disabilities, suggests that most people with severe or profound disabilities will require “considerable help in order to live, initially in their homes and later in appropriate residential accommodation”. Those with a mild or moderate degree of learning disability are more likely than the general population “to require additional emotional, mental, health and social support”. Some of these individuals may be people

whose behaviour is perceived as 'challenging' and/or brings them into contact with the criminal justice system.

2.2.2 Autism

Autism spectrum disorders (ASDs) refer to a set of behavioural syndromes of childhood onset characterised by a triad of impairments; in communication, imagination, and social interaction.

It used to be thought that the majority of people meeting criteria for ASDs also had significantly impaired intellectual ability (i.e. a tested full scale IQ score <70). However as more children are diagnosed, it now appears that about 4 in 10 of those with ASDs also meet the intellectual criterion for a learning disability (Baird, G. et al. (2006). It should be noted however, that:

- many people are still being diagnosed for the first time in adulthood and, for this group, the assumption that half will not have a learning disability may be misleading;
- people with ASDs often have patterns of skills that are uneven so that, while they are excluded from support on the basis that their combined (or Full Scale) IQ score is above 70, this is made up of very good performance skills, which are of little use in everyday life, and very poor verbal skills; and
- in some cases, even when the person's tested intellectual ability is uniformly high, in everyday life he or she is unable, because of difficulties associated with the psychopathology of ASDs, to complete many of the most ordinary tasks.

It is now accepted that the belief that 'high functioning' ASDs, such as Asperger's syndrome, are a 'mild' form of autism, is unwarranted (Howlin, 2004).

It is for these reasons that the Department of Health has produced guidance (Department of Health 2006). Amongst people with ASDs, the male : female ratio is about 4:1, raising important issues for appropriate service provision.

2.2.3 Mild Learning Difficulties

Access to Social Care support is only available to those meeting the County Council's eligibility criteria. People with milder learning disabilities as for some people with Aspergers syndrome may not be eligible for social care but may well need assistance to live independently or to manage their tenancy. *Supporting People* funded housing support can be a crucial service that enables independent living. Advice, information and access to low level support from voluntary organisations is often key as part of the broader preventative agenda. Agencies are keen to support and facilitate access to support in order to maintain people's independence within the community.

However, more is known about those people with severe learning disabilities as these people are more likely to be known to the statutory authorities so much of the information in this JSNA relates to adults with moderate / severe learning disability who are accessing services. Nevertheless we do know that people with mild learning disabilities:

- Are at higher risk of physical problems and disabilities than the general population, in part because they are particularly likely to come from disadvantaged backgrounds.
- At greater risk than the general population of mental illness and other mental health problems, and behaviour problems.
- Are more likely to be parents or be carers than those with severe learning disabilities.

- Are more likely than people with severe learning disabilities to come into contact with the criminal justice system if they have behaviour problems and to end up in prison.

2.3 Policy Context

There is clear policy direction set by central government through:

- *Valuing People (DOH 2001)*
- *Our Health Our Care Our Say (DOH 2006)*
- *Strong and Prosperous Communities (Local Gov't White Paper 2006)*
- *Commissioning Framework for Health and Well Being (DOH 2007)*

There are also several influential national reports and guidance which are helping to drive policy and practice:

- *Services for people with learning disabilities and challenging behaviour (Mansell 2007)*
- *Death by Indifference, Mencap, 2007*
- *No one knows, Prison Reform Trust, 2007*

In addition there are sound local policy foundations.

- *Overarching Strategy for Adult Support Services (CCC 2006)*
- *Strategy for the Delivery of Services to People with Disabilities (CCC2006)*
- *Single Equality Strategy. (CCC 2008)*
- *Strategic Commissioning Plan for People with Learning Disabilities (CCC2008)*

In recent years there have been a number of key national NHS + Social Care and Housing policies designed to improve access to and improve the quality of services and support. Some of the most relevant are listed in the references.

2.4 Principles

The Government's White Paper *Valuing People* for people with learning disabilities key themes can be summarised as follows:

- Promoting independence – ensuring that there is person centred planning and named workers for service users.
- Provision of better advice and information for service users and carers.
- Promoting people's rights and access to advocacy.
- Promoting inclusion – access to mainstream rather than specialist provision.
- Addressing the needs of ethnic minorities.
- Increasing choice and control including access to direct payments.
- Improving access to health care (including individualised Health Action Plans and named Health facilitators).
- Promoting a "new role" for specialist learning disability health services.
- Promoting the value of and access to work (paid or voluntary).

In 2007 the Government issued a consultation document called *Valuing People Now*. The main priorities of this are:

- **Personalisation:** People having more choice and control over their lives and services

- **Meaningful daytime opportunities:** What people do, days and evenings including getting a paid job.
- **Fair access to health:** People being healthy and getting a good service from the NHS.
- **Access to housing:** People having more choices about where they live.
- **Making it happen:** the role of the LDP Board and links to Local Area Agreements.

In addition, the recent version of the Mansell Report (2007), which has the status of guidance from the Department of Health, has emphasised the continuing neglect of the needs of people with learning disabilities whose behaviour is seen as ‘challenging’, many of whom remain placed ‘out of area’, often in services that are of poor quality, for long periods of time.

2.5 Local Context

2.5.1 Cambridgeshire County Council Adult Support Services Strategy and Disability Strategy

The responsibility for social care services sits within the County Council’s Adult Social Care service. The Adult Support Services Strategy and Disability Strategy (CCC 2006) set out the strategic direction for services for older people, adults and disabled people that will deliver the critical elements of independence, choice, control and inclusion. The commitment of the County Council and local Health Services to work in partnership to deliver improvements to the lives of the people of Cambridgeshire is well evidenced by current partnership arrangements. The strategies both acknowledge that partnerships with District Councils, housing providers and the voluntary and independent sector are key to delivering change.

The County Council act as “lead commissioners” for the assessment and provision of specialist health care for people with learning disabilities. This is managed by Cambridgeshire Learning Disability Partnership.

2.5.2 Cambridgeshire Learning Disability Partnership

The Cambridgeshire Learning Disability Partnership (the LDP) brings together specialist health and social care services for people with a learning disability. The LDP is responsible for commissioning and providing these services on behalf of Cambridgeshire NHS and Cambridgeshire County Council. Some staff are employed by the County Council and some by Cambridgeshire and Peterborough Foundation Trust, but they are all part of the LDP.

The LDP has a close working relationship with the Cambridgeshire and Peterborough Foundation (CPFT). Health professionals, whilst employed by the CPFT, are managed by the integrated management arrangement within the LDP.

2.5.3 Integrated Community Teams

The Integrated Community Teams provide specialist expertise to facilitate the health, well-being and social inclusion of those with the most complex needs. The exact make up of each Team varies a little, but may include:

- Community Nurses
- Care Managers
- Clinical Psychologists
- Psychiatrist
- Healthcare or Therapy Assistants
- Music Therapist
- Art Therapist
- Occupational Therapist
- Physiotherapist
- Speech & Language Therapist

2.5.4 Current access and provision

Cambridgeshire Learning Disability Partnership covers the District and City Council areas of:

- Cambridge City
- South Cambridgeshire
- East Cambridgeshire
- Fenland
- Huntingdonshire

It also covers what used to account for around 33% of the southern part of Peterborough Primary Care Trust area, but most of this area is now part of Cambridgeshire NHS. People with learning disabilities living in the Whittlesey and Yaxley (which used to be in Peterborough Primary Care Trust) area generally receive services from either Huntingdonshire or Fenland services.

In addition to the integrated community teams, the LDP also directly provides daytime support, respite care and some supported living accommodation in various locations across Cambridgeshire.

However the majority of daytime support, respite care, domiciliary care and supported living accommodation is commissioned by the LDP from a wide range of independent and voluntary sector care providers, acting in partnership with the LDP to deliver high-quality care options for people with a learning disabilities.

The LDP works with over 100 organisations, employing over 1500 staff through these organisations; the LDP also has a central role in delivering specialist health and social care for people with a learning disability. It enables people to live as independently as possible in their local communities, accessing mainstream services wherever feasible.

2.5.5 Eligibility for services

The Teams can give specialist advice, help and support to people with a learning disability and their carers on a range of issues associated with their learning disability, including:

- Assessing health and social care needs.
- Arranging packages of care.
- Assessment, treatment, and management of 'challenging behaviour' including criminal offending.

- Advice to the civil and criminal justice systems about issues relating to decision-making capacity.
- Counselling.
- Communication
- Developing self help, domestic and community skills.
- Epilepsy.
- Health education and health promotion.
- Monitoring mental health issues.
- Sexuality and relationships.
- Caring by people with learning disabilities for children and other dependent relatives /Supporting parents who have a learning disability.
- Help with bereavement and loss.
- Mental health.
- Sexuality, relationships and parenting.

The LDP provides both health and social care support to people with learning disabilities. The way the government arranges and funds health and social care means that there are slightly different rules about who is able to get health support and who is able to get social care services from the LDP. Health support is always free but sometimes there are charges for social care services. Assessments are free in both cases.

2.5.6 Social Care Support

Access to social care support is available only to those who have been assessed as meeting the County Council's eligibility criteria as set out in the Governments Fair Access to Care guidance Appendix 3 (web link also provided below). The majority of social care support is provided through one of the numerous independent providers. Social care might be provided via block or spot contracts with providers. Increasingly however there is a move towards direct payments or individualised budgets where the individual is able to purchase the support they require from their chosen provider.

http://www.cambridgeshire.gov.uk/social/accessing/Eligibility.htm?wbc_purpose=Basic%22%3ewww.cambridgeshire

2.5.7 Provision of services

Whilst the LDP provide some services directly the bulk of services are provided in the local independent sector market. There are well over 100 different providers in county, ranging from small single service providers to large national organisations. Similar diversity is reflected in the type of provider with a range of private individuals, small private companies, local charities, national charities and large independent provider organisations.

Many organisations provide more than one service. There are around 72 residential or nursing providers, the majority providing only residential care. A growing trend has been in the development of supported living providers with around 38 different organisations offering this service and further 14 offering specialist domiciliary support.

Cambridgeshire also has a well developed market of social training, employment and day activity providers with 18 organisations offering a range of day time, work experience or training opportunities.

There are good relationships with providers. An Independent Training Consortium meets bi monthly and Provider Consultative workshops are run twice year. There are provider representatives on the LDP Board and at local *Valuing People* Implementation groups across the county.

To ensure independent providers meet required levels of service and quality there are a number of processes and requirements in place including:

- Service specifications.
- Tendering and contracting process.
- Monitoring of services.
- Regular consultation with independent providers.

2.5.8 Eastern Region Disability Networks

There are a number of Eastern Region Networks that assist the development and implementation of government policy. Currently the Transitions Network are developing a generic Transitions Strategy and have drafted an Out of Area Placements Protocol that has been circulated for comment. The Eastern Region Learning Disability has also circulated a Protocol about Out of Area placements although this predominantly relates to residential placements. These are being adopted locally.

2.5.9 Data Issues

In the main, much of the data used in this JSNA relates to those people with severe learning disabilities as these people are more likely to be known to the statutory authorities. It is acknowledged that the quality and comprehensiveness of the data is limited. A lot of the tables use data from June 2007 covering people known to social care services; this data was extracted from SWIFT, the local authority database, which had been checked and cleansed. These figures will not include all of the users supported by the wider membership of the integrated teams; health professionals will be supporting some people with physical and mental health issues who do not meet the county council's eligibility criteria for social care. Where available we have supplemented this with more up to date information so this may result in some inconsistencies between tables.

Qualitative data is also important in the identification of need. We have used both the views of Cambridgeshire residents with learning disabilities and their carers and also used a large national survey of the views of people with learning disabilities undertaken by Emerson in England (ONS 2006).

Both local and national research has been used to explore and identify needs. We have applied national prevalence figures to the local population as an indicator of local prevalence and needs. However it is emphasised that disability is not categorical but occurs on a continuum.

3. DEMOGRAPHY

Key Messages

- Significant growth in population is anticipated over the next 10 to 15 years.
- A growth in the number of people with complex needs is expected because more babies with more complex needs are surviving into adulthood and people with learning disabilities are living longer and developing additional health needs.
- Much of Cambridgeshire is rural and there are major access and transport issues for people with learning disability, as with the rest of the population.
- Small pockets of diverse population risk being overlooked.
- Travellers represent the largest single ethnic minority group in Cambridgeshire making up about one percent of the population. There is a much higher than national prevalence of learning disability in the Traveller community.
- There is a significant risk that the compounding impact of disability, inequalities and social deprivation will affect health, wellbeing and opportunity and outcomes.
- There is a risk that the needs of people with low level needs or Autistic spectrum being unable to or having difficulty in accessing services.
- The location of people with learning disability is affected by service location, housing costs and development opportunity. As a result of cheaper housing, more people with learning disability live in Fenland.
- There is a need to look at equitable level of access and provision across the county.
- Resources in county need developing to minimise the need for out of county placements.
- Mainstream community services will need to respond to increasing numbers of people with learning disability living in their local community.

3.1 Demography and Geography of Cambridgeshire

Cambridgeshire is a geographically diverse county, incorporating relative urban affluence and poverty in Cambridge City, rural affluence in South Cambridgeshire and parts of Huntingdonshire and East Cambridgeshire, and profound rural poverty in parts of Fenland.

The market towns of Huntingdon and Wisbech also contain areas of more marked ‘urban’ deprivation.

In 2006 there were estimated to be 579,000 people living in Cambridgeshire. Table 1 shows population estimates for 2006 by age bands and Local Authority. More detailed charts are available in Appendix 1. The population forecasts for the county show an overall increase from 2006 to 2021 of about 16%, with significantly higher increases in Cambridge City and South Cambridgeshire.

Table 1: Population forecasts 2006 – 2021, All ages, Local Authority

Year	2006	2011	2016	2021	% change 2006-2021	Absolute change 2006-2021
Cambridge	113,800	131,700	147,700	149,400	31.3%	+35,600
East Cambridgeshire	76,400	80,700	82,200	81,300	6.4%	+4,900
Fenland	89,800	91,700	95,400	99,700	11.0%	+9,900
Huntingdonshire	160,800	168,200	166,000	166,300	3.4%	+5,500
South Cambridgeshire	138,200	150,400	162,000	172,700	25.0%	+34,500
Cambridgeshire	579,000	622,700	653,300	669,400	15.6%	+90,400

Source: Cambridgeshire County Council Research Group 2005-based ward age-group forecasts. Rounded to the nearest hundred. Totals may not add due to rounding

The index of multiple deprivation (2007) uses relatively up to date information on income deprivation, employment deprivation, health and disability, education, housing and geographic access to services. There is a clear north-south pattern across Cambridgeshire, with the majority of the more deprived areas located towards the north of the county, particularly around the Wisbech area. Within Cambridge, deprivation is concentrated to the north and east of the city.

Cambridgeshire Learning Disability Partnership covers both rural and urban areas. Access to and the availability of mainstream community resources and transport varies significantly across the county. This impacts on the ability of people with learning disability to access these community mainstream social and leisure opportunities and paid and voluntary work opportunities and also their ability to participate in their local community.

The level of disadvantage resulting from a learning disability is dependent on a variety of social, psychological and economic factors as well as the severity of the impairment. The levels of deprivation across the county are therefore likely to also impact on the needs of people with learning disability. Adults with learning disability on low incomes and/or those living with elderly relatives are likely to have their ability to access community facilities affect.

3.2 Ethnicity

Cambridgeshire has a small (but growing) ethnic minority population. Gypsies and Travellers make up with largest single ethnic group in the county accounting for approximately 1% of the population. South Asians together make up 2% with 0.9% being Bangladeshi and 0.5% Pakistani.

There is evidence to suggest that the prevalence of learning disability is higher among Traveller communities and also some South Asian populations, probably because of higher levels of material and social deprivation and co-sanguineous marriages which are compounded by poor access to health care and negative practitioner attitudes

Table 2 below shows the estimated number of people with learning disabilities by broad ethnic group. Note that these figures assume that the ethnicity of people with learning disabilities follows the same distribution as the ethnicity of all people in Cambridgeshire. The number of people from the Asian or Asian British ethnic group might be slightly higher than shown here, if the potentially higher prevalence of learning disability among this group were found locally. Numbers of Travellers are included in the White British or White Other groups; Gypsy / Traveller was not a choice on the 2001 census so they are often missed out as a distinct ethnic group. Further detail is available in the appendix.

Table 2: Estimated number of people with learning disabilities by broad ethnic group, 2005

Population	Ethnic Group						
	White British	White Other	Mixed	Asian or Asian British	Black or Black British	Chinese	Other ethnic group
Total population with LD	9,080	520	70	130	60	80	50
People with LD know to services	1,990	120	20	30	10	20	10

Source: Emerson and Hatton (2004) and CCC Research Group mid-2005 population estimates

At a national level there is considerable concern that the needs of people with learning disabilities from ethnic minority groups are inadequately considered.

From Emerson’s national survey (ONS 2006):

“People who described themselves as Black or Asian were more likely to be unemployed, poor, see their friends less often, have poor health and be sad or worried a lot. In addition, people from Asian communities were more likely to have less privacy, feel left out and not feel confident. (p9)”(ref no)

Some areas have large increases in the numbers for migrant workers from new European Union countries who may have limited English and may not know about local services. We would not expect large numbers of migrant workers to have significant learning disabilities but migrant workers may put pressure on local mainstream services such as health and education and on the funding of these services. Also migrant workers may bring in family members with learning disabilities as they settle.

Recorded ethnicity for those with learning disabilities is shown overleaf. The levels known to the LDP in 2005 and 2006 concur with prevalence expectations as can be seen in table 3 overleaf.

Table 3: Recorded Ethnic group of adults with learning difficulties known to social care services in Cambridgeshire in March 2005 and March 2006.

	People with learning difficulties known to services in March 2005 (aged 18+)	People with learning difficulties known to services in March 2006 (aged 18+)
White-British	1786	1890
Not Yet Known	107	123
White-Other	29	31

Not Recorded	15	24
Mixed-Other	7	8
Pakistani	5	6
Asian-Other	3	6
Black-Caribbean	4	5
Other	5	5
White-Irish	8	2
Black-Other	5	2
Indian	4	5
Black-African	2	5
White And Black Caribbean	5	5
Bangladeshi	1	8
White And Asian	2	2
Chinese	2	2
Asian-British	1	2
Irish Heritage Traveller	0	0
Not Relevant	1	0
White And Black African	1	1
Client Declines To Answer	1	1
Roma/Gypsy	1	1
Total	1995	2134

Source: Swift data March 2006

3.3 Demographic profile of people with learning disabilities

Across the total population, 2% of adults are estimated to have some form of learning disability. In Cambridgeshire, this corresponds to around 10,000 people aged 15 and above¹. If local service provision patterns reflected national patterns, we would expect around 2,200 of these people to be receiving support or services through the County Council. Of these, eight out of ten are likely to be aged between 20 and 64, one in ten is likely to be aged between 15 and 19 and one in ten aged over 65.

Cambridgeshire's population is forecast to grow by around 16% between 2006 and 2021. As the total population grows, we would expect the number of people with learning disabilities also to increase. In addition, as people with learning disabilities are living longer and more babies with complex needs are surviving, we would expect increased numbers of people with learning disabilities in the population.

As shown in Table 4, if the prevalence of learning disability were to remain constant, we would expect the number of people with learning disabilities in Cambridgeshire to increase by 15% between 2005 and 2021. If we allow for a small increase in prevalence, the increase would be greater, at around 22%, to a total of 12,800. In terms of the number of people likely to require support, at current prevalence rates we would expect a 12% increase to a total of 2,500; with slightly higher prevalence rates the increase would be higher at 17%, to a total of 2,650.

Table 4: Estimated current and future number of people with learning disabilities in Cambridgeshire

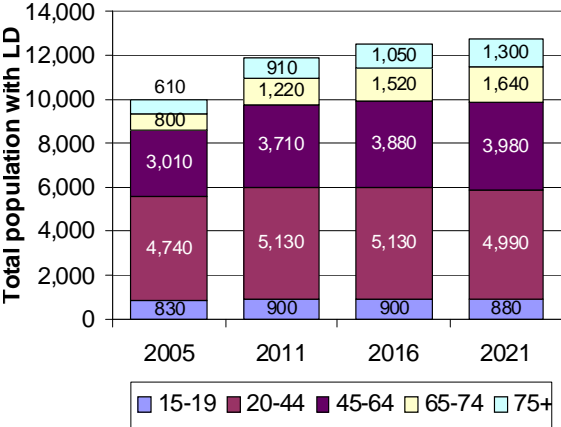
LD population	Future prevalence of LD	Estimate	Forecasts			% change 2005-2021
		2005	2011	2016	2021	
Total people with LD	Remains constant	9,990	11,000	11,510	11,670	14.6%
	Increased	9,990	11,870	12,480	12,790	22.4%
Number of people with LD receiving support	Remains constant	2,200	2,410	2,490	2,490	11.6%
	Increased	2,200	2,520	2,610	2,650	17.2%

Source: Emerson and Hatton (2004) and CCC Research Group mid-2005 population estimates

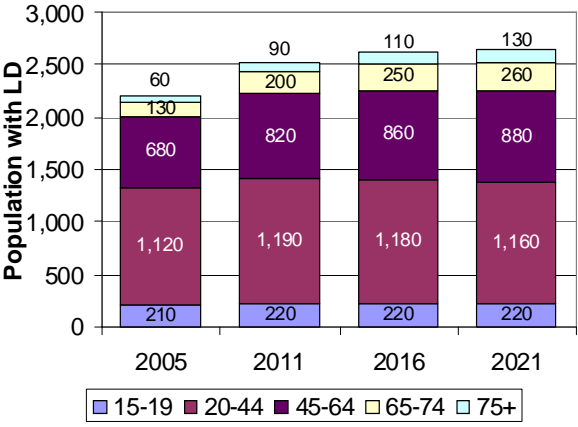
Figure 1 shows the likely age structures of the population with learning disabilities in the future. Although there will be an increase in people of all ages, the greatest increases will be among those aged over 45. The number of people with a learning disability aged over 65 is forecast to more than double by 2021

Figure 1: Estimated Age structure of people with learning disabilities 2005-2021

a) Total population with learning disabilities



b) People with learning disabilities receiving support



Source: Emerson + Hatton (2004) and CCC Research Group mid-2005 population estimates.

3.4 Autistic Spectrum Disorder

It is difficult to give definite numbers for adults with autistic spectrum disorders. There is no doubt however that over the past decade or so there has been an increase in awareness of the condition by families, practitioners and funders². According to The National Autistic Society the prevalence rate is 91 per 10,000 of the population. Based on that prevalence the table below shows the estimated number of people of working age with autistic spectrum disorder in Cambridgeshire by district. Working age is defined as males aged between 16 and 64 and females aged between 16 and 59. For the total number of people with Autistic Spectrum Disorder (ASD) a prevalence rate of 91 per 10,000 of the population was applied to mid-2006 population estimates for Cambridgeshire.

The table below suggests there are likely to be approximately 3,400 people with Autistic Spectrum Disorder (ASD). Of these those with low-functioning autism includes people who meet the criteria for the autistic spectrum and also have a learning disability (IQ<70). This means we would expect 750 people with typical autism who should be known to services.

Those with high functioning autism (IQ>70) includes people with Asperger Syndrome (36 per 10,000 population) and Other Spectrum Syndrome (35 per 10,000 population) and we would expect there to be around 2,650 people in this category. These individuals may not fit the learning disability criteria for services but may still have considerable support needs.

Table 5: Estimated number of people of working age with Autistic Spectrum Disorder in Cambridgeshire by district

Local Authority	Total 18 – 64 years	People with ASD (IQ<70)	Kanner Autism	Other Spectrum Disorder	People with learning disabilities (IQ>70)	Asperger Syndrome	Other Spectrum Disorder	Total people with ASD
Cambridge City	82,180	160	40	120	580	300	290	750
East Cambridgeshire	47,380	90	20	70	340	170	170	430
Fenland	54,170	110	30	80	380	200	190	490
Huntingdonshire	102,880	210	50	150	730	370	360	940
South Cambridgeshire	87,010	170	40	130	620	310	300	790
Cambridgeshire Total	373,610	750	190	560	2,650	1,340	1,310	3,400

Source: Paul Shattock & Paul Whiteley, “The changing prevalence of autism?”, Autism Research Unit, University of Sunderland & Cambridgeshire County Council Research Group, mid-2006 population figures. Number may not add due to rounding.

Some years ago it was considered that about 70% of people meeting criteria for the autistic spectrum also had a learning disability. However, this figure is changing as more people with Asperger’s syndrome and high functioning autism are identified, now it is generally considered that only about 20% to 40% of those meeting criteria for an autistic spectrum disorder also have a LD. These people would by definition meet the access criteria for Learning Disabilities services. Therefore, all community teams have people with autism and Learning Disabilities on their caseload.

The reliance on IQ alone in assessing whether people with ASD meet the criteria for services has been criticised. People with ASD often have patterns of skills that are uneven, and some people are excluded because their skills’ scores combined come above IQ 70 and therefore do not have access to Learning Disability services. People with ASD have a range of needs that will not be addressed by one agency. Within the current arrangements the needs of people with ASD are not easily met by the current service provision in either adult mental health or learning disability services. The Cambridgeshire and Peterborough Mental Health Partnership NHS Trust (2005) has highlighted the need for a clear lead within both mental health and learning disability services to prevent people being passed between the two services or not receiving any services at all.

3.5 Demography of Cambridgeshire’s service users

This section provides a demographic profile of Cambridgeshire’s service users, comparing the observed profile with that of Cambridgeshire’s total population and of national prevalence rates for learning disability.

The LDP Teams currently provide health or social care support or advice in some way to around 2,230 individuals with learning disability. All of these **do not** receive a social care funded package or regular support which is why the figure is larger than that identified by the council’s SWIFT information alone. Health professionals within the teams offer support to

individuals who may not meet the Council’s eligibility criteria. These broader figures concur with the levels we would expect for Cambridgeshire (table 2). The geographic spread of this broader number of individuals in contact with the LDP is not equitable across the county. 50% are linked to the South and City Area teams, the reason for the inconsistent spread is due to historic and service development reasons.

Table 6 below presents the age and gender profile of the 1,704 people with learning disabilities known to the Social Care element of Cambridgeshire Learning Disabilities Partnership (LDP) in June 2007. 52% of service users are male and 48% are female, compared to Cambridgeshire’s total population where 49% of those aged 15+ are male and 51% are female.

Table 6: Age and gender of service users

Figure 2: Age and gender profile

Source: Head, V., MPhil dissertation “A new geography of learning disability?” University of Cambridge, 2007

Age Group	Gender			Total
	Male	Female	Unknown	
5-9	1			1
15-19	42	20		62
20-24	144	106	3	253
25-29	91	93	1	185
30-34	96	82		178
35-39	105	92	1	198
40-44	93	81	2	176
45-49	82	79	1	162
50-54	78	79	4	161
55-59	68	72	1	141
60-64	50	50	2	102
65-69	13	15		28
70-74	12	12		24
75-79	5	8		13
80+	2	8		10
Unknown	3	7		10
Total	885	804	15	1,704

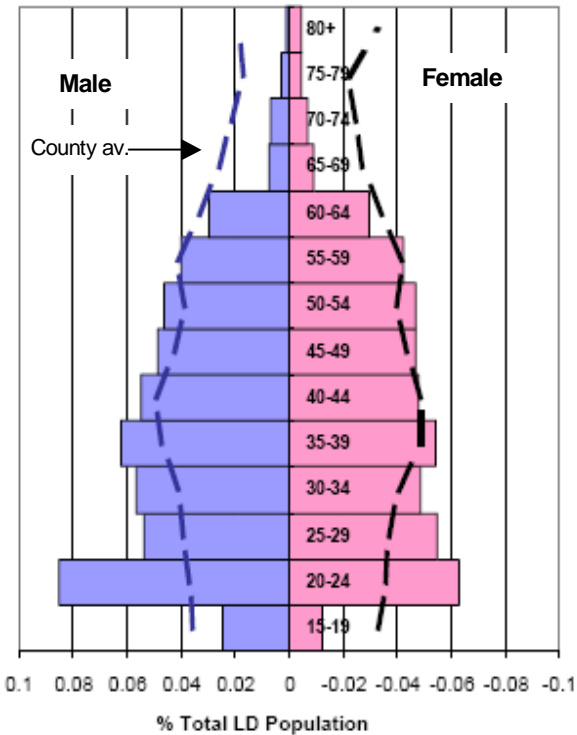
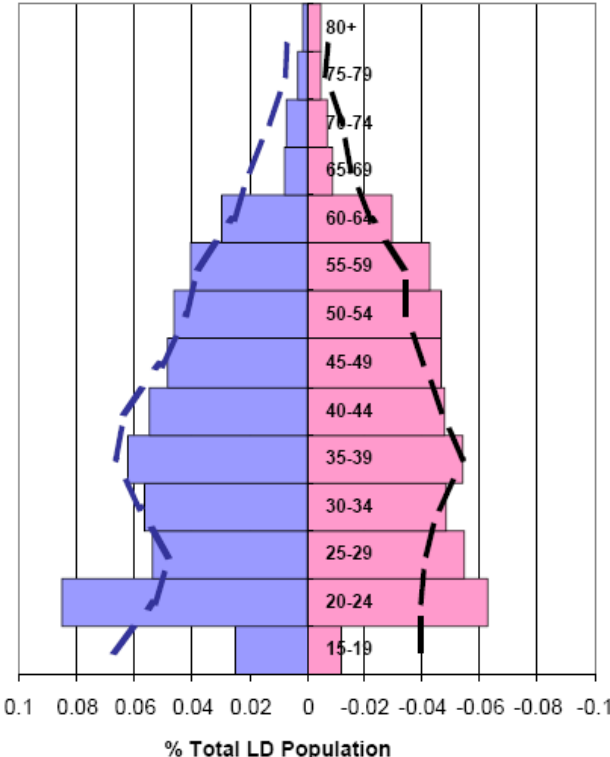


Figure 2 above compares the age and gender profile of service users with that of Cambridgeshire’s total population. Service users have a younger age profile than the overall population. Just a small proportion of service users are aged 15 to 19 because many people of this age are still in full time education and therefore have yet to come into contact with the Learning Disabilities Partnership. At the time a small number of LDP staff were working with children. The LDP works with adults with learning disabilities. A much higher proportion of service users are aged 20 to 24 than seen in the total population. This may reflect an underlying increase in the prevalence of learning disability, or may result from the way that services are structured. It is possible that during ‘transition’, when young people transfer from education-based services to adult services, a high proportion receive support in the form of training for work programmes or supported living.

As they grow older, they may cease to receive support, perhaps because they move into employment, such that a higher proportion of people are not known to services and some will die younger than the rest of the population. Only a small number of service users are aged

over 65. In part this may reflect the lower life expectancy found among people with some learning disabilities such as Down’s Syndrome. However, it is also possible that some people may be transferred to services for older people and are therefore no longer supported by the Learning Disability Partnership.

Figure 3: Age and gender structure of Cambridgeshire LD service users compared to Emerson and Hatton (2004a)



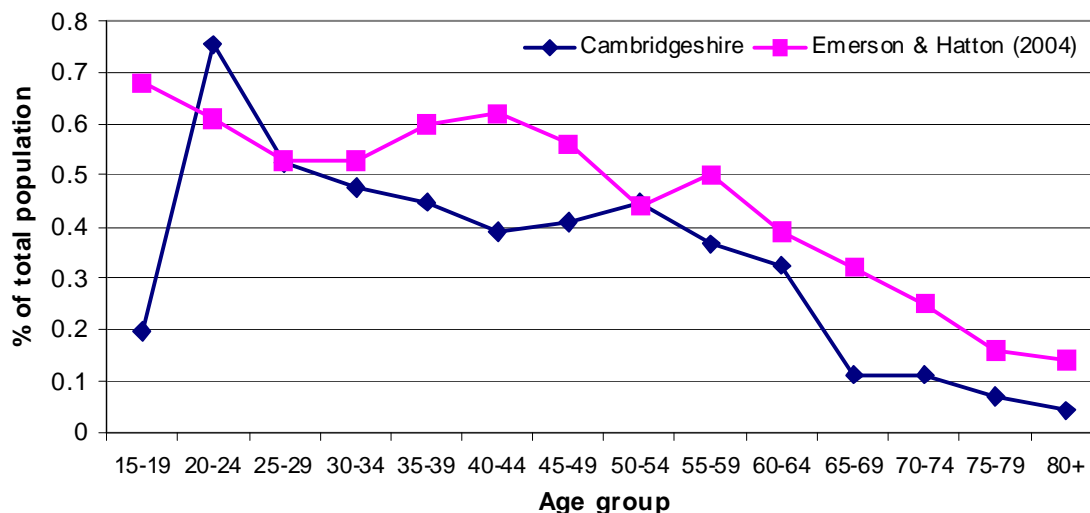
Source: Head, V., MPhil dissertation “A new geography of learning disability?”, University of Cambridge 2007.

Figure 3 compares the age and gender profile of learning disability service users in Cambridgeshire with Emerson and Hatton’s (2004a) ‘administrative population’ prevalence estimates. Again, this shows a high proportion of 20 to 24 year olds in Cambridgeshire and a low proportion of 15 to 19 year olds and over 65s. Within the 25 to 59 age groups, the age profile is more similar to Emerson and Hatton’s. A slight bulge can be seen in both the Cambridgeshire and national age structures at 35 to 39, although it is perhaps less pronounced in Cambridgeshire. Although apparent, the gender bias towards males is less in Cambridgeshire than estimated by Emerson and Hatton (2004a), who suggest that nationally around 56% of LD service users are male.

3.6 Impact of growth

Growing numbers of people with complex and multiple disabilities. More and better skilled staff required to provide care, increasing need for specialised transport and more accessible buildings with appropriate toilets, changing areas and lifting equipment in the wider environment.

Figure 4: Age-specific prevalence rates of LD service users in Cambridgeshire compared to Emerson & Hatton (2004)



Source: Head, V., MPhil dissertation “A new geography of learning disability?”, University of Cambridge, 2007.

Figure 4 compares the age-specific prevalence rates of LD service use in Cambridgeshire with those estimated by Emerson and Hatton (2004a). Aside from the 15 to 19 age group, described previously, both show a general decline in prevalence as age increases. Prevalence is lower in Cambridgeshire at most ages, with the most similar prevalence occurring at 25 to 29 and 50 to 54.

3.7 Local authority of residence

Of Cambridgeshire’s 1,704 social care service users in June 2007, 1,510 were resident within Cambridgeshire (88.6%), 163 were resident outside Cambridgeshire (9.6%) although some of these were living on our boundaries. 31(1.8%) service users address details were not properly recorded. This section considers the distribution of service users between local authorities, first in terms of those living outside the county, and then those living across Cambridgeshire’s five local authority districts.

Map 1 overleaf shows the distribution of service users living outside Cambridgeshire in June 2007. As might be expected, the counties hosting the highest number of service users are those immediately surrounding Cambridgeshire. Of the 163 living outside Cambridgeshire, 40 service users live in Norfolk (of whom just under half live in King’s Lynn and West Norfolk district, which borders Cambridgeshire and covers part of Wisbech) and 21 live in Peterborough.

small numbers, including places as far away as Devon, Cornwall and Northumberland. A further two people live in Scotland and one lives in Wales.

Those placed out of county will receive local health services that may not be adequately resourced to meet their needs in addition to the local population. Likewise, people with learning disability from other counties placed in Cambridgeshire will access our primary care, secondary and sometimes specialist health services that may equally not be adequately resourced to meet their needs. Improved monitoring of people placed into Cambridgeshire is required.

The majority of out of county placements are due to the complexity of the service users' needs and/ or the lack of specialised suitable facilities within the county. There are at least 2 distinct groups that need to be considered:

a, People in semi-secure or high-secure NHS or independent sector hospital placements, detained for treatment under the Mental Health Act. All of these are 100% NHS funded and have normally been placed as a result of challenging behaviour, mostly of a kind that brought them into contact with the criminal justice system. With appropriate social care support and forward planning, many of these people could be cared for in the community, within the county.

b, People in enhanced residential or supported living placements. They have complex needs beyond those normally managed in social care settings, but few if any have needs that could not be managed locally with adequately resourced social care provision. They are split funded according to various formulae.

Within Cambridgeshire housing and support services are currently provided in a range of models either provided by statutory agencies (Social Services in-house or Mental Health Trust), voluntary, or independent providers. The Housing section covers this in more detail. A small but increasing number of individuals live in their own / shared ownership properties. Further details of the geographic spread are shown in the next section.

3.8 Cambridgeshire residents

Table 6 shows the number of service users that would be expected to live in each district, if service users were equally distributed across the county according to the distribution of the total population. The standardised ratio³ of service users is shown, along with 95% confidence intervals.

If one used the figures of people using Social care services it would appear that overall, Cambridgeshire had fewer resident service users than expected because around 10% live outside the county. However just as Cambridgeshire have individuals placed in other local authorities so too are people placed in Cambridgeshire from other local authority areas.

The figures quoted in tables 6, 7 and 8 refer to those users receiving social care services. The wider integrated teams workload is higher as it includes users with specific health or psychiatric problems, some of whom are not be eligible for social care, but are under the care of health professionals.

Table 7: LD service users by local authority district of residence - observed and expected

The standardised ratio of service users is the observed number of service users in a district divided by the expected number based on the district’s population and Cambridgeshire’s average age-specific prevalence of service users.

Local authority district	LD service users	Expected number of service users	Standardised ratio of service users	95% Confidence Interval
Cambridge City *	244	332	0.74	0.64 - 0.83
East Cambridgeshire	197	221	0.89	0.77 - 1.02
Fenland	347	257	1.35	1.21 - 1.49
Huntingdonshire	384	479	0.80	0.72 - 0.88
South Cambridgeshire *	338	405	0.84	0.75 - 0.92
Total	1,510	1,693	0.89	0.85 - 0.94

* Includes adjustment to include all living in the Cambridge City urban area within the data for Cambridge City

CI (95%) = Standardised ratio ± (1.96 × Standard Error); Standard Error = Standardised Ratio / √n
Source: Head .V Mphil “A new geography of learning disability” University of Cambridge 2007

However using the figures of people using Social care services the ratios for East Cambridgeshire, Huntingdonshire and South Cambridgeshire are similar to that of the county as whole; in East Cambridgeshire the ratio of observed to expected does not differ significantly from one. Cambridge City has 26% fewer resident service users than expected; this difference is significantly lower than average for the county. Fenland has 35% more service users than expected; this difference is significantly higher than the county average and significantly higher than one. This is partly due to recent service developments and the cheaper cost of housing in the north of the county. The table therefore suggests that service users are unequally distributed between the Cambridgeshire districts, with fewer than expected in Cambridge City and more than expected in Fenland

However Table 8 shows the observed and expected caseloads by Key Team which shows a different pattern with higher than expected caseloads for Fenland and Cambridge City, and lower for South Cambridgeshire.

Table 8: Observed and expected Key Team caseload

Service users	Key Team				
	Cambridge City	East Cambs	Fenland	Hunt’shire	South Cambs
Observed Key Team caseload	379	197	370	454	304
Expected Key Team caseload	332	221	257	479	405
Ratio Observed:Expected caseload	1.14	0.89	1.44	0.95	0.75
95% Confidence interval	1.03-1.26	0.77-1.02	1.29-1.59	0.86-1.04	0.67-0.84

Source: Head, V., MPhil dissertation “A new geography of learning disability?”, University of Cambridge, 2007.

Table 8 considers service users according to both their Key Team and their local authority district of residence. This gives an indication of the extent to which service users are now living in the area to which they have ties. Across Cambridgeshire, just over three quarters of service users lived in the same district as their Key Team allocation, although this proportion varied for different Teams. In all districts, except for Cambridge City, around 80% or more of the Key Teams’ caseloads lived within the district. In Cambridge City just 61% of the caseload lived within the district; 26% lived in other districts within Cambridgeshire and a

further 11% lived outside the county. This was the highest proportion of out-of-county placements across the Teams; the lowest was East Cambridgeshire, where just 6% lived outside the county.

Table 9: Residential location by Key Team

Service users	Key Team					Total
	Cambridge City	East Cambs	Fenland	Hunt'shire	South Cambs	
Number living in district	232	170	301	358	245	1293
Total in other Cambs districts	97	11	29	35	32	217
Total living outside Cambs	42	12	35	50	25	163
No address	8	4	5	11	2	31
% Living within district	61.2%	86.3%	81.4%	78.9%	80.6%	75.9%
% Living in other Cambs districts	25.6%	5.6%	7.8%	7.7%	10.5%	12.7%
% Living outside Cambridgeshire	11.1%	6.1%	9.5%	11.0%	8.2%	9.6%
Ratio Residents:Key Team caseload	0.64	1.00	0.94	0.85	1.11	0.89
95% Confidence interval	0.56-0.72	0.86-1.14	0.84-1.04	0.76-0.93	0.99-1.23	0.84-0.93

Source: Head, V., MPhil dissertation "A new geography of learning disability?", University of Cambridge, 2007.

Table 9 also shows the ratio of the number of service users living in each district to the number on each Key Team's social care caseload. This gives an idea of the extent to which people with links to particular areas go on to live within that area. East Cambridgeshire has the same number of service user residents as on the Key Team's caseload. In South Cambridgeshire there are 11% more service user residents than on the social care caseload. Fenland, Huntingdonshire and Cambridge City all have fewer service user residents than reflected by the social care caseloads, although in Fenland's case the difference is not significant. The greatest difference is found in Cambridge City, where the number of residents is 36% lower than the caseload. This could imply that Cambridge City, Fenland and Huntingdonshire are net 'importers' of service users, while South Cambridgeshire is a net 'exporters'. Some case records may have still been allocated to their originating teams at the time the data was interrogated. Further information regarding types of area and type of residence can be found in section 7 on Housing.

3.9 Service Uptake

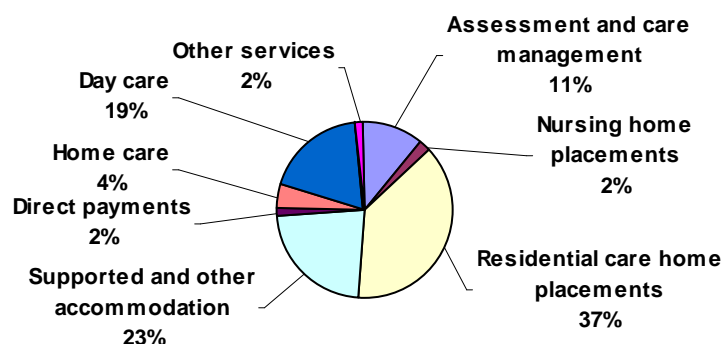
3.9.1 Assessments and reviews

The nature of learning disabilities means that the number of new referrals is lower than that in some other client groupings. However individuals require regular reviews or reassessments. During 2006/2007 64 new people with learning difficulties had completed assessments. The known "population" to teams remains fairly static. The main growth to the adult teams being young people moving into adult services.

3.9.2 Expenditure

The chart below shows the proportional spend of social care funds in Cambridgeshire learning disability services. The chart is encouraging in comparison with the national picture (Getting to Grips with the Money CSIP 2007). Twice the number of people with learning disabilities are using direct payments in Cambridgeshire compared to the national average. The proportion of funds spent on residential and nursing care is smaller than the national average and balanced by a larger than average spend on supported living.

**Spending on personal social services
for people with learning disabilities -
Cambridgeshire**



From Emerson's national survey (ONS 2006):

- *“One in fifteen of the people we interviewed (7%) had children. Of the people who had children, just over half (52%) looked after their children”.*
- *81% had help in looking after children and 21% would like more help.*
- *26% live with someone elderly, ill or has disability*
- *“Men were more likely to have less privacy in their home, see friends who have learning difficulties less often, be a victim of crime and smoke.*
- *Women were more likely to be unemployed, have been bullied at school, attend a day centre, not exercise, feel sad or worried.*
- *Younger people were more likely to live in unsuitable accommodation, have less privacy at home, not have a voluntary job, have been bullied at school, be poor, not have voted, not know about local self-advocacy groups. They were also more likely to not feel safe, be bullied, be a victim of crime, smoke, be unhappy, feel sad or worried, left out and helpless and not feel confident.*
- *Older people were more likely to not be taking a course, have no control over their money, see friends who do not have learning difficulties less often, do fewer community-based activities, have poor health and to not exercise”.*

4. CHILDREN, YOUNG PEOPLE AND TRANSITIONS INTO ADULT LIFE

To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family, and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment. (*Valuing People DOH 2001*)

Key Messages

- If a child with learning disability is placed out of county for schooling there is risk they will not return or the transition process to adult services will be more difficult.
- Experience in childhood impacts future expectations and opportunities.
- Need for forward planning and accommodation options to be considered at an early stage
- Increased expectations from families and young people may impact on budget and opportunities.
- Access to information, person centred approaches, FE education and forward planning are key for the life chances and wellbeing of families and young people.
- New transitions protocols underpinned by person centered planning.
- Recent development of in county FE provision having positive impact.

4.1 Context

This JSNA covers adults with learning difficulties; children with learning disabilities are covered in the JSNA for Children and Young People. However clearly the level and provision of support and services received as children and young people will impact on future abilities, needs and expectations. Valuing People's expectation is that disabled children should gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed eligible needs are adequately met and reviewed. These expectations follow on through to adulthood. In Cambridgeshire all partners are working towards the removal of barriers which disabled children face, whether environmental, cultural or attitudinal.

4.2 Education

Education has significant bearing upon future opportunities to access employment and social inclusion, both of which impact upon mental health. Currently opportunities exist for attendance at one of the Special Needs Schools or within mainstream schools, with discreet support. Children and young people may also be placed Out of County in order to go to a special school to meet their educational needs. Out of County solutions are generally seen as a last resort. Issues can occur when comprehensive planning is needed to enable the young person to return to the county as a young adult.

From Emerson's national survey (ONS 2006):

- *“Nearly three in four people (72%) went to a special school. One in ten (10%) went to a special unit in a mainstream school. Less than one in five (18%) went to ordinary classes in mainstream school. The numbers changed a lot with age of person interviewed”.*
- *43% were bullied at school*
- *Of those aged under 25, 43% left school with at least one qualification.*
- *Of those aged under 25, 52% were attending school/ college and 36% of people of all ages were currently doing some kind of course or training*

4.3 Accommodation

Whilst younger children might be accommodated by the local authority in foster placements we are aware that there are small numbers of 16 – 18 year olds who for different reasons might need access to long term accommodation. There is a danger that if solutions are not available when these situations occur particularly with family emergencies the young person may move to out of county placements.

Plans are currently being developed to re-provide an existing respite unit to develop a more suitable facility. The new unit will offer an opportunity to support young people who would have been at risk of being placed out of county and also medium term accommodation to return young people in current out of county placements. The facility will enable individuals to develop social and independence skills and support families.

The draft Cambridgeshire Disability Housing Strategy states the importance of forward planning to take account of 16+ needs to avoid the need for out of county placement. It will be important to develop working practices and a protocol between local housing authorities and social care including young people with an aim if possible to include 16+ young people when planning future housing and support options. Plans are already in place to take this forward.

4.4 Expectations

Valuing People notes that as young people with learning disabilities move into adulthood, they need continuity of care and support for the young person and their family. This is seen as vital to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

This has not always been the experience in the past by families and young people in Cambridgeshire. There have been inconsistencies of experience leading on occasions to poor transitions and planning. Following Cambridgeshire's Joint Area Review a member led Scrutiny review was undertaken leading to a substantial "Life after School" report (CCC 2007). The main issues and shortfalls identified were in respect to: limited information; poor access to Further Education, limited training and employment opportunities; a poorly co-ordinated response to transitions planning and limited person centred services.

4.5 Actions Undertaken

Since the review significant progress has been achieved both in operational and strategic development. A Transitions Partnership Board has been established bringing together Adult and Children social care services and other key strategic partners who have responsibility for transition. Members use the Board as the primary strategic focal point for Transition arrangements for young people with community care needs when considering changes in service and policy that may impact upon other Board stakeholders. Actions are undertaken by a multi-agency Senior Operations group.

Information has been produced and distributed including a 14+ Information pack distributed to all year 9 pupils. In addition to written materials there is web based information and a DVD. Most recently additional resources have been identified and allocated to the "Transitions Team". The Team's responsibilities will expand as a result to include care planning for when a young person becomes supported by adult services. Team Members may sometimes be case accountable for a short period following transfer to adult services to enable adult support arrangements to be successfully implemented.

At a local level the Early Identification of Need (EIN) is vital to ensure forward planning is undertaken. Area Transition Review Groups based around the geographic make up of Team areas: (Cambridge South and City; Huntingdonshire; Fenland and East) provide a planning and review forum for key partners to ensure a smooth Pathway through Transition to adult services for young people with community care needs. Membership is agreed and attendance is generally good.

Significant progress has been made in undertaking Person Centred 14+ Reviews. Following a successful pilot a Transitions 14+ review Toolkit has been created and the format is to be cascaded across the county. These aim to:

- Identify and discuss what people like to admire about the young person; what is important to the young person (now and for the future); and what help and support the young person needs.
- Identify and discuss what is working and not working from different perspectives (the young person, the staff/school, the family and others).
- Undertake the statutory duties to review the Statement of Special Educational Needs (SSEN).

4.6 Ongoing Needs

The needs of young people, and their families in this transitional phase remain the same. They need a clear point of contact, good information, choice and co-ordinated support. Delays in identifying, assessing or planning support can be costly in time, family stress and actual costs of support.

At present there are still some issues around consistency of approach, delays in identification, late allocation of care management and lack of choice and control. It is anticipated that as the enhanced Transitions Team and the revised referral protocol are embedded in to practice these variations of quality will diminish.

Current key pressures include:

- Current demand to work with 18 years olds is meaning forward planning is being delayed.
- Limited availability of care managers in teams resulting in late allocation of care management resulting in anxiety in families, as care packages have still to be agreed.
- Increasing number of people with high support needs reaching adulthood has resulted in a high demand on Adult Social care budgets
- Inconsistent involvement / information from health to ensure smooth transition over health issues.

Although the move towards self directed support (personalised budgets) and person centred support plans should make choice and forward planning a little easier in the longer term. The reported poor levels of care managers in teams continue to impact. It is also hoped that applications for Independent Living Funds will be made at an earlier stage.

During 2008 the Transitions Team will be expanded with 3 additional Transitions Care Managers to be appointed and additional Team Manager time. They will also begin to develop/set up services with young people for their social care support from 19 taking young people through to their first review of care after 19. Processes have been put in place to develop a robust budget forecast to meet the needs of young people in the year 2009 – 2010.

4.7 Health

Section 7 will look in more detail about the Health needs of people with learning disabilities however there are some specific needs relating to the transition from Children's to adult health care. Family carers report significant anxiety as they feel the process is confusing and uncertain. The move from a single "point of contact" to a multi-professional mainstream approach is reported as difficult by families. The planned review of the transitions protocol and EIN intends to explore how this can be improved. Families want to have clear information regarding who and when takes over responsibility and where their dependents health needs can be addressed.

4.8 Further Education Opportunities

People with learning disabilities and their families report a wish to receive choice and opportunities within Cambridgeshire although there are still some individuals who opt for specialised FE provision out of county.

Local FE Colleges run a number of discreet courses for people with learning disabilities. A smaller number of individuals have opportunities to be supported in mainstream courses. Partnership arrangements also exist with the Social Training Enterprises where worked based training is provided. Historically some people with higher support needs have found accessing FE provision difficult however new initiatives have been addressing this issue.

Following on from a LSC funded pilot for people with higher support needs the Improving Choice FE provision is continuing to develop. Learning from the successful pilots in Huntingdon Regional College (Autism spectrum) and Cambridge Regional College (Bespoke packages) is being used to enhance and develop FE service provision. The success has been partly attributed to using a broker to liaise between Connexions Personal Advisors, FE colleges, families and social care supporters. The “Broker” role is acknowledged to be a key aspect to the success of enabling individuals with quite complex needs to remain in county to receive their further education. Locally there is a commitment to retaining this post, the region are also exploring Learning Skills funding to retain the post.

The Improving Choice opportunity has now also been extended to cover the Fenland area of the county. Huntingdon Regional College, Cambridge Regional College, Peterborough Regional College, Sense East and the College of West Anglia all now deliver education to young people who require an individual package of support due to their complex needs. These were often young people who previously stopped their education at 19 or would have gone to an out of county college.

In 2006/07 330 learners took up out-of-county placements and 93 learners (22%) remained in-county For 2007/08 274 learners have taken up out-of-county placements with 162 learners (37%) remaining in-county. Young people who have left the course have gone on to enter mainstream course, take up places working within social firms and volunteering in the community. These were all young people who previously were not able, due to the extent of their needs, to access these provisions.

Improving Choice Learners	
Year	Number of Learners
2005-06	31
2006-07	94
2007-08	186
Specialist College Placements	
Year	Number of Learners
2005-06	348
2006-07	332
2007-08	272

4.9 Continuing work

Many local authorities have a transition to adult services at 18 years. Historic provision means Cambridgeshire retain a transition into adult social care at 19years. An “in principle” decision has been made that this will move to 18 years although the exact timescales and process of this has yet to be clarified. The Connexions service remains an important component of the transition from children to adult life.

Other on going work is also looking to:

- Identify work opportunities and aspirations with disabled people at an earlier age (14+) to prepare young people for work, identify vocational skills and to develop an expectation of work.

- work with individuals to identify the most suitable work-focused training opportunities for them post-16 or -19, including college, social training enterprises or other programmes.
- develop appropriate capacity within Cambridgeshire (across day services, housing and support) to minimise the requirement for people to go out-of-county, and to provide the opportunity for people currently out-of-county to return
- ensure continuity in the advice and support provided to disabled people and parents/carers – both in the transition to adulthood and in later life, to maintain expectations and progression towards volunteering or paid work.

In the longer term the Transitions Board has agreed a need to move toward transitions to adult services for young people with disabilities at 18.

Further work is also planned to further improve the 14+ review issues currently include:

- Possibility of insufficient opportunities for difficult/sensitive conversation in front of Young Person and more difficult conversation regarding Post 16
- Complications of personalising – resources, symbols, communication etc
- Timing of Review during school year in relation to preparatory work and Connexions interviews
- Code of Practice guidance is currently not always implemented

Budget Pressures

Pressures on budgets remain a concern. In 2008/09 there are 43 young people moving into adult services. The estimated cost for support services is in the region of £2.8 million.

5. CHOICE AND CONTROL

To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need. (*Valuing People DOH 2001*)

Key Messages

- Access to good information, advocacy and Person centred planning underpin choice and control and opportunities for self directed support.
- Continued access to direct payments and the implementation of self directed support will enhance individualised arrangements and develop a greater focus on self-advocacy.
- Services need to develop to better meet the individualized and cultural needs of people from diverse communities.
- Users and carers wish to influence and drive service improvements.
- Advice, training and information services need to be developed further.
- Advice, training and information services need to be developed further to meet the changing needs relating to self-directed support.
- Developments to increase access to individual budgets needs to ensure equity or access within budget.
- Some service users and carers may need support and advice to manage individual budgets.

5.1 Personalisation

The Governments priority is " to put people first, through a radical reform of public services, enabling people to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, well-being and dignity." This wish to have as much choice and control as possible over their lives through advocacy and a person-centred approach is also the wish of people with learning disability and their families.

From Emerson's national survey (ONS 2006):

- *Just over half of the people asked (54%) said someone else decided how much money they could spend each week and 82% have some help in managing their money. 54% said someone else received their benefits.*
- *39% attend a day centre and 42% of those attended 5 days a week*

- “Just over one in ten (12%) said that someone else decided what they could spend their money on.
- About half of the people we talked to (54%) had an independent advocate
- One in five people (20%) were aware of a self-advocacy group in their area. About one in thirty of all people we talked to (3%) regularly attended self advocacy groups”.
- When asked if people with learning difficulties “needed someone to go with them when they needed to get somewhere, over half the people... (57%) said they did need someone to go with them”.
- “Nearly one in three people (29%) said they did not feel safe using public transport.
- Altogether, one in three people (32%) said they did not feel safe either in their homes, their local area or using public transport”.
- “Over one in three of people (38%) said they had heard about Direct Payments. Just under one in five people (19%) were receiving them”.

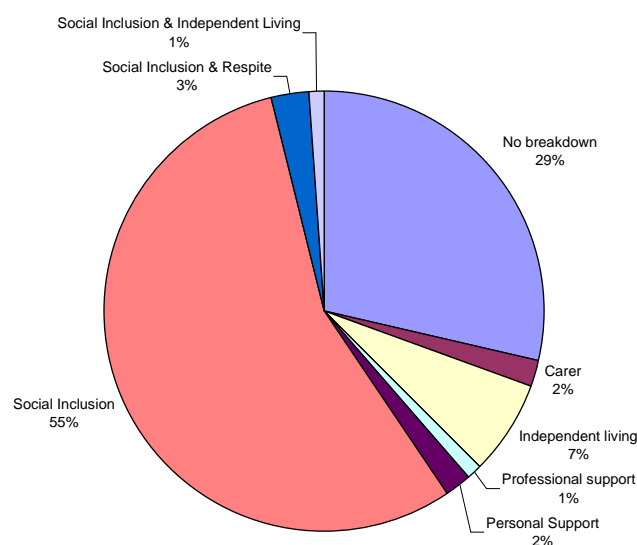
In summary we know that people with learning disabilities and their carers want:

- To feel valued and be respected and to be free from unfair treatment.
- To have information about what is available
- To make choices and have control

5.2 Direct payments

Cambridgeshire already promotes access to Direct payments enabling individuals to purchase the type of service they need. In June 2007, 59% of all direct payments went to social inclusion services this would include access to Social Training Enterprise and day time activities.

Figure 5: Service breakdown of direct payments, June 2007



Source: SWIFT data, Cambridgeshire County Council, June 2007

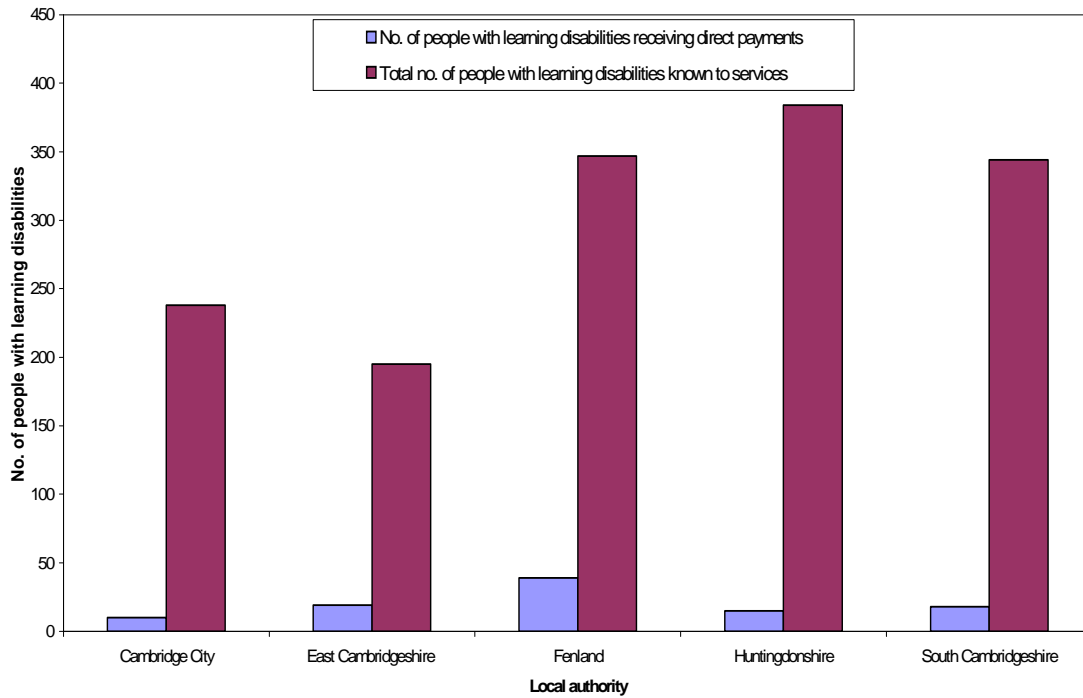
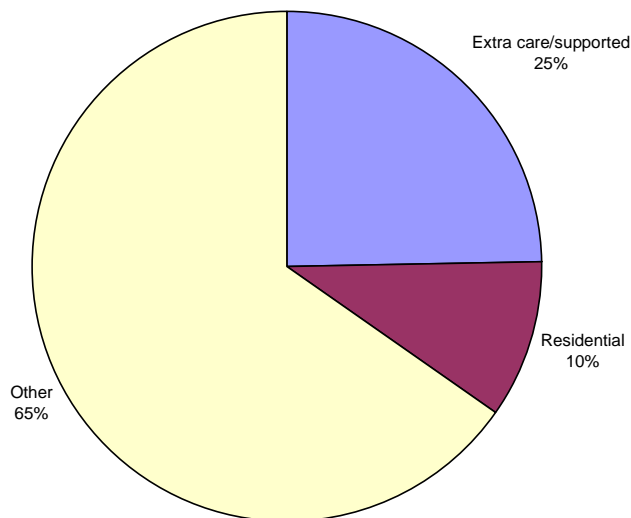


Table: Number of people receiving direct payments by district
Source: SWIFT data, Cambridgeshire County Council, June 2007

There were 101 people with learning disabilities, or 6% of those who are known to services, receiving direct payments in Cambridgeshire in June 2007. The chart below shows the distribution of those according to residency. Fenland has the highest proportion of people receiving direct payments with 11% of people with learning disabilities who are known to services followed closely by East Cambridgeshire at 10%. A lower proportion is receiving direct payments in Cambridge city (4%), Huntingdonshire (4%) and South Cambridgeshire (5%).

Figure 6: Direct payments by home type, June 2007



5.3 Self directed support / Individual Budgets

In addition to the growth of people using Direct Payments Cambridgeshire is also increasing the numbers of people using individualised budgets. The aim of self directed support or individual budgets is to give recipients of social care and associated services increased opportunities to design a package of services that meets their specific needs. Service users will be given a notional or cash sum of funding to use in developing their care package. This can be provided either as a direct payment or in the form of commissioned services. The principles of choice and control are critical to this policy development.

Individual Budgets can, in the longer term, include a variety of existing service and funding streams including Local Authority provided social care services, Supporting People, Independent Living Fund, Community Equipment Services, Access to Work and Disabled Facilities Grants. Cambridgeshire are currently introducing individual budgets

5.4 Person Centred Planning

Person Centred planning must remain the key underpinning principle to gaining more choice and control. Recent initiatives have included:

- Grant funding independent voluntary groups
- Appointment of PCP review staff to prioritise day service users
- Appointment of Family Support Co-ordinators to support Individualised budget / self directed support.

5.5 Advocacy

Access to support to speak up and voice your views and needs is a basic right. Whilst Cambridgeshire has Advocacy organisations providing these services funding is not always secure. The LDP invests in a Community Advocacy service for disabled adults providing short term, issue based advocacy. Speaking Up enhance this investment through grant submissions, recently £160,000 has been awarded to them for the provision of additional services aimed at young people with learning disabilities up to the age of 25 years and to parents with learning disabilities.

A separate Independent Mental Capacity Advocate (IMCA) service is commissioned service by the County Council as lead for the county. The criteria for the service is very specific.

The LDP also fund a separate User Participation Contract partly funding the Cambridgeshire User Parliament. This contract also facilitates user involvement in the LDP Board and other planning and development forums

An independent advocacy service called Cambridgeshire Advocacy Service is currently providing for people with profound disabilities. The complex needs of these individuals make the need to access advocacy important. The time needed to ensure that people with profound disabilities are understood and supported to raise their needs is lengthy.

Requests for more general support for individuals may sometimes not be met as resources are limited. Pressure areas include:

- People who cannot advocate and have services changed with limited choice
- Those living in rural areas with little or no services or networks

5.6 Communication and Information

Consultation with people with learning disabilities and their carers has indicated that the provision of advice and information is a significant issue of concern for disabled people. Disabled people have indicated that information is needed in easy read, braille or large print formats. People with learning disabilities indicate that lack of easy read formats are a problem in a number of areas including transport, health care, leisure and social opportunities. Whilst the Disability Discrimination Act requires organisations to make reasonable adjustments, access to information is often disregarded. Statutory organisations undertaking Equality impact assessments should include access to information and ensure that communication meets needs.

5.7 Offending by people with learning disabilities

There has been a considerable amount of research that has attempted to investigate the extent to which people with learning disabilities are involved in criminal offences. The general message is that offending by people with learning disabilities occurs but the rates are low and that people with learning disabilities are more likely to be victims of crime, than to be perpetrators.

Most of the research has adopted one of the following approaches (Holland, Clare and Mukhopadhyay, 2002):

1. Studies, primarily from the perspective of the criminal justice system, that have looked at the prevalence of people with learning disabilities brought into police stations, seen by probation, or in the remand or convicted prison population. These studies suggest that up to 30% of those in contact with the criminal justice system are intellectually disadvantaged (Gudjonsson, Clare, Rutter and Pearse, 1993; Murphy, Harnett and Holland, 1995; Loucks, 2006). However, these studies have relied predominantly on data about previous educational status and/or intellectual functioning, rather than information about early development and/or functional abilities. It is far from clear whether or not these identified individuals would meet the criteria for statutory services for people with learning disabilities.
2. Studies, primarily from the perspective of learning disability services, that have looked at the number of people known to services who have contact with the criminal justice system over a defined period of time. In the largest and best of these studies (McBrien, Hodgetts and Gregory 2003), based on all 1326 adults known to intellectual disabilities services within a city with a general population of almost 200,000, it was found that:
 - 0.8% were currently in prison
 - 3% had a criminal conviction of some kind (current or past)
 - a further 7% had had contact with the criminal justice system as a suspect but did not have a criminal conviction
 - an additional 17% engaged in challenging behaviour that was 'risky', in the sense that it could have been interpreted as offending. However, it is not clear whether or not the people involved could have participated meaningfully in the criminal justice process.

These data suggest that about 10% of those known to learning disability services will have contact with the criminal justice system over the course of their lives. However, families and

paid staff are often uncertain about whether or not to involve the police in alleged offences, even serious offences, and this figure must be viewed with caution.

Information on offending is needed as Government policy is that services for people with learning disabilities are expected to provide support to the men and women alleged to have committed offences. This includes the provision of an Appropriate Adult during a police interview, advice and support throughout any trial process, and a response if further assessment and/or treatment is thought to be appropriate prior to and/or after conviction. Since the 1990s there has generally been a policy of diversion of people with learning disabilities from custody because of their perceived vulnerability and in the belief that treatment is appropriate and possible. As far as possible, this should take place in the community, and there are an increasing number of community sentencing options available that provide frameworks for the treatment, support, and supervision of offenders with learning disabilities.

6. SUPPORTING CARERS

To increase the help and support carers receive from all local agencies in order to fulfill their family and caring roles effectively. (Valuing People DOH 2001)

Key Messages

- Support, information and assessment for services are vital in order to maintain carers in their role.
- Access and allocation of short breaks for carers needs to offer choice and equity.
- Carers need access to emergency support.
- Forward planning promotes both carer and user wellbeing..
- Carers, in particular older carers, may need support at times to articulate their needs.

6.1 Assessment and planning, Information and Support

From Emerson's national survey (ONS 2006):

- *“One in ten people (10%) with learning difficulties living in private households helped care for another adult who was elderly, ill or had a disability”.*

Each individual carers' needs will vary in much the same way as that of the individual with learning disability. However it is generally accepted that carers needs generally fall into one of the following areas:

- Recognition (to be listened to and valued)
- Information (general and on services or conditions)
- Practical support (including advice on benefits)
- Short breaks (day care, sitting or longer respite)
- Emotional support
- Involved (in planning and monitoring services)

The needs of carers should be seen as separate to those of the person with a learning disability and an assessment of those needs should be undertaken. Services and support provided to the service user should then be provided which reflect the needs of the carer

Carers in particular frequently express their concern about the lack of planning for the future. Service users and carers want to know that they can get the same level of service where ever they live in Cambridgeshire. Planning for the long term is particularly important when the needs of people with learning disabilities are diverse and changing.

When young people move from childrens' to adulthood services – Planning and preparation for the move from children's to adult services needs to be improved. Poor co-ordination is likely to exacerbate problems for people with learning disabilities and increase the impact of their disability unless agencies ensure that help is provided.

When people get older - People with learning disabilities are living longer. This means there are more adults being cared for by increasingly elderly carers. The increased prevalence of mental illness in adults and the earlier occurrence of Alzheimer's disease in people with Downs syndrome also contribute to increased needs. In many situations currently, people stay in the services they were in as younger or middle aged adults. More planning for older people with learning disabilities needs to be undertaken.

When relatives are no longer able to care. Changing expectations from both carers and people with learning disabilities regarding their right to live independently needs to be taken into account. In some cases when an elderly relative becomes seriously ill or dies the person with a learning disability faces a crisis. More planning is needed in order that alternatives are looked at earlier, assessing how well the elderly relative / carer is coping and whether a planned move into independence can be achieved.

Complex needs - People with learning disabilities who have challenging behaviour or who present as offenders offer particular challenges to agencies.

Family carers are able to access the Carers Support Projects for advice and support.

6.2 Short breaks and Emergencies

Access to short breaks are key to providing support to family carers and are provided across the county. The main methods of this support are either through home based support, residential short breaks or adult placements. Generally a maximum of 22 nights are provided although the amount of respite offered varies depending upon the needs of the individuals.

Short breaks beds are sometimes used for emergency placements. The main reasons being:

- Carer ill or in hospital
- Carer death
- Service user at risk
- Person waiting for permanent accommodation.

There are a total of 19 residential respite beds covering the county. Occupancy rates are often 95 – 100% as breaks are planned carefully.

Plans to extend the Adult Placement service to offer both short breaks and independent skills training across the county are in hand.

6.3 Carers Grant and Budget Pressures

The LDP receive an allocation of the Carers grant. Some is allocated to grouped day time respite services but the rest is used for individual care breaks either a Carers Direct Payment or Carers Service.

Carers of people with learning disabilities are also able to access support from the Carers Support Project staff. Additional funds have been allocated to the Council for the development of home base emergency carer support covering the first 48 hours. This will be available for carers who “register” on the scheme. It will require carers to have an “emergency plan” in place.

In 2008 /09 there are an anticipated 46 carers who are unlikely to be able to maintain their caring role for a number of reasons. This is likely to result in additional services being needed costing in the region of £1million.

7. GOOD HEALTH

To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary. (*Valuing People DOH 2001*)

Key Messages

- people with learning disability are at significant risk of major health problems
- people with learning disability and their carers have experienced significant health inequalities and barriers to mainstream services.
- Joint work is needed to:
 - identify people with learning disabilities in primary care and ensure they have health action plans that are implemented and monitored.
 - ensure equality of access.
 - ensure health is promoted by preventive action and maximum practical self-care.
 - develop broad appreciation, knowledge and skills related to the increasing longevity of people with learning disabilities.
- It is important to address priority risks as raised by National Patient Safety Agency. Swallowing problems is a major cause of death.
- The management of challenging behaviour through restraint and / or medication is a cause for concern.
- There is a need to develop specialist capacity in mental health, challenging and offending behavior management in county and in the community where possible.
- Specialist services need to be available equitably across the county.

7.1 National Evidence

The 2006 report *Equal Treatment: Closing the Gap*, by the Disability Rights Commission (DRC) looked at the health needs of people with learning disabilities and people with mental health problems. The findings clearly show quantifiable evidence of unequal treatment and the true extent of health inequalities. It notes that there are a number of reasons for inequalities, including social deprivation. The report provides evidence that in England and Wales, people with learning disabilities are much more likely than other citizens to:

- Experience significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease.
- Die younger than other people.

- Develop major illness at a younger age (5-10 years earlier).
- Experience poverty and the compounding effects of social exclusion, discrimination and isolation.

These issues are commonplace across the country and within Cambridgeshire. The report also noted:

- An increase in the numbers of people with complex multiple disabilities.
- They are more likely to have undiagnosed illnesses i.e diabetes
- People with learning disabilities are less likely to receive evidence-based checks and get evidence-based treatment.
- Efforts to target their needs specifically are ad hoc.
- They face real barriers to accessing services.
- They have a high rate of unmet health needs.
- Diagnostic overshadowing is commonplace.
- There is a complacent attitude towards their exclusion.
- Primary care response has been very patchy.
- There is little or no evidence that information on the physical health needs of people with learning disabilities is either regularly collated or used locally by commissioners to develop improved services.
- Primary care services are not generally making 'reasonable adjustments'
- some health needs, particularly among people with learning disabilities and/or mental health problems, may remain unidentified and unrecorded.
- The health needs were often "offloaded" onto specialist services rather than addressed through regular primary healthcare.
- Additional barriers were sometimes experienced i.e ethnicity or complex needs.
- There is particular concern about the management of healthcare needs at transition to adult life.

People with more severe intellectual disabilities are at higher risk than those with mild learning disabilities of sensory, communication, physical, and behavioural and/or psychiatric difficulties.

Overall, the prevalence of difficulties among people with learning disabilities is very high. An estimated 11-23% of adults are verbally or physically aggressive to others (Taylor, 2002), with few differences between men and women, while some 1-2% of those known to services engage in some kind of self-injury. The prevalence of inappropriate sexual behaviour or sexual offending or fire-setting remains uncertain. What is known is that such behaviours are persistent, often multiple, and have a very severe impact on the quality of people's lives (Emerson, 2001).

Equality of access and treatment

The evidence in the DRC report and in earlier studies broadly recognises that people with learning disability not only experience poorer health, have a risk of earlier death but also experience significant discrimination in accessing diagnosis and treatment.

In March 2007 the Mencap report, '*Death by indifference*' accused health services of institutional discrimination that leads to people with a learning disability receiving worse health care than non-disabled people. An independent inquiry has recently been launched following the Mencap report.

From Emerson's national survey (ONS 2006):

- *“One in six (15%) said that their general health was ‘not good’.*
- *“People who had poor general health were more likely to live in unsuitable accommodation, be poor, see friends who have learning difficulties less often and do fewer community-based activities. They were also more likely to not feel safe, have been bullied, be a victim of crime, not be happy, feel sad or worried, left out and helpless and not feel confident.”*
- *61%, nearly two out of three people said they had an illness or disability that they had had for a long time. “This is much more than people in the UK in general”.*
- *19% one in five said they smoked*
- *“46% said they did exercise that made them out of breath and sweaty” and “15% said they did this three times a week”*
- *“99% said they were registered with a GP” and 78% have “seen their doctor in the last year“*
- *“27% said they had had problems with their teeth in last six months”. 78% had been for a check up with a dentist and “...four out of five 82% said they were registered with a dentist.*
- *52% eyes tested in last year*
- *21% hearing test in last year*
- *27% of women one in four had ever had cervical smear*
- *one in four 24% had ever had their breasts checked for lumps*

“When the effects of age, support needs and ethnicity were taken into account, people who either had generally poor health or had a long-standing illness or disability were less likely to live in supported accommodation”.

7.2 Local Evidence

7.2.1 Views of people with learning disabilities and family carers

During 2007 the LDP Board and Speaking Up (Advocacy organisation) sought the views and experiences of people locally both in respect to their experience of primary and acute care. The comments, issues and outcome from this recent consultation exercises with people with learning disabilities and family carers reflects the national picture. These provide a stark picture of what the experience is like in Cambridgeshire. Issues locally reported include:

- Lack of easy read / accessible information
- Poor attitude from some Health staff / Difficult to trust staff when needs not understood/met
- The views of carers and/or paid staff are often ignored resulting in reports of ill health/symptoms being put down to the disability.
- Insufficient care available whilst person with learning disability is in Hospital. Over reliance on family carers for day to day care, personal hygiene, feeding.
- Lack of facilities for relatives – particularly if supporting over night
- appointments not long enough (due to complex needs)

- Disabled toilets facilities inadequate, cannot move in dignified way
- Poor access to physiotherapy - carers resorting to paying privately / availability through LDP/generic services a big problem
- Unfair treatment in dental care
- Delay in referral for tests and treatment.
- Insufficient details about people accessing screening- recording needs to be improved

As part of the consultation exercise people with learning disabilities and family carers were keen to make recommendations as to future actions. Some of the key needs identified by them were:

- Training/ awareness raising for all core mainstream health professionals about the needs of people with learning disabilities
- More in-depth training for smaller number to act as “champions / resources on wards and in Out patients etc
- Role of Hospital Liaison Nurse seen as not just “best practice” but as essential to ensure equality of access for people with learning disability.
- Equality of access to treatment is a right – a need to challenge attitude by some.
- Importance of staff reading notes / handover information
- Vital to listen to carers and paid staff who know the individual well – don’t assume it is the disability / or that parents are over anxious.
- Carers need information too – not just the people with learning disability as they may need to explain at a later stage.
- Access to Health checks and Health Action planning is key.

7.2.2 Local experience amongst professionals

We know from local staff working with people with learning disabilities that users and carers concerns and experience is not unfounded. Staff have also highlighted demands and issues. Pressures include:

- An increase in the numbers of people with profound and multiple disabilities requiring specialist assessment, equipment and care.
- support and training to manage challenging behaviour.
- People with autism spectrum disorders, particularly those with additional mental illness and other mental health needs and/or challenging behaviour and/or behaviour that brings them into contact with the criminal justice system.
- Autism spectrum - support and training to maximise communication, employment opportunities, and inclusion, adequate support for those who do not meet social care eligibility criteria and for whom some mainstream services are inappropriate.
- Parents with learning disabilities (including those with milder learning disabilities).
- Young people who are not in education and want to work, there is little viable or useful support in the voluntary sector.
- Sensory needs of people with profound learning disability.
- Clients with physiotherapy needs.
- Clients stuck in unsuitable care environment that are not meeting their needs and adversely affecting their mental health and well being.

- Treatment and/or support, including the provision of appropriate social care, for people with challenging behaviour, including behaviour that brings them to the attention of the criminal justice system.
- Ease of movement within specialist/mainstream services in the persons best interests.
- People who live around county boundaries with social and health care split, not getting effective integrated service response and unpicking who is responsible slows down responses.

7.2.3 Initial Response

People with learning disabilities and family carers presented their findings to local Councillors recently to raise awareness of some of the issues. Cambridgeshire LDP Board have noted local experience and are working with local Hospitals to attempt to address local issues through the development of the Disability Equality Schemes and action plans. The LDP Board have written to the lead of the Clinical Governance Committees at the local hospitals. The relevant leads at the Hospitals have started to look at the issues raised by the LDP Board. LDP staff are starting to work with the Hospitals to address some of the issues – both individual problems and more general issues.

7.3 Associated health needs

As noted in section 7.1 people with learning disabilities are more likely than non disabled people to experience significant health issues.

From national data, we have estimated the proportion of those with severe intellectual impairment having one or more associated disorders, as shown below.

Table 20: Estimated Numbers of Learning disabled people aged under 24 with associated disorders, by district, 2006.

		Cambridge	East Cambs	Fenland	Hunts	South Cambs	Cambridgeshire
<i>Number of LD people aged <24</i>		180	84	98	186	155	703
Epilepsy	20-50%	36-90	17-42	20-49	37-93	31-77	141-352
Cerebral Palsy	15-40%	27-72	13-34	15-39	28-74	23-62	105-281
Visual disorders	10-30%	18-54	8-25	10-30	19-56	15-46	70-211
Hearing defects	5%	9	4	5	9	8	35
Speech defects	60-85%	108-153	51-72	59-84	112-158	93-131	422-598
Serious disturbed behaviour	5-10%	9-18	4-8	5-10	9-19	8-15	35-70

Source: Fryers T. Public Health approaches to mental retardation: handicap due to intellectual impairment. In: Holland WW, Detels R, Knox G. Oxford Textbook of Public Health. Oxford University Press 1991; 29-499-500. Ellis D. the epidemiology of visual impairment in people with a mental handicap. In: Ellis D (ed). Sensory impairments in mentally handicapped people. London: Croom Helm, 1986 Kropka Bl. Williams C. the epidemiology of hearing impairment in people with mental handicap. Sensory impairments in mentally handicapped people. London: Croom Helm, 1986 Lund J. The prevalence of psychiatric morbidity in mentally retarded adults. Acta Psychiatrica Scandinavica. 1985; 72: 563-570.

		Cambridge	East Cambs	Fenland	Hunts	South Cambs	Cambridgeshire
No of LD adults aged ≥4		183	124	142	266	226	942
Impaired communication or social difficulties	50%	91	62	71	133	113	471
Visual disorders	15%	27	19	21	40	34	141
Hearing defects	20%	37	25	28	53	45	188
Mental illness or problem behaviour	25-50%	46-91	31-62	36-71	67-133	57-113	235-471

Table 21: Estimated number of Learning disabled people aged over 24 with associated difficulties, by district, 2006

Source: Fryers T. Public Health approaches to mental retardation: handicap due to intellectual impairment. In: Holland WW, Detels R, Knox G. Oxford Textbook of Public Health. Oxford University Press 1991; 29-499-500. Ellis D. the epidemiology of visual impairment in people with a mental handicap. In: Ellis D (ed). Sensory impairments in mentally handicapped people. London: Croom Helm, 1986 Kropka Bl. Williams C. the epidemiology of hearing impairment in people with mental handicap. Sensory impairments in mentally handicapped people. London: Croom Helm, 1986 Lund J. The prevalence of psychiatric morbidity in mentally retarded adults. Acta Psychiatrica Scandinavica. 1985; 72: 563-570.

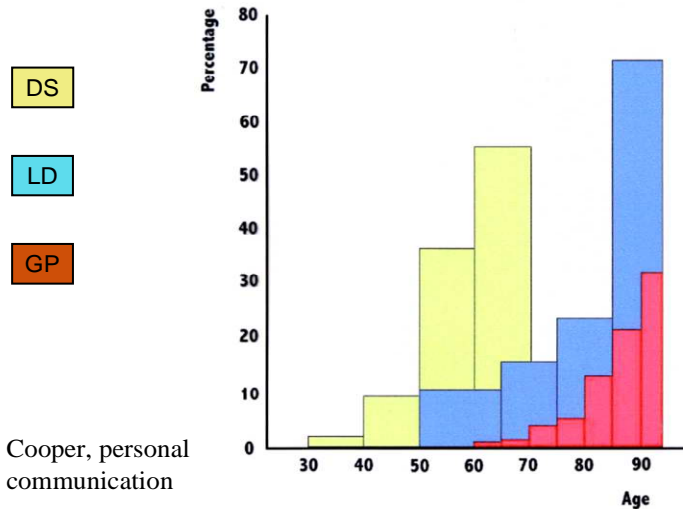
Risk of dementia

The increase in prevalence of people with learning disabilities in the population is largely due to improved life expectancy – people with learning disabilities are living longer as are those without learning disabilities. This has meant that those illnesses commonly associated with later life, such as dementia, are increasing in prevalence. However, life expectancy still varies depending on the severity of the person’s learning disability and sometimes the cause. Thus, the picture is complex and there are many unknowns. In general the life expectancy of those people with mild learning disabilities is approaching that of the rest of the general population and like the general population it is influenced by well recognised socio-demographic factors. People with more severe learning disabilities and/or specific causes for their learning disability may still have a reduced life expectancy – for example, the mean life expectancy of people with Downs Syndrome is approximately 55 years and people with Prader Willi Syndrome appear rarely to live beyond their 50’s. For those with severe epilepsy (such as people with tuberose sclerosis) or significant physical disabilities (such as cerebral palsy), there is a risk of premature death across the lifespan. Overall it has been estimated that the number of people with learning disabilities over 65 will have doubled by 2020 and by that time the total population of people with learning disabilities will have increased by 20% and a third of the total will be 50 years or older. Given that dementia is predominately an age-related illness these observations on the increase in life expectancy need to be considered. Whilst the age-related prevalence of illness such as dementia is stable the overall prevalence and the numbers will increase as more people live into the age at risk.

There have been a number of studies investigating prevalence rates for dementia in people with learning disabilities. Such studies are not easy for a number of reasons including ascertaining all people with learning disabilities in one geographic area and the problems of diagnosis because of the person’s pre-existing learning disabilities. In general, the findings are that people with learning disabilities (excluding people with DS) have an age-related pattern that is similar to that of the general population but brought forward by a few years. In

one study 20% of people with learning disabilities (excluding those with DS) over 65 years had clinical evidence of dementia. People with Down's Syndrome also have an age-related increasing risk for dementia but in this case it is brought forward by about 40 years. In a study in Cambridge it was found that people with DS aged 30 and over had approximately the following rates of dementia: 1% in their 30's; 10% in their 40's; and 40% in their 50's. Other studies have found higher rates. These general observations are illustrated by the graph below.

Comparative Rates of Dementia - Down's syndrome, L.D., General Population



7.4 Limiting Long Term Illness

The nature and level of disability has been impacted by improved healthcare and a lower mortality rate. These relate to all types and causes of disability both from birth and acquired. There has generally been an increase in the numbers of people with higher levels of a disability as a result of these factors. 25% of households have identified a member as being disabled in some way.

The map in the Appendix shows the variation in self-reported health status across Cambridgeshire, taking the age and sex structure of the population into consideration. There is a fairly consistent pattern across the county, with residents being more likely to have a limiting long-term illness or to perceive their health to be poor in wards to the north of the county particularly in and around Wisbech, Huntingdon North, and in parts of Cambridge City. The pattern of poor health, as measured by the Census, is broadly similar to the pattern of deprivation as measured by the Index of Multiple Deprivation.

Epilepsy

Epilepsy is common in those with a learning disability and its frequency increases progressively with more severe intellectual impairment. Overall lifetime prevalence of epilepsy in those with mild to moderate learning disability (IQ 50 - 70) has been estimated at

15% whilst in those with severe learning disabilities (IQ less than 50) prevalence of 30% has been reported (Sillanpaa, 1996).

A Swedish study noted that the standardised mortality ratio for those with learning disability without epilepsy was 1.6 but SMR increased to 5.0 in those with concomitant epilepsy (Forsgren et al. 1996). Within the UK epilepsy management in those with LD has been provided by various combinations of primary care, specialist epilepsy and neurology services as well as learning disability mental health services and social care agencies.

Some research has also been undertaken locally (Ring, Zia, Lindemand + Himlock). Out of 1487 individuals identified as receiving care from teams surveyed at the time of the study (April 2005) a total of 183 individuals provided data for this survey, representing 12% of all the individuals with learning disabilities under the care of these teams and 71% of the total number of individuals with epilepsy and learning disability identified by the participating community learning disability teams as being under their care. It noted that epilepsy occurs at increased frequency in those with learning disability compared to the general population and the literature suggests that it is generally more difficult to treat. It is unclear whether this increased difficulty in treatment results from the nature of the epilepsy itself, from co-morbid pathologies in this clinical group or from historical difficulties that people with learning disability have had in gaining access to appropriately skilled health services. The results of this survey suggest that not being referred to a specialist neurology-based epilepsy service is not in itself a predictor of poorer seizure control.

Research demonstrates that epilepsy occurs at increased frequency in those with learning disabilities compared to the general population and the literature suggests that it is generally more difficult to treat. It is unclear whether this increased difficulty in treatment results from the nature of the epilepsy itself, from co-morbid pathologies in this clinical group or from historical difficulties that people with learning disabilities have had in gaining access to appropriately skilled health services.

The majority of those with epilepsy and learning disabilities included in the local survey did not have an additional diagnosis to explain their epilepsy. The most commonly identified brain disorder in this survey of people with epilepsy and a learning disability was cerebral palsy. Whilst a wide range of seizure frequencies were observed, approximately one third of the sample had been seizure-free over the three months preceding the survey.

Other key findings included:

- There were no significant differences in seizure frequency with respect to which of geographical learning disabilities services patients were managed by.
- The single most common epilepsy syndrome described was idiopathic generalized epilepsy.
- Mood disorders, most commonly depression, were common in the survey population, occurring in 37%.
- 38% of the participants were being prescribed at least one psychotropic medication at the time of the survey.
- All participants were receiving at least some care from their community learning disability teams. In addition, 37% of the participants also received epilepsy care from a specialist neurology service.
- The patients' GP contributed to their epilepsy care in 63% of cases.
- No differences in recorded epilepsy variables were identified that might have explained why some patients but not others had been referred to specialist neurology-epilepsy services.

Dysphagia Prevalence and Associated Health Risk

Feeding, swallowing and nutritional problems have a high prevalence among people with learning disabilities. They can have serious repercussions including poor nutritional status, dehydration, aspiration and asphyxiation. They can be life threatening or lead to life threatening problems. Adults with cerebral palsy and those with severe intellectual and physical disabilities have a high incidence of dysphagia and patients with spastic quadriplegia are at particular risk of aspiration. Although there is limited research into people with learning disabilities who have dysphagia, there is evidence that successful management decreases risk.

7.5 Physical activity

There is robust evidence for the impact of physical activity on mental health: as a treatment or therapy for existing mental health problems; to improve the quality of life of people with mental health problems; to prevent the onset of mental health problems; and to improve the mental wellbeing of the general population. This has been well summarised by the Mental Health Foundation³.

Ideally people with learning disabilities and their families would seek mainstream physical activity community opportunities. However access to them is often more difficult for people with learning disabilities due to physical access issues; lack of transport; lack of staff support; limited finances; lack of easy read information and limited targeted suitable activities to meet their limited abilities. There are however some positive initiatives however even these are sometimes difficult to access due to limitations in support staff or transport.

7.6 Healthy Eating

While it is too early to state definitively the links between diet and mental health or ill-health, there is sufficient evidence to suggest that nutrition may have an important part to play, and that the essential fatty acids (especially omega-3) may be particularly significant. Anti-oxidants and minerals in fruit and vegetables may also be relevant.

Overweight and obesity in the Learning Disability population

Reducing obesity and excess weight is a global and national priority. The prevalence of obesity in the general population has been increasing Zaninotto et al 2006 estimated that if the trend continues to rise one third of adults will be obese by 2010. The World Health Organisation 2006 projects by 2015 approximately 2.3 billion adults will be overweight and 700 million will be obese.

Obesity has a substantial direct and indirect health care cost associated with it. It contributes to illness, disease, disability and premature mortality.

For people with Learning Disability prevalence of co morbidities is higher than the general population and the rate of premature death is increased as well as the widely recognised health inequalities that are evident and documented. (Poynor 2008, Valuing people 2007, Our health, our care, our say 2006, National Patient Safety Agency 2006, Disability Rights Commission 2006 and Mencap 2004,2007.)

7.7 Challenging behaviour

Among people known to services for people with learning disabilities, the prevalence of challenging behaviour, that is, behaviour that is of 'such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 1995, cited in Emerson, 2001, p. 3), is high.

Very few attempts have been made to identify the prevalence of challenging behaviour among all people with learning disabilities in the total population living in a defined geographical area. Three studies in the North-West of England (see Emerson, 2001, for a review), however, which have examined all those known to people known to LD services have indicated that 7-8% of people with a learning disabilities have serious challenging behaviours which

- at some time have caused more than minor injury to themselves or others, or destroyed their immediate living or working environment;
- at least once a week have required the intervention of more than one member of staff to control, or placed them in danger, or caused damage that could not be rectified by care staff or caused more than one hours' disruption; or
- at least daily have caused more than a few minutes' disruption.

Only 22 % (2200) of the estimated local population with learning disabilities currently have some kind of contact with either health and/or social care services within the LDP. Based on the figures in the research reviewed by Emerson (2001), an estimated 154-176 of these men and women would be expected to have challenging behaviour. However, at least some of the remaining LD population probably also have challenging behaviours, but their difficulties lead them elsewhere. The recent report *No One Knows* (Loucks, 2006) suggested, for example, that, among prisoners, some 20%-30% have learning difficulties or disabilities that interfere with their ability to cope.

Most of the challenging behaviours of people known to learning disabilities services involve physical aggression, and the destruction of property, self-harm, fire-setting, and sexually inappropriate behaviour. Such behaviours are best thought of as long-term conditions. They can normally be managed successfully in community-based services provided adequate treatment and support is available to the person with a learning disabilities. Since caring for people for people with challenging behaviours is often both practically difficult and emotionally exhausting, support is also often needed for families and paid staff (see Clare and McGill, 2000; Emerson, 2001).

Challenging behaviours among people who could not participate meaningfully in the criminal justice system because of the severity of their learning disabilities, are more common when men and women have:

- Additional sensory or communication difficulties
- Profound, rather than severe, learning disabilities
- Mental health problems
- Autism spectrum conditions, and certain specific disorders such as Cornelia de Lange syndrome, Lesch-Nyhan syndrome etc.

As the local population grows, there will be more people with challenging behaviours. Assuming the same prevalence of people with learning disabilities, and the same proportion requiring support, in 2021 there will be 11, 670 people with learning disabilities, of whom

2490 will be known to the LDP. Using an estimated prevalence of 7-8%, 174-199 people of these individuals will have challenging behaviours. However, it is very likely that this will be an *underestimate* because:

- there will be more older people with learning disabilities, a high proportion of whom will develop dementia, which is associated with challenging behaviour,
- more vulnerable babies, who will have many of the risk factors for challenging behaviours, are surviving into adulthood.

In addition, it is not unlikely (in view of the current review being carried out by Lord Bradley) that there will be changes in policy, changes so that men and women with mild learning disabilities who come into contact with the criminal justice system are not remanded or sentenced to prison, but instead receive community-based sanctions.

The management of challenging behaviour through restraint and or medication is a cause for concern.

7.8 Current Specialist Services and Support

All people with learning disabilities have access to mainstream health services the same as everyone else, however in addition they might access specialist support. People with learning disabilities will use inpatient mainstream Hospital beds however data bases do not record their take up by client group so we have no data on this but only on specialist inpatient beds. Due to the fact that people with learning disabilities have greater health needs than the general population we would expect to see a higher than average take up of hospital services.

7.8.1 LDP Integrated Community Teams

The integrated community teams (see 1.5.3) provide valuable support to individuals to access mainstream health care and for specialist assessment and care. Access to this specialist health support across the county is currently not equitable for largely historical reasons.

7.8.2 Community Intensive Assessment and Support Service (IASS)

In S. Cambridgeshire, City and South Community Teams are supported by a tertiary service. The IASS community team was identified by the National Development Team's Tough Times project as a model of good practice in a) preventing placement breakdowns for people with learning disabilities and/or autism spectrum conditions whose behaviour is described as 'challenging' and/or has brought them into contact with the criminal justice system, and b) assisting those who are placed 'out of area' (within the mental health, criminal justice, or social care systems) return to, and rebuild their lives in, their local communities.

7.8.3 In patient service

Cambridgeshire service users receive a service either from the IASS for Cambridge, South and East Cambridgeshire and Huntingdonshire, or from the Gloucester Centre, Peterborough for the Fenland area.

Referrals Made to LDP Teams From April 2007 to January 2008

Due to limitations in activity monitoring systems these figures should be regarded as indicative not precise. Commissioners and CPFT are working to address this issue for future years.

Table: Referrals made to LDP Teams in Cambridgeshire, April 2007 to January 2008.

Referrals Made to LD Teams		
Location	Service name	Number of referrals
Cambridge	City Learning Disability Services	27
	Community IASS	5
	IASS Unit	4
	South Learning Disability Services	22
Referrals made to LD teams - Total		58

Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008. External referrals to Trust - recorded on CRS up to 20th February, 2008.

Team Activity For April 2007 to January 2008

Table: Team activity in Cambridgeshire, April 2007 to January 2008.

Team Activity		
Location	Service name	Number of activities
Cambridge	City Learning Disability Services	1438
	Community IASS	262
	East Cambs LDS	242
	South Learning Disability Services	2122
Grand Total		4064

Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

This activity includes face-to-face, telephone, domicilliary, and proxy contacts that have been recorded on CRS up to and including 20th February, 2008 within teams.

Available Beds			
Tat Inp	Ward name	Cumulative available beds 07-08	Available beds per day
		IASS	1836
	Larches - Bun1	143	3
	Larches - Bun 2	90	3
	Pembroke House	1530	5
	Willow	1106	7
	The Hollies	1480	10
	Total	6185	34

Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

Table: Admissions to LD Wards in Cambridgeshire, April 2007 to January 2008.

Admissions to LD Wards	
Ward Name	Number of patients
IASS Unit	12
Larches Bungalow 2	2
Pembroke House	349
The Hollies	20
Willow House	15
Total	398

Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

Table: Available beds in Cambridgeshire, April 2007 to January 2008.

Occupied beds	
Ward name	Cumulative Occupied Beds 07-08
IASS	1766
Larches - Bun1	134
Larches - Bun 2	78
Pembroke House	648
Willow	988
The Hollies	968
Total	4582

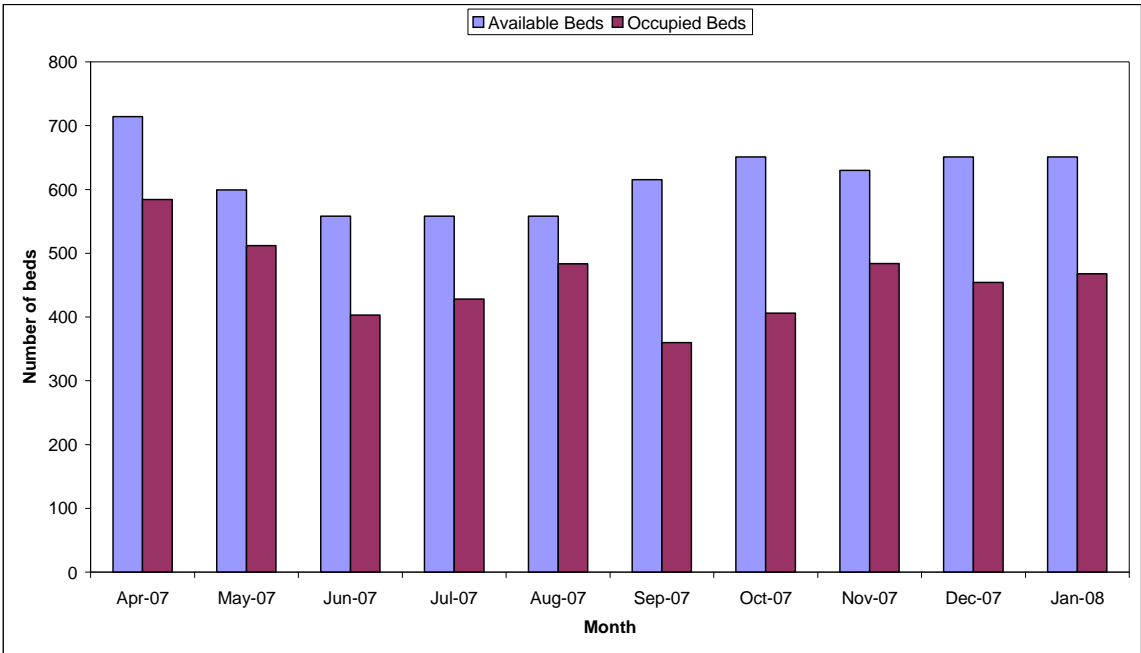
Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

Table: Discharges to LD wards in Cambridgeshire, April 2007 to January 2008.

Discharges to LD Wards	
Ward Name	Number of patients
IASS Unit	11
Larches Bungalow 1	3
Larches Bungalow 2	5
Pembroke House	350
The Hollies	21
Willow House	13
Total	403

Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

Figure: Available beds compared to occupied beds in Cambridgeshire, April 2007 to January 2008.



Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

Table: Average length of stay for discharges in Cambridgeshire, April 2007 to January 2008.

Number of Ward Attenders	
Ward name	Grand Total
Pembroke House	47
Willow House	111
Learning Disability Total	158

Source: Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, LD Report, January 2008.

7.8 Primary Care Learning disability registers

The idea of a learning disability register for adults in primary care has been widely recommended by professionals and charities alike. The national QOF dataset defines learning disabilities, like *Valuing People*, as the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood (18 years), with a lasting effect on development.

Over the past three decades, almost all the people who lived in long-term hospitals for patients with learning disabilities are now living in the community and depend on GPs for their primary health care needs.

The Quality and Outcomes Framework (QOF) is a method of collecting information on 146 evidence-based health care indicators in primary care. The data used for this indicator comes from QMAS data. QMAS (Quality Management and Analysis System) is the system which records GP practice performance on the QOF targets set in their General Medical Service (GMS) contracts. Charts for each area are in the Appendix.

There is still uncertainty around the quality of information, particularly around consistency of recording. As such, caution should be used when interpreting data as “disease prevalence”. The data is also not standardised for age and sex composition of the Practices. It is not possible to interpret this in terms of prevalence of learning disabilities, the recording issues, or access to primary care services. It may be more appropriate initially to consider the indicator a measure of utilisation and quality of service at primary care level for people with severe mental health problems.

Table 22: Unadjusted Recorded Prevalence rate in GP Practices, by old PCT areas, QoF 2006/2007.

PCT area	Disease Register Learning Disability	Unadjusted Recorded Prevalence	Range in GP Practices
East Cambridgeshire & Fenland	392	0.22%	0.04 - 0.66%
Greater Cambridge	450	0.17%	0.02 - 0.34%
Huntingdonshire	403	0.26%	0.02 - 0.84%
Cambridgeshire PCT	1,245	0.21%	0.02 - 0.84%
England	139,321	0.26%	0.00 - 5.15%

Source: QoF 2006/2007 IC Oct 2007.

Learning disability register for adults in primary care **Figure 6: Huntingdon PCT**

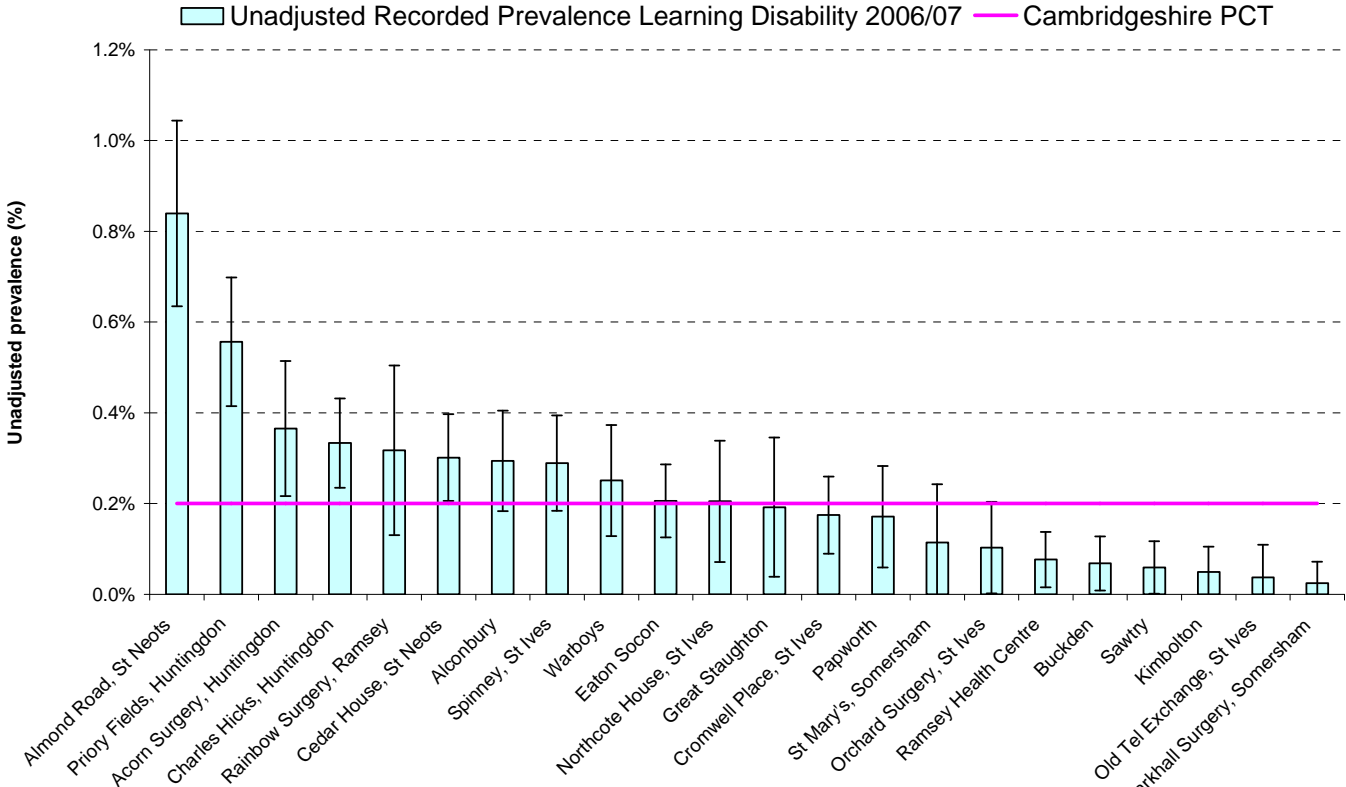


Figure 7: Cambridge and South Cambridgeshire

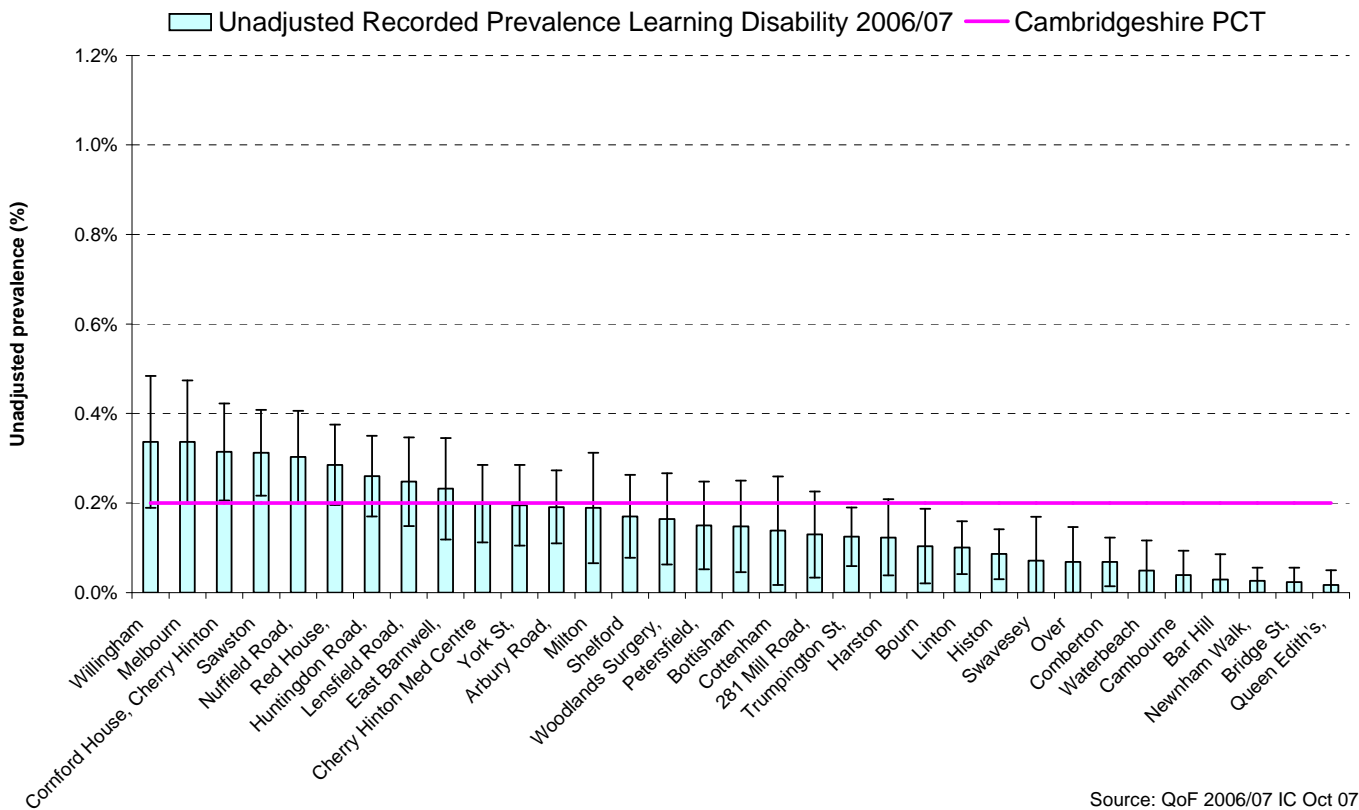
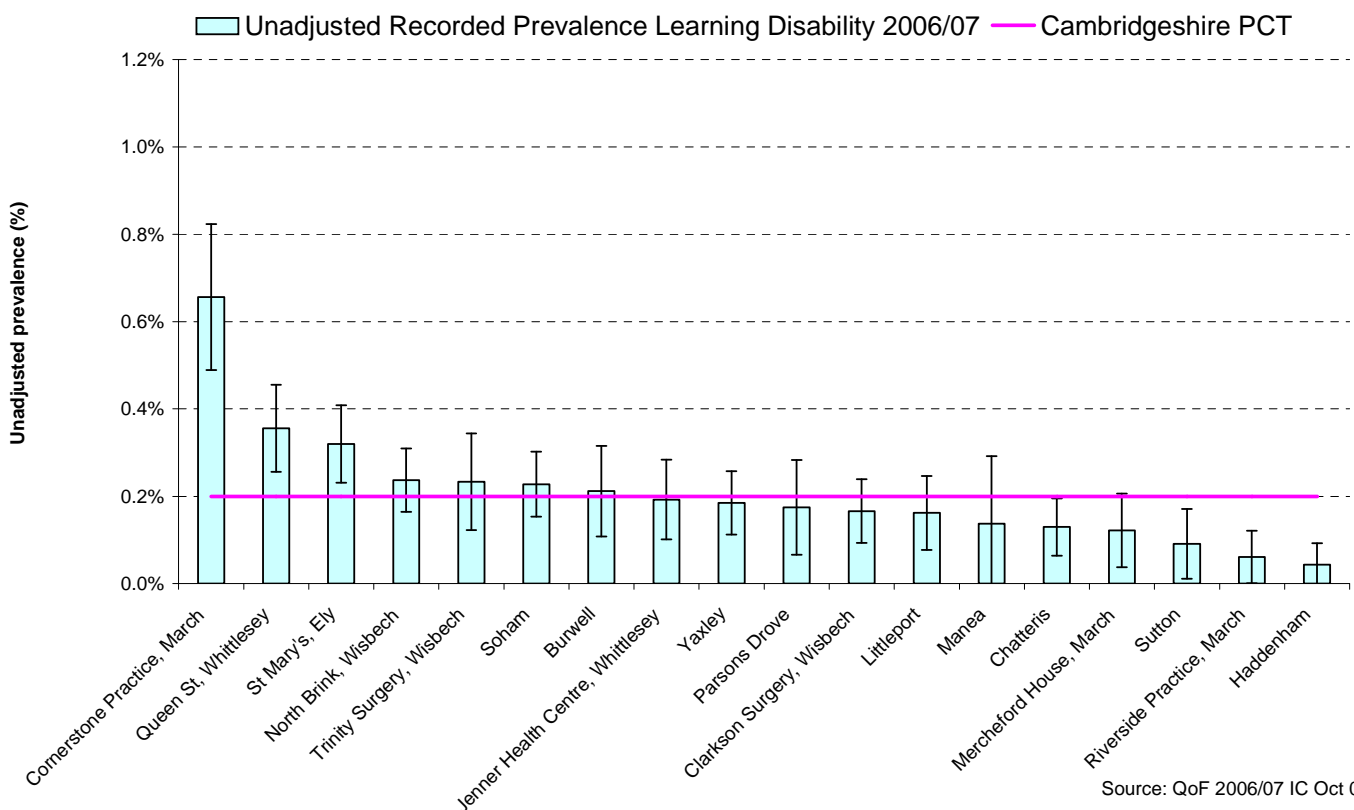


Figure 8: East Cambridgeshire and Fenland



8. HOUSING

“To enable people with learning disabilities and their families to have greater choice and control over where, and how, they live.” (*Valuing People DOH 2001*)

Key Messages

- The demand for quality housing and support is increasing.
- Joint work with the housing agencies is key to:
 - Ensure access is fair and prioritized appropriately.
 - expanding the range of housing available including rental, shared ownership and full ownership.
 - Ensuring the needs of disabled people are taken into account in future developments.
- The development of in county services is needed to enable people living out of County to move back to the Cambridgeshire.
- Supporting People services need to be flexible, user focused and not accommodation based.
- People want choice about the type of accommodation, where they live and who they live with.

8.1 National Picture

From Emerson’s national survey (ONS 2006):

- *“10% of people living in private households helped care for another adult who was elderly, ill or had a disability”.*
- *“ The living arrangements for people with learning difficulties were very different from the living arrangements for adults in the UK in general...”*
- *“...69% are living in private households...” and “...31% have some form of support accommodation”.*
- *Of the private households, 73% live with parents, 17% with other relatives, 6% on own and 4% with partner*
- *Of those living in supported accommodation, 62% residential care homes, 34% supported under Supporting People programme and 3% living in NHS hospitals*
- *“Two out of three people in supported accommodation (64%) had no choice over either who they lived with or where they lived...”*
- *...Half of all adults with learning difficulties (50%) were still living with their parent(s). Another one in ten (12%) were living with other relatives. Only about one in fifteen (7%)*

were living either on their own or with a partner. Few adults who do not have learning difficulties live with their parents or with other relatives”.¹

- *“...27% may be living in unsuitable accommodation... People were more likely to live in unsuitable accommodation if...they were poor, living in a deprived neighbourhood, had poor general health or were younger”.*
- *“...The majority of people with the highest support needs were living in private households”.*
- *“...people living in private households are much more likely to live in hard pressed communities than more affluent communities. It also shows that people in support accommodation were more likely to live in prosperous urban communities than other types of communities”.*
- *“People living in private households and people supported under Supporting People were more likely to live in poor and deprived areas”.*

8.2 Local picture

Access to Housing and support is one of the priority areas in Valuing People Now. We know from both national evidence and local consultation that people want:

- a secure and homely place to live.
- to live alone or with people whom they choose and like to be with.
- Sufficient levels of support to live full lives in their local community.

People do not usually choose to live in residential accommodation tenancies provide a more secure opportunity in the community. People need access to:

- Advice and general support services
- A range of opportunities including; Social rented Housing; private rented or low cost / shared ownership housing.
- Home aid agencies
- Equipment and Assistive technology.
- Support to manage their tenancies and care needs,

Whilst some individuals live in residential or nursing care current trends are to access mainstream housing opportunities. Details of current provision were in section 2. 6.

Current non-residential/nursing housing provision used by disabled people varies according to the individual need. In broad terms housing could normally be seen to fall into one of the following formats

- Ordinary housing not adapted (single or multiple occupancy with family or non disabled others but used by / identified for small group)
- Ordinary housing but adapted
 - to meet individual need (single or multiple occupancy with family or non disabled others)
 - used by / identified for small group.
- Single clustered accommodation
 - Adapted

- not adapted
- Purpose built
 - Single adapted (individual or grouped occupancy)
 - Clustered accommodation (likely to be adapted)

There is a gradual increase in the number of people considering shared ownership. This can be a real option for people using special schemes facilitating mortgage and rent payments via benefit entitlement.

The table below shows the residential location by type of users known to social care services. It should be noted that some people will still be living with their relatives or in individual tenancies with visiting support, These will be shown as other and not broken down into separate groupings.

Table: Residential location by home type, June 2007.

Home type	Cambridge City	East Cambridgeshire	Fenland	Huntingdonshire	South Cambridgeshire	Out of county	Total
Extra care/supported	55	31	62	71	43	9	271
Residential	18	57	67	43	117	118	420
Nursing	-	5	-	-	-	11	23
Other resi/group	-	-	-	-	-	12	19
Other	165	102	210	269	179	15	940
Total	238	195	347	384	344	165	1673

Note: '-' denotes where there are less than 5 individuals

Source: SWIFT data, Cambridgeshire County Council, June 2007

Map 3 overleaf show the location of people living in residential and nursing care within Cambridgeshire. This also shows the sizes of these establishments. The second map shows the location of people living in grouped settings (residential and supported living). Larger grouped settings are not the preferred model. People are increasingly wishing to exercise their choice as to where and who they live with or to live on their own.

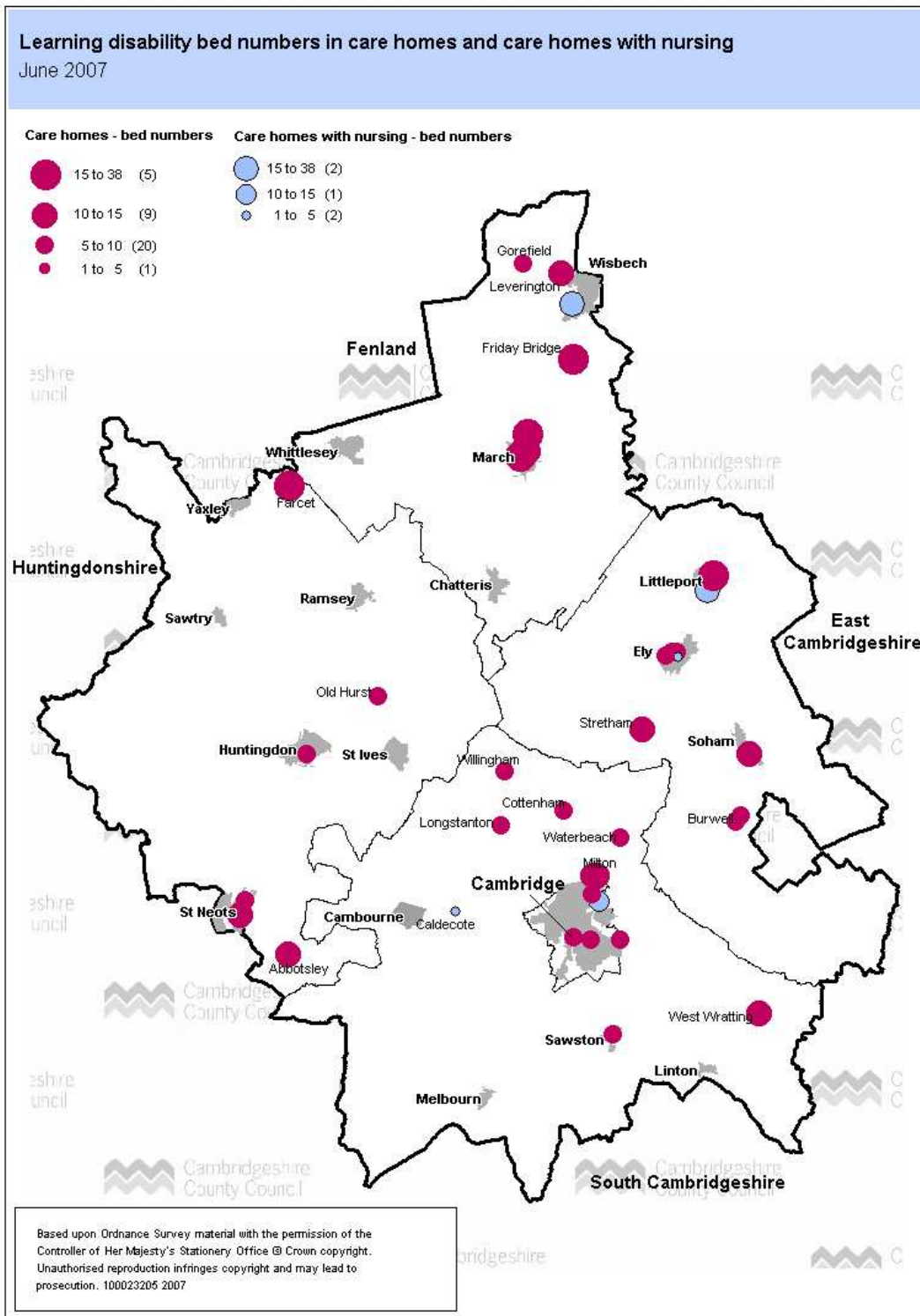
8.2.1 Social care support

Support is available to people in different settings and in different ways.

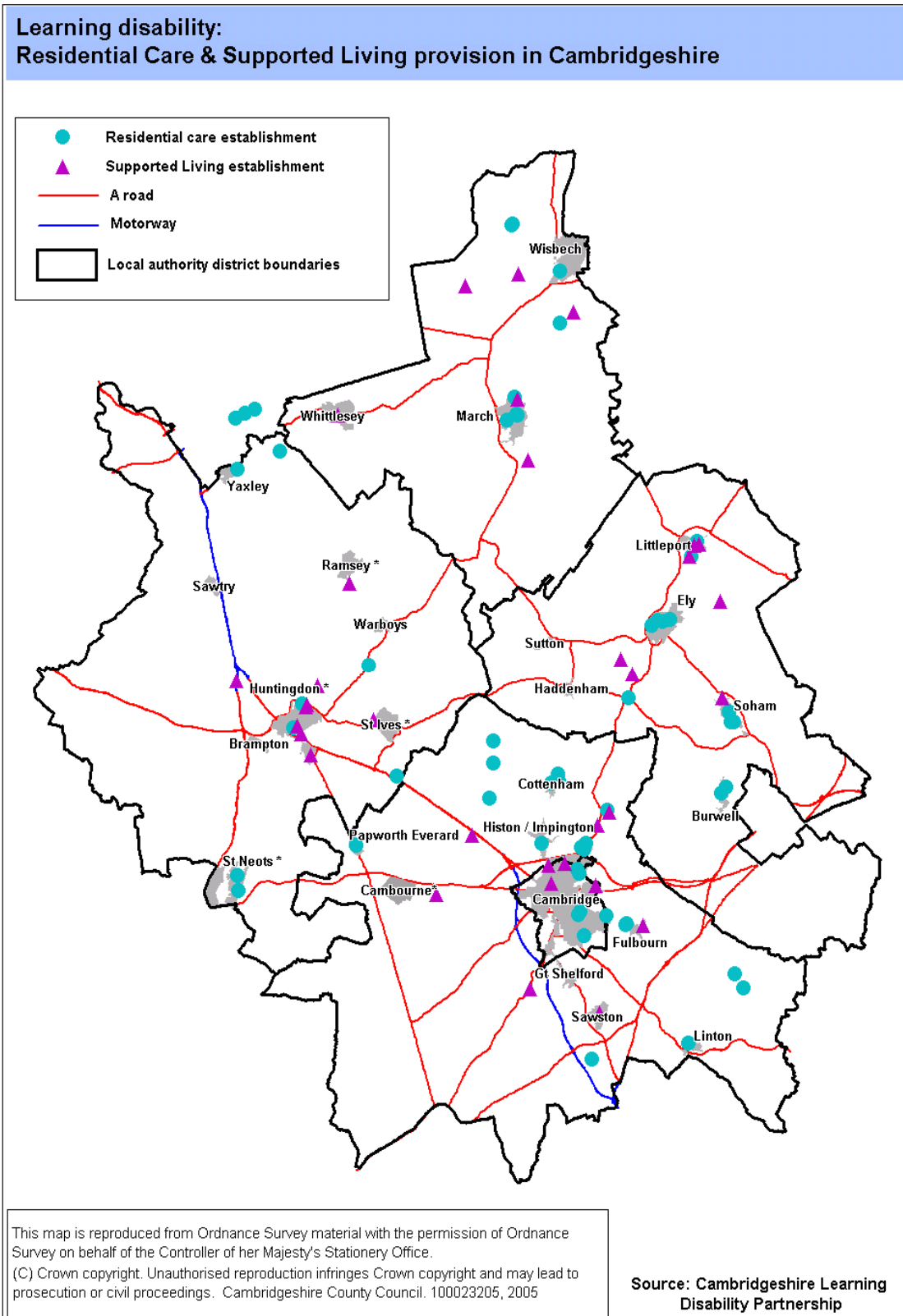
- Individual tenancies or own homes where the individual receives direct payments or an individual budget to buy their own support.
- Individual tenancies or own homes with commissioned visiting support.
- Small group tenancies with visiting support.
- Small group tenancies with 24-hour support.

Those who receive visiting support might have this provided via Supporting People funded Housing support providers and /or social care funded domiciliary social care providers. Those living in grouped tenancies are most likely to receive some social care support. This could be as part of a commissioned “supported living” service, this is most common where 24hr support is provided.

Map 3 Residential and Nursing Care provision in Cambridgeshire



Map 4 Residential Care and Supported Living Provision in Cambridgeshire



8.2.2 Supporting People

Supporting People funds over 400 services in Cambridgeshire providing housing related support aiming to enable people to live more independently. Each service is monitored and reviewed to ensure the support provided to the end user is of good quality. Housing related support helps people with things such as:

- Setting up utilities such as gas and water
- Setting up a budget and paying bills
- Accessing training, education and employment
- Claiming benefits

Supporting People does not fund care services like: personal care; domestic tasks; specialist counselling; childcare.

The projected spend for learning disability services 2007/08 is £1,979,000. There are 73 separate services under for this client group. The maximum number of individuals / households that can be supported is 210. 158 are currently being funded. The distribution of provision is generally more even although historically the provision means the largest amount of funding goes to Huntingdon and then Cambridge. South Cambs has by far the lowest amount of funding. The Supporting People budget is decreasing year on year in real terms and a retrenchment policy is being reviewed currently. People with learning disabilities are not identified as a priority group for any new investment. Some current SP funded services are linked to named accommodation this does not provide the flexibility that is required to offer individualized support that follows the person. It will be important to explore ways the address this. National comparators indicate Cambridgeshire Learning Disability services have low investment from Supporting People.

8.2.3 **Access to Social Housing arrangements**

From Feb 2008 Cambridgeshire housing authorities are part of a Sub-regional Choice Based Lettings (CBL) scheme, Home Link. Whilst the local housing authority lettings policy may vary on some issues all of the policies operate through the same principles including the same banding system which prioritises housing need. Fenland plans to implement in November 2008. Available properties are advertised and the onus is on the applicants registered on the housing register to submit an expression of interest for the properties.

The result being that all homes are allocated to those in the greatest need who have specifically requested to live there, and thereby increasing choice to the applicants and sustainability of the tenancy.

The LDP are able to indicate to housing authorities if they consider the person with learning disability to be in priority need. There are significant financial pressures on social care budgets. In order to prioritise limited resources the Disability Service has identified priority groups.

High priority:

- Person is in 'unsafe' accommodation (ie Protection of Vulnerable Adults).
- Person is homeless or at high risk of becoming so in very near future.
- Young person is currently 'looked after' (Leaving Care).
- Family / carer unable to maintain their role or at high risk of becoming unable to do so.
- The person is unable to remain in their current accommodation.

8.3 Demand

Current demand for both housing and support outstrips available resources. The main pressure points are seen as:

- People living longer (low move through rate).
- increased health needs impacting on the type of accommodation and care needs
- Increased expectation of carers particularly younger carers – early solutions needed.
- Increased expectations of service users (independence / small or individual homes).
- Cost of property / rent levels / housing benefits / home ownership.
- Availability of staffing affecting the viability of services.
- Older carers reaching crisis point and unable to maintain caring role.
- Hidden older carers needing emergency placements.
- Appropriate shared accommodation in all areas / local to family.
- Limited revenue and the need to exploring other funding streams.
- Some individuals currently placed in out of county residential placements wish to return to Cambridgeshire were suitable property and support available
- Increase in prevalence of obesity and the numbers of people with other larger space requirements for equipment and wheelchairs.

Comments from people with learning disability, family carers or partner agencies have noted:

- real choice is often not available particularly in shared living arrangements.
- Accommodation and support is not always available when people want it.
- limited staff support impacts on choice and life opportunities.
- Limited staff time to monitor services and practice regularly.
- Contract monitoring needs to link with individual reviews better.
- Service users and carers could be involved more in monitoring of services.
- Difficulties in recruitment and retention of staff.
- Concerns that lack of training results in under performing services.
- The cost and availability of training creates problems for some support providers.
- Larger homes are often needed for families with disabled children to meet the additional space for wheelchairs; hoists; moving and handling and storage.
- High density developments sometimes impacts on parking or access.
- Small Housing units or lack of garden space might limit ability for future adaptations to meet acquired disability needs or facilitate an individual or family to move in if a there is a disability.
- 3 storey Town Houses are not generally suitable for adaptations – ie not able to use through floor lifts.

8.4 Issues

Work is ongoing and is taking into account current issues including:

- People who want to move on from home, but are not in crisis, therefore they are not a priority Crisis cases always get funding, however this means that proactive interventions are not funded
- People living with older carers are not always getting a service until crisis. Lack of preparation work to move on. Those eligible for health but not social care i.e people stuck in our service not able to move on; people with Aspergers / parents with learning disabilities/ borderline learning disabilities.
- Out of county and services for people with challenging behaviour.

9. FULFILLING LIVES

To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.
(*Valuing People DOH 2001*)

Key Messages

- People with learning disabilities want the same range of opportunities as their non disabled counterparts.
- There has been an over reliance on building based services. Access to community facilities and opportunities needs development. The recommendations from the Day Services Review will address some issues.
- Joint work with the third sector, leisure Services voluntary and community groups is needed to develop to a fuller range of user led opportunities.
- There is good access to training and adult education across the county through social training enterprises.
- Inclusion is affected by area of residence, finances, access to transport and staff or informal carer support.

9.1 Views and rights

9.1.1 Opportunities

For many individuals friendships are linked to occupation and work activities but the area requires a section in its own right. It is noted that support from professionals is often needed for people to achieve their aspirations.

Evening and weekend opportunities are limited. Generally people would like:

- to increase the choice and opportunities they currently have.
- To have more opportunities to spend time in the community like:
 - college or adult community education classes
 - leisure and sport activities.
 - And to have access to the resources to facilitate it.
- To have opportunities to work or volunteer.
- Develop friendships and relationships.
- To be cared for and have help with personal care if needed.
- To get help with problems and to have someone to talk things through with.
- To learn new skills, cooking and independence skills.
- To be involved in recruiting and training staff. And in how services are run.

The right of people with learning disabilities to have personal and sexual relationships can be a concern to carers and guidance is needed by professionals. Some Service users need information in order to understand their bodies and protect themselves from abuse. Whilst

there is county policy and guidance not all service users are currently accessing this type of information.

9.1.2 Parents with learning disabilities

More people with learning disabilities are having children. However, large numbers of parents with learning disabilities end up having their child removed by the courts following the involvement of child protection teams (Harwin et al 2001) In some cases no doubt this is the right thing for the child as they have to be protected from abusive or neglecting parents. However evidence suggests that people with learning disabilities are not getting treated fairly by the child protection system and discrimination is taking place.

Parents with learning disabilities are more likely to have their children taken in to care than parents who don't have learning difficulties. A study of care orders found that one in four (25%) of children involved in a care order had a parent with a learning disability (Harwin et al 2001). Another study on child protection applications to family courts found that 15% involved a mother and/or father with learning disabilities (Booth et al, 2003). People with learning disabilities report that they are often treated as "the problem" rather than being seen as people who need support. They say that the services that support parents in general don't know how to support parents with learning difficulties. This means that when problems arise, they are more at risk of having their children taken away.

Many people believe that the legal system doesn't help. Judges and lawyers often have little training or experience of people with learning difficulties. The time limit put on care proceedings can, at times discriminate against parents with learning difficulties who tend to struggle to keep up with the pace of events.

It is therefore important to help people with learning disabilities to be good parents. The National Gathering of parents with learning disabilities (CHANGE, 2005) noted the importance of:

- Accessible information about how to look after your baby
- Coming together with other parents
- Getting support before things go wrong
- Being assessed in your own home – not a separate assessment centre.
- Assessment and support by people who understand learning disabilities
- Advocacy when you need it
- The courts being more accessible
- Support for dads with a learning disability.

Research by Booth and Booth (2003) has found that there are certain things that make it possible for people with learning disabilities to be good parents

- Believing that people can be good parents rather than starting off with the belief that they can't
- Good advocacy support
- Specialist services for parents with learning disabilities
- Being willing to learn from parents themselves

An overview of all the research on parents with learning disabilities by Sue McGaw (2000) found that the main things that stop people looking after their children properly were:

- Not enough support
- The only support out there being designed for non disabled parents
- Lots of different people involved and not talking to each other or agreeing what should happen
- Few role models
- Little support from family and friends

Services for adults with learning disabilities usually only help people with high levels of disability. Most parents have mild to moderate learning disabilities and don't qualify for help. Many parents find this a very intimidating, confidence-sapping experience.

The national evidence would suggest a similar pattern in Cambridgeshire as elsewhere in the country. Anecdotal evidence from advocacy organisations, parents themselves and social workers suggest that many of the issues highlighted here happen in Cambridgeshire today as much as anywhere else.

Following the successful workshop in November 2007 which used the Department of Health's Best Practice Guidance in Working with Parents who have a Learning Disability, the Health Strategy Group submitted a report to the Local Safeguarding Children's Board. The executive board thought that some of the points in the report were very important. They are going to think about ways they can help to: Facilitate a multi-agency group to write new Learning Disability guidance/protocol based on DoH guidance and best practice that will bring together existing protocols.

They also plan to consider a model for multi-agency supervision alongside any recommendations from the LSCB supervision audit. Meanwhile some specialist health staff from all Cambridgeshire areas are producing and delivering a course on Understanding Learning Disabilities, which will be advertised by the LSCB.

9.2 Learning and Development

Percentage of working-age people who received job-related training in the past 13 weeks, employed and unemployed.

The Annual Population Survey 2004 was a new survey of approximately 65,000 household interviews, which was combined with data from the Labour Force Survey and English Local Labour Force Survey to provide enhanced annual data for England. The survey found that more than one in four of all working age adults when interviewed had received some form of job-related training in the previous thirteen weeks.

Rationale and background

There is an extensive literature on the mental health benefits of learning, which may include both personal growth and development and the value of participation in learning opportunities. Improved health outcomes may relate to increases in human capital, (knowledge and skills), social capital (trust and dependency) and identity capital (positive self-image, assertiveness and confidence).

People who flourish at school enjoy better health and wellbeing than those who do not, though the effect may not be causal. Adults who participate in adult education in their 30s

tend to enjoy positive transformations in their health and well-being more than their peers who do not. Adult learning is also associated with positive outcomes in health and well-being of adults who did not flourish at school.

Participation in adult learning therefore does not narrow the gap between those who did and did not flourish at school, but if appropriate provision is available at the right time, it may play an important role in promoting healthy lifestyles, wellbeing and mental health⁴.

There is no significant difference between the districts with regard to the amount of job-related training received when compared to the Cambridgeshire figure. However, it is statistically significantly higher in East Cambridgeshire and Cambridge City when compared with East of England and England.

There are 9 Social Training Enterprises in Cambridge that run a range of courses and work experience opportunities including:

- horticulture
- catering and cookery
- woodwork
- basic skills
- retail and office skills
- using the computer

9.3 Violence and Safety

We have used two measures of crime, focusing on violent crime. The percentage of the population who had a 'high level of worry about violent crime' from the British Crime Survey 2006/07 ('fear of crime')

The total incidence of violence per 10,000 adults reported by people in the British Crime Survey 2004/5 ('reported crime')

9.3.1 Rationale and background

Crime, particularly violent crime, is linked to mental health in a number of ways. Firstly they may have similar determinants such as drugs, alcohol and deprivation. Secondly, victims of crime are more likely to suffer mental health problems such as depression. Those who suffer from mental illness are more likely to be victims of crime than commit crime although violent crimes committed by people with mental illnesses are more frequently reported

We would therefore expect areas with higher levels of violent crime to have higher levels of mental health problems. We have used 'all violent crime' to allow comparison between fear, reporting, and recording.

Learning Difficulties in the criminal justice system

Experience both locally and nationally shows that people with learning disabilities or learning difficulties experience a number of problems once they enter the criminal justice system. Murphy

and Mason (2005) notes that poverty and social deprivation are often associated both with a raised prevalence of offending and with intellectual disability.

Particular issues relate to:

- Their learning difficulties may not be identified unless their behaviour gives cause for concern.
- Struggling with police questioning and cautions.
- Police not being aware of specific conditions that could result in presenting issues.
- Without being identified, they are more likely to incriminate themselves even if they are innocent
- Lack of understanding resulting in non-compliance with community-based orders.
- If detained the general health of people with learning disabilities is often poorer than for the general population, particularly with regard to mental health.

Research into anti-social behaviour orders, for example (BIBIC 2005), found that people with learning disabilities or autistic spectrum disorders often did not understand the terms of the order or why a community order had been imposed. This makes compliance with such community-based penalties highly unlikely, which in turn increases the likelihood of eventual custody.

Once people with learning disabilities or learning difficulties reach custody, they are likely to have difficulty understanding and adjusting to complex rules and regimes. They end up being targeted by other prisoners and barred from available programmes, including offending behaviour programmes, due to their impairments.

Requests for “appropriate adult support” are frequent and time consuming but are a vital aspect in order to ensure individuals access the support and communication assistance they need.

While issues around prevalence remain uncertain, those with less severe learning disabilities often require support, particularly around their mental and physical health and well-being, and as carers, particularly for older family members or dependent children. The extent to which they need support can often depend on the level of assistance they receive from family members and within their local communities. Sometimes, relatively small environmental changes can lead to major changes in needs. Without support, they may become socially excluded and vulnerable to victimisation. The case of Steven Hoskin (Flynn, 2007), who was killed by so-called ‘friends’ who had taken over his home, highlights the potential risk to this group of men and women.

9.4 Day Services Review

Recent review of day services outcomes

Some of the shortfalls highlighted through the evaluation related to:

- The slow introduction of person centred planning, which limits the leading of services by service users and results in a failure to provide appropriate levels of choice and control for service users
- The very high majority of opportunities for service users beginning at the day centre building, rather than from home or in the community.
- The ongoing cancellation of developmental opportunities for some service users.
- Limitation of developmental opportunities for some service users.

- Small number of service users leaving the service to access community-based employment or volunteer opportunities.
- Failure to appropriately agree, set and review outcomes for both services and for individuals

Table 23: Number of people with learning disabilities receiving day care services by local authority and home type, as at June 2007.

No. of people with learning disabilities in Day Care	Local Authority					
	Cambridge	East Cambridgeshire	Fenland	Huntingdonshire	South Cambridgeshire	Total
Extra care/supported Residential	31	13	35	53	11	143
Nursing	16	34	24	17	60	151
Other resi/group	-	-	-	-	-	-
Other	-	-	-	-	-	-
Total	55	41	62	115	50	323
	102	89	122	188	123	624

Source: SWIFT data, Cambridgeshire County Council, June 2007.

Note: '-' denotes where there are less than 5 individuals

Transport services

Table 24 shows the number of people with learning disabilities who are receiving transport services by house type and district. Over half (54%) belong the house group "other" and just over a third lives in Huntingdonshire.

Table 24: Number of people receiving transport services, by local authority and home type, as at June 2007.

Home type	Local Authority					
	Cambridge City	East Cambridgeshire	Fenland	Huntingdonshire	South Cambridgeshire	Total
Extra care/supported Residential	7	-	-	5	-	19
Nursing	-	8	-	-	12	30
Other resi/group	-	-	-	-	-	-
Other	-	-	-	-	-	-
Total	5	9	8	26	13	61
	15	21	15	36	25	112

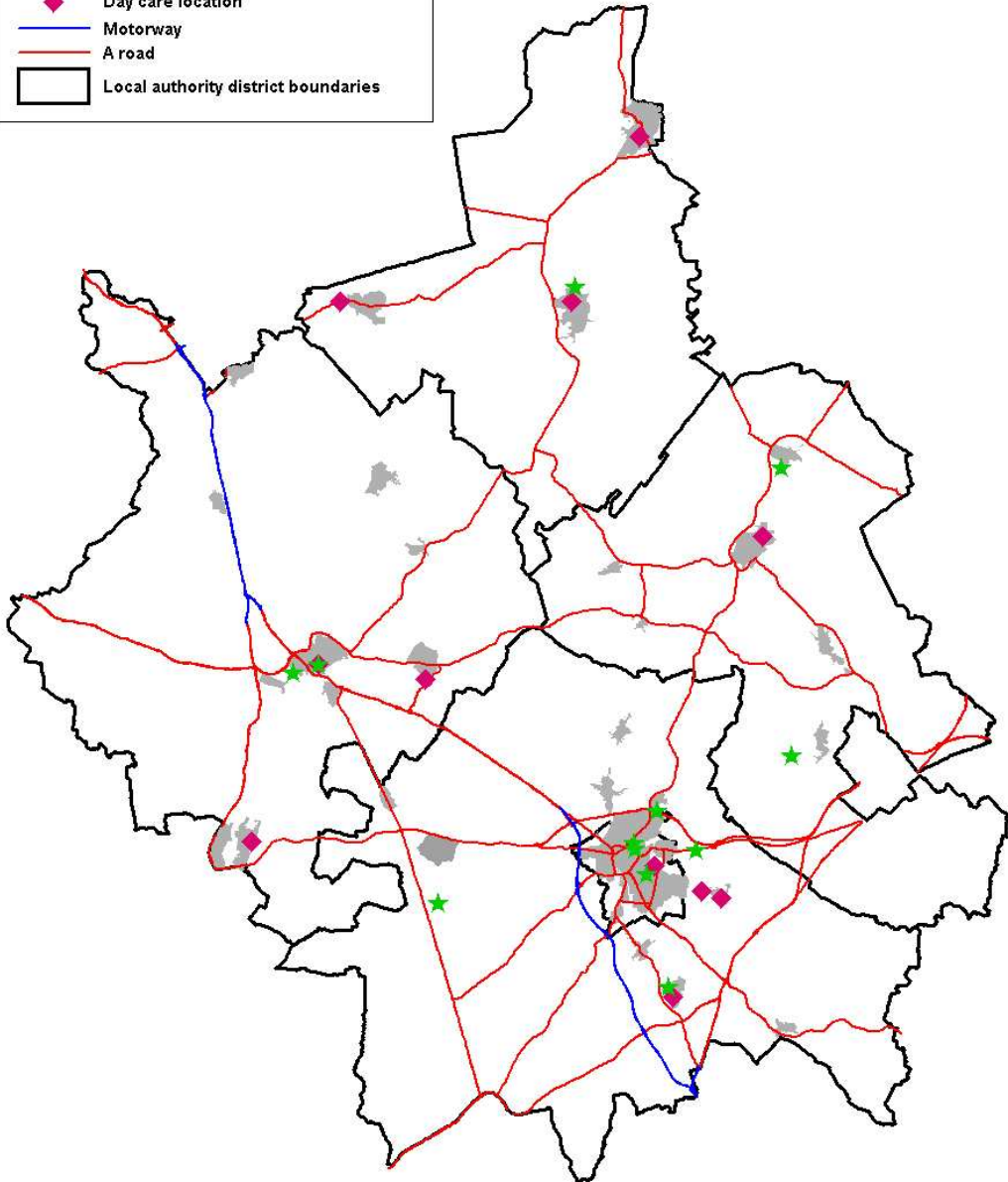
Source: SWIFT data, Cambridgeshire County Council, June 2007.

Note: '-' denotes where there are less than 5 individuals

Increasingly people with learning disabilities are being supported to live in tenancies however historically independent provision has developed Map 2 shows the spread of existing provision in Cambridgeshire. Map 3 shows the broader spread to include small grouped supported living units. It is not possible to show on this map all of the individual tenancies now taken up by people with learning disabilities.

Learning disability: Day Care & Social Enterprise in Cambridgeshire

- ★ Social enterprise location
- ◆ Day care location
- Motorway
- A road
- ▭ Local authority district boundaries



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Source: Cambridgeshire Learning Disability Partnership

Commentary

From Emerson's national survey (ONS 2006):

- *"...people with learning difficulties are at least as likely to participate in some types of community based activities as people in general".*
- *"...people with learning difficulties had much less contact with friends than people in Britain in general".*
- *"...people with learning difficulties had much less contact with members of their family that they were not living with".*
- *"We asked people who were not living with their parents or another relative how often they saw members of their family. Nearly half (44%) saw them at least every week or nearly every week. Just under one in five (19%) never saw members of their family. People who had learning difficulties were much more likely not to see members of their family than people who do not have learning difficulties.*
- *Just over two out of three people (69%) had contact with friends at least once a year. Nearly one in three (31%) said they did not have any contact with friends. People who had learning difficulties were much more likely not to see friends than people who do not have learning difficulties.*
- *Over two out of three people (69%) had friends who also had learning difficulties. One in four people (25%) had friends who did not have learning difficulties.*
- *One in twenty people (5%) had no friends and did not see anyone from their family...*
- *...Less than one in three people (31%) said that they voted in the 2001 general election. In surveys of the general population nearly four out of five people (73%) said that they voted in the 2001 general election".²*
- *"We asked people how happy they felt about their life at the moment. Nearly half (47%) said they were very happy. But one in twenty (4%) said they were mostly unhappy.*
- *One in ten people (9-11%) said they felt sad or worried 'a lot', felt left out 'a lot', and felt helpless 'a lot'. Over one in ten people (13%) said they 'never' felt confident".*
- *"Over one in three (39%) said they felt confident 'a lot'...*
- *Nearly all people (95%) said they had someone to talk to if they felt sad or down".*
- *"...over one in three (39%) did not have enough privacy..."*
- *29% didn't have job, weren't doing a course and didn't attend a day centre. Only 3% did all of these things.*
- *"One in three people (32%) said they did not feel safe either in their homes, their local area or using public transport*

- *Nearly one in three people (32%) said someone had been rude or offensive to them in the last year because they have learning difficulties*
- *Nearly one in ten people (9%) said they had been the victim of crime in the last year. People with learning difficulties were less likely to be a victim of crime than other people, but they were slightly more likely to be attacked”.*
- *“One in three people (39%) did not have enough privacy”.*³
- *“...one in ten people (9%) said they had been the victim of crime...” which is “...less than the chances of being a victim of crime reported in 2003/04 British Crime Survey (26%)”.*

9.5 Autism Spectrum

It is difficult for some people with AS/ASD but without a recognised learning disability to access services. The needs of these individuals with AS/ASD are not easily met by the current service provision in either adult mental health or learning disability services.

There are very few specialist services and no focused and systematic service delivery

People with AS/ASD have a range of needs that will not be addressed by one agency. For many individuals their health care needs will be managed in primary care. Functions that may require secondary services include;

- Diagnostic assessments
- Post diagnosis information and support
- Psychological treatments focused on the psychological consequences of AS
- Treatment for co-occurring mental health problems
- Treatment for co-occurring developmental problems

People with AS/ASD experience difficulties in social interaction and may require support to develop independent living skills. Different providers, including voluntary organisations could deliver these functions, to include;

- Training/employment
- Education
- Housing
- Leisure and social activities
- Welfare support
- Information

10. MOVING INTO EMPLOYMENT

To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work. (*Valuing People DOH 2001*)

Key Messages

- People want the right to paid employment but need the information, support, training and opportunity to achieve their goals.
- People with learning disabilities experience significant barriers in accessing paid work and numbers in paid employment are low.
- A range of ways of enabling people to prepare for and gain paid employment is needed.
- Work is also needed with employers, including statutory organisations to promote access to work experience opportunities and paid employment

10.1 Inclusion and Value

A recent Cambridgeshire Parliament confirmed that people with learning disabilities want:

- The right to get part-time work, voluntary work or work experience as well as a full-time paid job dependent on their wishes.
- To get information about opportunities and schemes that provide support.
- To get advice about the impact on benefits.
- To get training and work experience that leads to real work.
- To get support with “getting ready for work”, like job clubs.
- To have support when looking for work and applying for a job. This would include to get support in interviews and when in

There is considerable anxiety for both people with learning disabilities and their families around paid work, particularly the impact on benefits. There is a lot of confusion about government employment projects and benefits that help a person to work. Whilst people are clear about their rights to be paid the same money as other staff that do the same job; to have reasonable adjustments changes made to the workplace and to be treated equally many individuals are very concerned about making the step.

10.2 Local Research

During 2007 an Investing in Communities grant funded local research, undertaken by Papworth Trust, into the barriers and experience of people with disabilities. The key findings from this were:

- People with learning disabilities had a broad interpretation of work, many valued work experience and training activities in their own right.

Using a person-centred approach to planning services, which is easily accessible to individuals and parents/carers, covering a wide range of support needs (day opportunities, training, respite care, housing and support, transport etc.), supported by good information and personal guidance.

10.3 Local Actions

A multi agency group has developed an action plan to look at some of these issues. Resources are however limited. Some of the key areas to be addressed include:

- looking at the roles, capacity and potential joint working among existing providers of information, advice and guidance in this sector.
- Facilitating access to clear, simple and consistent guidance to individuals and carers on the issue of benefits and paid work, including permitted work etc., and how they can get 'better off in work' calculations.
- Recognising the value of micro jobs (paid work sometimes of just a few hours a week) and to provide support and benefits guidance to make these possible, and financially beneficial for individuals.
- Promoting access to transport solutions for disabled people, building on good practice, looking at issues such as the proximity of service delivery to where people live (eg provision for people in rural areas), transport training and information on Access to Work. To work with transport providers to improve disability awareness and physical access. Promote Transport training and use of modern technology to allow more independent travel
- Influence major new developments taking place across the county (such as Northstowe) to maximise access by disabled people to public transport and employment opportunities in the future.
- Work with employers to promote positive attitudes towards employing disabled people. Promote positive working practices with employers such as flexible and part-time working arrangements, making adjustments and installing equipment in the workplace (which may be paid for by Access to Work) and offering work trials, which could lead to paid work.
- Share good practice within the county and look at good practice elsewhere (including Europe) and to promote joint-working.

A copy of the detailed action plan can be made available.

10.4 Training and support for work

There is considerable evidence to support the beneficial effects of employment on an individual's mental health. Employment can protect a person's mental health by boosting confidence and self-esteem; unemployment can be both a consequence and cause of mental health problems⁵. People with mental health problems can be particularly sensitive to the negative effects of unemployment.

Whilst being in employment can reduce the symptoms of mental health problems and reduce service use, prolonged unemployment is linked to worsening mental health. There is a

strong relationship between unemployment and the development of mental health problems, including an increased risk of suicide.

Social Training Enterprises work closely with Further Education providers to run a number of work based training courses. Attendance at “Job Clubs and support from specialised assessment and support into employment is key to successful work placements. The numbers of people with learning disability known to the local authority are still low with in the region of 130 people currently in part or full time employment. Fifteen new people commenced work in 2007-08.

10.5 Incapacity Benefits

People with lower needs not meeting social care eligibility criteria also experience difficulties in accessing employment. Support is available from the Job Centre’s Disability Employment Advisors.

Incapacity benefit is a social security benefit, which can be claimed by working age adults unable to work because of illness. Payment of the benefit depends on an adequate history of national insurance contributions, but disabled people not eligible for payments on the grounds of national insurance contributions may still claim, thereby gaining national insurance credits.

Numbers claiming Incapacity Benefits are significantly lower in Cambridgeshire as compared to England. However, within Cambridgeshire these are substantially higher in Fenland and Cambridge City (even higher than those in the East of England). Details can be found in Appendix 1.

From Emerson’s national survey (ONS 2006):

- *“...89% said they receive some benefits...”*
- *38% (just over one in three) had heard about Direct Payments and 60% of these had applied for them*
- *“Only one in six people with learning difficulties who were of ‘working age’ (17%) had a paid job”.*
- *“Many people worked part time. Over one in four men (28%) and nearly half of women (47%) who had a paid job worked for less than 16 hours a week*
- *Nearly two out of three people (65%) who were unemployed (and said they were able to work) said they would like a job”.*
- *One in twenty (6%) had an unpaid job*
- *“...9% had heard of the WORKSTEP programme...23% had heard of the New Deal for Disabled people...66% had heard about Connexions service...52% received some help when looking for a job...”*
- *We had a list of things that most people in England think others should be able to have. These were things like being able to buy new clothes. We asked people whether they had*

enough money to buy these things. People with learning difficulties were less likely to have enough money to buy these things than people who do not have learning difficulties.

- *“Being poor or living in a poor area had an impact on just about every aspect of peoples’ lives. This is important because people with learning difficulties are much more likely to be poor than people who do not have learning difficulties. People who were poor or lived in poor areas were more likely to live in unsuitable accommodation and to have less privacy at home. They were also more likely to be unemployed, not have a voluntary job, not have enjoyed school, be bullied at school, not be taking a course and not attend a day centre. They were also more likely to not have control over their money. They were also more likely to see members of their family less often, be an unpaid carer, see their friends less often, do a smaller range of community activities, not have voted and not know about local advocacy groups. They were more likely to not feel safe, be bullied and be a victim of crime. Finally, they were more likely to have poor health, have a long-standing illness or disability, smoke, not be happy, be sad or worried, feel left out, feel helpless, not feel confident, have unmet need and to have wanted to complain about the support they receive”.*

11. QUALITY

To ensure that all agencies commission and provide high quality, evidence based, and continuously improving services which promote both good outcomes and best value. (*Valuing People DOH 2001*)

Key Messages

- Person centred reviews and regular monitoring of services are important in maintaining and developing quality services.
- People with learning disabilities are vulnerable to abuse or bullying.
- Joint work with Cambridgeshire Police must continue to ensure protection of vulnerable adults maintained and to tackle hate crime.
- Managing risk is important but should be balanced against choice and independence.
- Independent Mental Capacity Advocacy services in line with new guidance will seek to maintain individual's rights.
- Access to preventative services for adults with learning disabilities who may not need an assessed health or social care service will maintain people's independence and well being.
- Guidance and training for appointees will increase skills in administering welfare benefits on behalf of people unable to manage their finances.

11.1 National evidence

From Emerson's national survey (ONS 2006):

- *“One in ten people (10%) with learning difficulties living in private households helped care for another adult who was elderly, ill or had a disability.*
- *One in twenty people (6%) said they had an unmet need for support.*
- *Nearly two out of three people (63%) said they were very happy with the support they received. A few people (7%) said they were not happy.*
- *One in ten people (10%) said they had wanted to complain about the support they received”.*
- *“People with higher support needs were more likely to be living in supported accommodation, to have less privacy, to have less choice, to be unemployed and not to have a voluntary job. They were more likely to not to have done to a mainstream school, not to be taking a course, not to receive Direct Payments, not to have control over their*

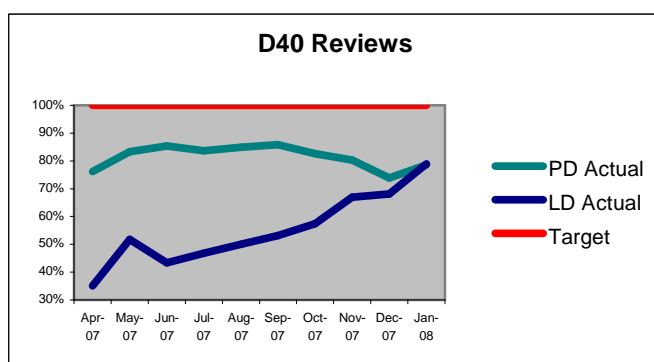
money. Finally, they were more likely to see friends who not have learning difficulties less often, not to feel safe, feel helpless and not feel confident.

- *People with lower support needs were more likely to be poor, a victim of crime, be unhappy have poor general health and to have been bullied at school”.*⁴

11.2 Methods for assuring Quality

The LDP uses a range of methods to monitor, maintain and drive up the quality of its staff and commissioned services. The primary objective is to ensure that individuals have their needs met in the most effective way that maintains their independence and wellbeing. We know that using a person centred approach to the assessment, care management and review process is the best way to check and review the quality and appropriateness of services. The annual review provides a good opportunity to see what is working well and what needs to be changed.

Ensuring people receive an annual review is a key performance indicator.



The Business Objects Report show we are achieving an increase of between 2% and 3% a week to achieve our targets of over 90% of reviews in the current financial year.

More information regarding social care performance indicators can be found in Appendix 2.

11.2.1 Consultation and Involvement

Listening to and involving service users and carers in the services they receive is an important way of improving care. A number of one off and regular methods are used including: Citizens Panels; User Surveys; consultation events; LDP Carers Network; Valuing People Implementation groups and the Cambridgeshire Service Users Parliament. Meeting regularly with service users and carers provides valuable opportunities to discuss issues, problems and developments. The Parliament and the LDP Carers Network regularly report to the LDP Board. People with learning disability and their carers are also able to use the Complaints and comments process and Patient Advice and Liaison Service (P.A.L.S).

11.2.2 Checking and Auditing

LDP health and social care services are also subject to a range of checks and audits. Audits are undertaken periodically, these may relate to finances, procedures or Clinical effectiveness.

Professional staff are keen to use best practice and evidence based practice throughout their work.

11.2.3 Contracts and Accreditation

Commissioned services are subject to a clear tendering process. All providers must be approved/registered providers. Service specifications and contract monitoring ensure that these are routinely monitored. Teams are asked to identify services requiring a higher priority for monitoring. Services receiving Supporting People funds are required to submit data on quality (QAF).

Issues and Opportunity – limited Contracts staff means services are not monitored as frequently as would be liked.

11.2.4 Training and Professional Workforce

The quality of services is often reliant on the level and quality of its workforce. Methods used to drive up quality include: Supervision and Performance Review (Appraisal); Continuous education and training; Development of clinical and social care Leadership; Professional registration and regulation.

11.2.5 Managing Risk

Whilst there is an expectation that professional self regulation places a responsibility on all practitioners to behave safely there are a number of measures in place to ensure the safety of people with learning disabilities and staff are maintained to a high level. Operational and Practice Guidance is in place to cover a range of potential situations. Health and Safety guidance is also issued. Risk assessments are undertaken for individuals as relevant. Where incidents occur there are clear Incident Management guidelines.

11.3 Protecting of Vulnerable Adults (POVA)

People with learning disabilities are amongst the most vulnerable within our society. Whilst there are robust POVA policies and training are in place this does not prevent the occurrence of incidents. The safety of people with learning disabilities is of paramount importance.

During the period April 2006 to March 2007 there were 55 reported cases of abuse against people with learning disabilities. There were in total 627 adult (including older people) cases reported to Cambridgeshire Adult Support Services. Any or all types of abuse may be perpetrated as a result of deliberate intent, negligence or ignorance. Abuse or mistreatment:

- can be a violation of an individual's human or civil rights by another person or persons

- may consist of a single act or repeated acts
- can occur in any relationship
- may result in harm to, or serious exploitation of, the person subjected to it.

What type of abuse was perpetrated against people with learning disabilities?

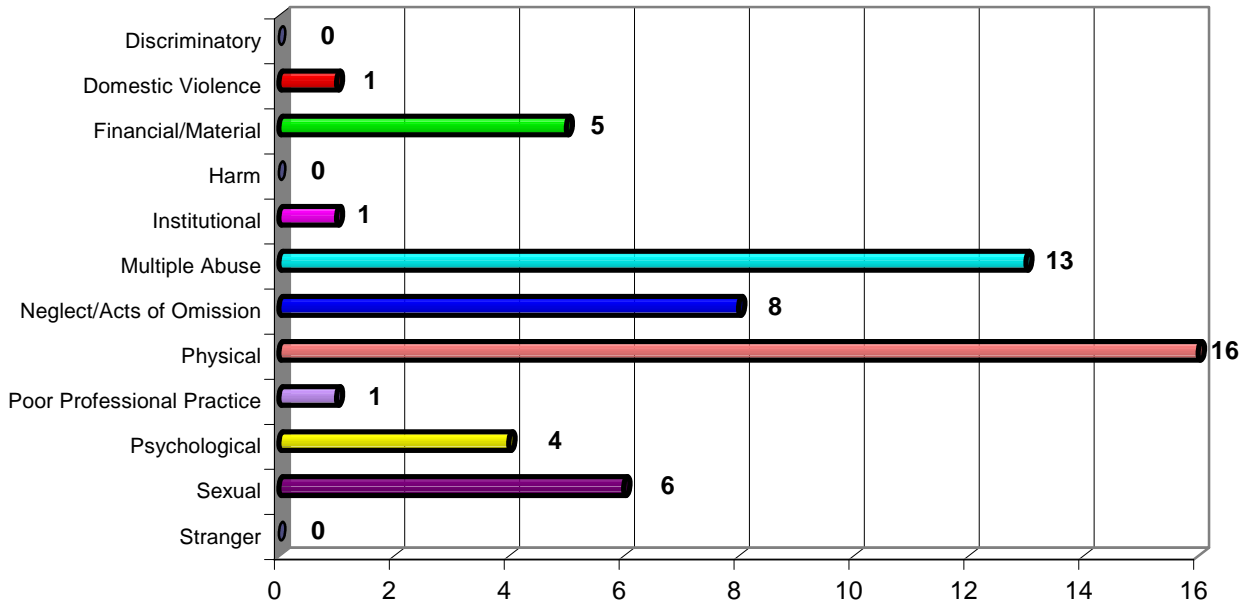


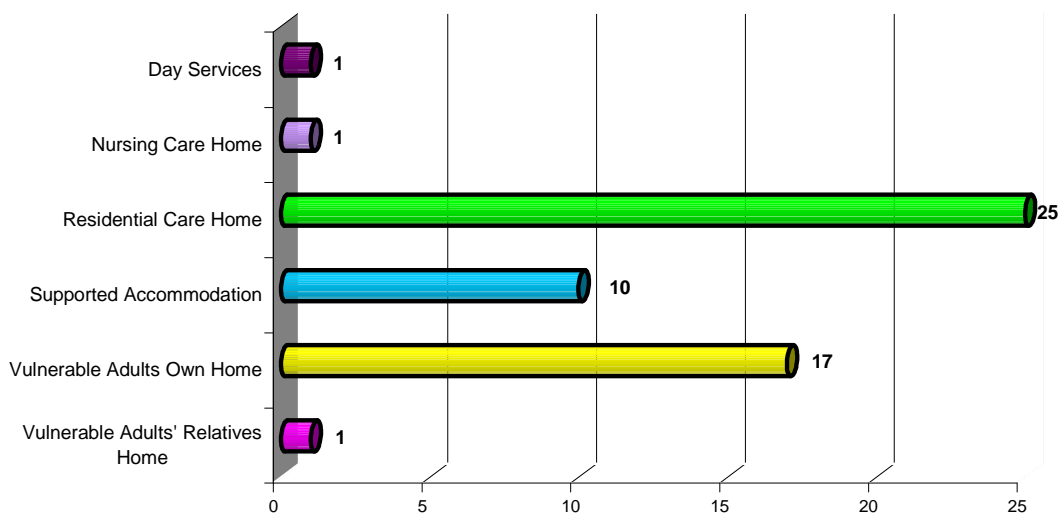
Fig. Source: Protection of Vulnerable Adults Annual Report 06-07

There were thirteen cases where the vulnerable adult had suffered a combination of two or more forms of abuse.

Fig Where did the abuse of learning disabled people happen?

Source: Protection of Vulnerable Adults Annual Report 06-07

There were seventeen incidents of abuse in the learning disabled person's own home.



Protection of vulnerable adult activity receives a high profile from all agencies. Training is mandatory for staff in statutory and commissioned services. Not all abuse or bullying is reported.

2006 - 07 saw an increase in the level of protection of vulnerable adult activity. Statutory agencies work closely with colleague agencies to monitor and improve standards. Multi agency practice guidance and procedures are in place and reporting of incidences has improved accordingly.

The Mental Capacity Act Regulations extended the powers of Local Authorities and the NHS to instruct Independent Mental Capacity Advocates (IMCA) in adult protection cases. This means that an IMCA can be instructed when protective measures are being put in place and a person lacks capacity to agree to one or more of those measures. It applies in situations where there are allegations that a person has been abused or neglected or a person is alleged to be the abuser.

IMCAs have an important additional safeguarding role in the adult protection process. They are knowledgeable about the Mental Capacity Act, know about best practice in making best interest decisions and can independently represent a person who lacks capacity through the use of non-instructed advocacy.

Mult-agency work continues on:

Developing and implementing practice guidance and procedures across Cambridgeshire to further improve the arrangements for protecting vulnerable adults from abuse in Cambridgeshire. A training strategy continues to ensure the availability of a comprehensive training programme.

Other work in progress includes:

- The development of a training manual for the independent sector.
- Establishing stronger links with both independent and voluntary Housing Sector.
- Planning the second adult protection conference towards the end of 2008.
- Establishment of an e learning package for the independent sector.
- Establish links with East Anglia NHS Ambulance Trust.
- Explore the development of an eastern region training strategy.
- Deprivation of Liberty/ Mental Health Act changes.

12. WORKFORCE AND PLANNING

To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce. (*Valuing People DOH 2001*)

Key Messages

- A well trained and equipped workforce is vital to meet need.
- Recruitment and retention continues to be an issue.
- Independent sector staff have access to a comprehensive training programme.
- Workforce development needs to evolve and should include an appreciation of
 - Changing roles
 - The development of individualized budgets
 - The availability of assistive technology
- The importance of Diversity Equality Training and raising awareness for the wider workforce about the needs of people with learning disability.
- Training is also needed by family carers and care staff appointed using individual budgets.

12.1 Learning Disability Partnership

The LDP is responsible for commissioning and delivering all specialist health and social care for people with a learning disability in Cambridgeshire. The LDP directly manages about 500 staff employed either by health or social care. The LDP also has a responsibility for approximately 1000 staff working in services commissioned by the LDP. Workforce development is not just about training. It is also about operational planning, assessment, monitoring and then identifying development needs for individuals and the service - some of which may be met by training.

Effective workforce development should link job descriptions and person specifications, to clear competencies, thus making appraisals and personal development plans a continuous process. Current practice ensures that the LDP links its staff into national occupational standards and awards, and, that all staff are able to demonstrate continuous professional development.

The LDP's Workforce Development Team through its Training Consortium organises and runs training for its staff and from any of its commissioned providers. The range of training is comprehensive and includes training around strategies for people whose behaviour presents a challenge. Training is provided locally to help improve practice. This partnership approach includes the pooling of resources and a joint approach to training which improves services.

12.2 Recent Developments

Good workforce development involves the analysis, planning and action to meet workforce needs as part of an overall strategic approach – linking at all times to development in the wider health and social community.

The LDP have built good links with Skills for Care and secured resources for a range of local projects such as the Social Care Careers Project. The appointment of a Careers Advisor and establishing an Ambassador programme has increased the number of services able to take on students for work experience and targeted schools and college careers seminars. Comprehensive reviews of local workforce and user demographics, including an analysis of training requirements to meet user need are periodically undertaken.

Cambridgeshire's partnership approach to training relating to challenging behaviours and mental health needs was recently highlighted as good practice by Professor Mansell in his report to Government (Mansell 2007)

12.3 Access to Training and Professional Development

The aim of workforce development within the LDP is to provide an environment where all staff within and across the LDP and its commissioned services can map potential career paths. So for example we want to develop opportunities whereby the care assistant in a group home can gain the necessary training to take on a professional qualification and then come back to work in the LDP, in that profession as an LDP team member supporting service users living in the community the care assistant once worked in.

The LDP works in partnership with commissioned services on a model that pools training resources and centrally coordinates training and development across the LDP and its commissioned services.

12.4 Engaging service users and carers

In Cambridgeshire there has always been good levels of services user and carer involvement in training and development. However, it is important to continually review involvement and ensure that service users and carers can be actively engaged in as many aspects of workforce development as possible.

12.5 Training and awareness for the wider workforce

The wider workforce includes NHS staff, the police, children's services, the leisure and service industries etc. The challenge is to ensure that training related to meeting the needs of people with a learning disability is part of each organisation's workforce plan and that content delivered is appropriate and compulsory. The opportunity is about identifying existing good practice and creating the networks to share that practice.

Whilst many organisations undertake general Diversity training some of these courses lack the depth of awareness of the needs of people with learning disability. Recent consultation with service users and family carers have raised concern about the lack of knowledge by some about the specific needs of people with learning disabilities.

Of most concern was the need for mainstream Health professionals to be fully acquainted with the additional communication and other needs of people with learning disabilities.

Social and leisure providers in the community have been identified by users as being in need of additional training in order to maximise opportunities for involvement by people with learning disabilities in the use of their facilities.

12.6 Priorities

Cambridgeshire has a range of problems with recruitment and retention of health and social care staff. These recruitment and retention difficulties are reflected in the LDP and its commissioned services. From a service commissioner and provider perspective, person centred planning and direct payments remain key areas for workforce development activity. Other key issues, challenges and opportunities outlined include:

- Continue to map training need and develop workforce development activity.
- Identifying examples of good practice and ensure that this is shared.
- Build a workforce development programme related to targets and priorities.
- Build our own models of good practice in training for and with users and carers.
- Highlight development requirements arising from new roles and how recruitment and retention needs to be adapted to meet the new roles agenda.
- Ensure that resources for vocational training are maximised and used to raise vocational skill levels.
- Build a framework for continuing professional development that helps us to recruit and retain a diverse and flexible workforce.
- Develop and implement a range of workforce development activity related to ethnicity and diversity.
- Ensure that workforce development activity related to person centred planning is meaningful and focussed.

13. PARTNERSHIP WORKING

To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services. (*Valuing People DOH 2001*)

Key Messages

- Adult Support Services and Children's Services need to work to improve the capacity of parents with learning disabilities to raise their children and plan their families.
- Services within generic older people's services are needed where this is more appropriate for older people with learning disabilities.

Continued partnership work will need to do:

- Support the partnership work that the LDP have started to do with the Hospital Trusts
- Look at how the Local Area Agreement actions can include people with learning disabilities – for example are screening or smoking cessation actions also including people with learning disabilities. An Equality Impact Assessment on action areas could identify if the work is inclusive of people with learning disabilities.
- Ensure PCT Commissioners consider they needs of people with learning disabilities when they commission services (Acute / Primary care) so that:
 - funding levels and skills levels are adequate to meet the additional needs of people with learning disabilities/ are able to meet DDA requirements.
 - They ensure people can register with a GP and access services in the practice in particular that they can access regular health checks / screening services to help address high levels of unmet health need.
 - Equitable treatment and interventions once people have received the health check.
 - Improved staff training explicitly to reduce the risk of 'diagnostic overshadowing' and unequal treatment.
 - There is effective targeted health promotion to improve health and that data is able to record the take up / or not of people with learning disabilities.
 - The involvement of disabled people and carers in influencing and leading service improvements.

Next Steps

The JSNA will inform the Joint Commissioning Strategy for people with learning disabilities It should also influence the PCT and the County Council 's strategies and commissioning plans including the Local Area Agreement. The JSNA will be revised in the light of new developments and guidance; changing needs and priorities and ongoing consultation.

Appendix 1

Additional Data: Demography of Cambridgeshire

Table: Population estimates, mid 2006, Local Authority

Local Authority	Age band										Total
	0-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
Cambridge City	5,610	10,070	27,220	20,900	14,670	11,710	9,720	6,560	5,120	2,110	113,700
East Cambridgeshire	4,860	9,180	8,350	8,570	12,540	10,210	9,860	6,560	4,580	1,520	76,200
Fenland	4,700	11,370	9,780	10,530	13,040	11,620	11,480	9,070	6,370	1,930	89,900
Huntingdonshire	9,180	21,260	18,450	18,610	26,860	22,890	20,840	12,550	7,500	2,680	160,800
South Cambridgeshire	8,190	17,410	15,230	15,680	22,520	19,390	18,120	11,140	7,460	2,900	138,000
Cambridgeshire	32,540	69,300	79,020	74,290	89,620	75,810	70,020	45,880	31,020	11,130	578,600

Source: Cambridgeshire County Council Research Group. Totals may not add due to rounding.

Table: Population estimates, mid 2006, People of working age (18 to 64 years), Local Authority

	Male	Female	Total 18 – 64 years	% of total population
Cambridge City	42,530	39,640	82,180	72%
East Cambridgeshire	23,500	23,880	47,380	62%
Fenland	26,920	27,250	54,170	60%
Huntingdonshire	51,620	51,250	102,880	64%
South Cambridgeshire	43,710	43,310	87,010	63%
Cambridgeshire	188,280	185,330	373,610	65%

Source: Cambridgeshire County Council Research Group

The working age group (18-64 years) in Cambridgeshire in 2006 constitutes 65% of the total population. The proportion is noticeably higher in Cambridge City (72%).

Table: Population forecasts 2006 – 2021, Working age (20 – 64 years), Local Authority

Year	2006	2011	2016	2021	% change 2006-2021	Absolute change 2006-2021
Cambridge	81,540	95,970	105,660	102,380	26%	+20,840
East Cambridgeshire	46,620	48,840	47,600	45,340	-3%	-1,280
Fenland	53,320	54,100	55,310	56,930	7%	+3,610
Huntingdonshire	101,460	105,570	100,760	98,660	-3%	-2,800
South Cambridgeshire	85,840	90,460	92,820	95,230	11%	+9,390
Cambridgeshire	368,780	394,940	402,150	398,540	8%	+29,760

Source: Cambridgeshire County Council Research Group 2005-based forecasts.

Population forecasts for an approximation of the 'working age' population – shown here for the age groups 20 to 64 years, show that the greatest increases in the population are likely to be in Cambridge City and South Cambridgeshire. A relatively small increase is forecast in Fenland with a decline in the working age population in Huntingdonshire and East Cambridgeshire. This has implications for the ratio of people of working age to the number of older people in the population (the dependency ratio).

Table: Ethnicity, 2001, Local Authority

Percentage	England and Wales	Cambridge	East Cambridgeshire	Fenland	Huntingdonshire	South Cambridgeshire
White	90.9	89.4	97.9	98.6	97.2	97.1
Mixed	1.3	2.0	0.7	0.6	0.9	0.9
Asian or Asian British	4.6	3.8	0.5	0.4	0.9	0.9
Indian	2.1	1.8	0.3	0.2	0.4	0.5
Pakistani	1.4	0.5	0.1	0.0	0.4	0.1
Bangladeshi	0.6	0.9	0.1	0.1	0.1	0.1
Other Asian	0.5	0.6	0.1	0.1	0.1	0.2
Black or Black British	2.1	1.3	0.3	0.2	0.5	0.4
Caribbean	1.1	0.5	0.1	0.1	0.2	0.2
African	1.0	0.7	0.1	0.1	0.1	0.2
Other Black	0.2	0.1	0.1	0.0	0.2	0.1
Chinese or Other Ethnic Group	0.9	3.5	0.7	0.3	0.5	0.8

Source: Census 2001 © Crown Copyright 2003 - Table KS06

The table above gives the ethnic composition in different districts of Cambridgeshire. Cambridge City has the highest proportion of people from a non-white ethnic group. The other districts have a significantly lower proportion of non-white ethnic group as compared with England and Wales.

Table: Ethnicity, Cambridgeshire 2001 and 2004. Persons, all ages

	Number of people		% of population	
	2001	2004	2001	2004
White	531,600	544,500	95.8%	94.1%
White: British	504,100	511,100	90.9%	88.3%
White: Irish	4,900	5,300	0.9%	0.9%
White: Other White	22,600	28,100	4.1%	4.9%
Mixed	5,900	7,500	1.1%	1.3%
Asian or Asian British	7,700	11,400	1.4%	2.0%
Indian	3,700	5,600	0.7%	1.0%
Pakistani	1,400	2,300	0.3%	0.4%
Bangladeshi	1,400	1,700	0.3%	0.3%
Other Asian	1,200	1,800	0.2%	0.3%
Black or Black British	3,400	6,100	0.6%	1.1%
Black Caribbean	1,300	2,200	0.2%	0.4%
Black African	1,400	3,000	0.3%	0.5%
Other Black	700	900	0.1%	0.2%
Chinese or Other Ethnic group	6,400	9,500	1.2%	1.6%
Total	554,700	578,900	100.0%	100.0%

Source: ONS Census 2001 © Crown Copyright 2003 - Table KS06 and ONS Experimental Statistics (2006)

Table: Ethnic population, estimates for 2004 by district. People of working age (men aged 16 – 64 and women aged 16 – 59 years)

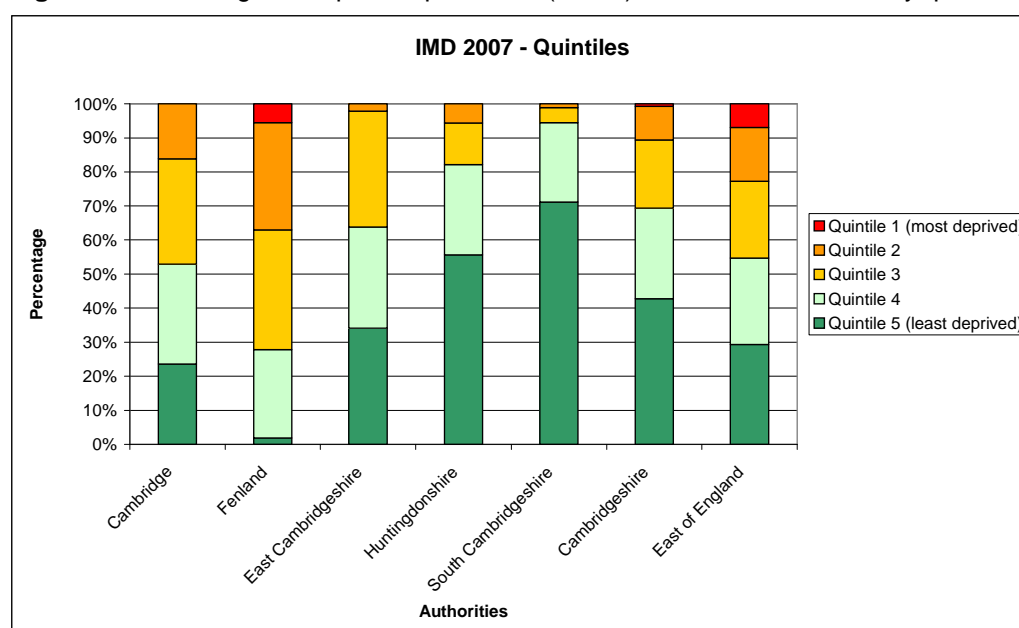
	Cambs	Cambridge City	East Cambs	Fenland	Hunts	South Cambs
White	336,100	68,500	43,900	48,200	96,200	79,300
White: British	315,400	58,700	41,600	47,200	92,200	75,600
White: Irish	3,500	1,300	400	300	800	800
White: Other White	17,200	8,500	1,900	700	3,200	2,900
Mixed	3,000	1,300	300	300	700	600
Asian or Asian British	5,500	3,200	200	100	1,000	800
Indian	2,900	1,700	200	100	500	500
Pakistani	900	400	-	-	300	100
Bangladeshi	800	600	-	-	100	-
Other Asian	900	500	-	-	100	200
Black or Black British	2,600	1,200	200	100	700	500
Black Caribbean	1,000	400	100	100	300	200
Black African	1,100	700	-	-	200	200
Other Black	500	100	100	-	200	100
Chinese or Other Ethnic group	5,200	3,300	400	200	500	800
Total	696,600	150,400	89,300	97,300	197,000	162,600

Source: ONS Experimental Statistics (2006)

The table above shows the number of people by ethnic group for 2001 and 2004 (Cambridgeshire) using information from the 2001 Census and 'experimental' statistics for 2004 produced by ONS. The estimated number of people is shown and the percentage of the total population. Table 7 shows the experimental estimates for 2004 by Local Authority for people of working age.

Additional Data: Deprivation

Figure 9: Percentage of Super Output Areas (SOAs) in each local district, by quintile of deprivation



Source: IMD 2007

Indicator description

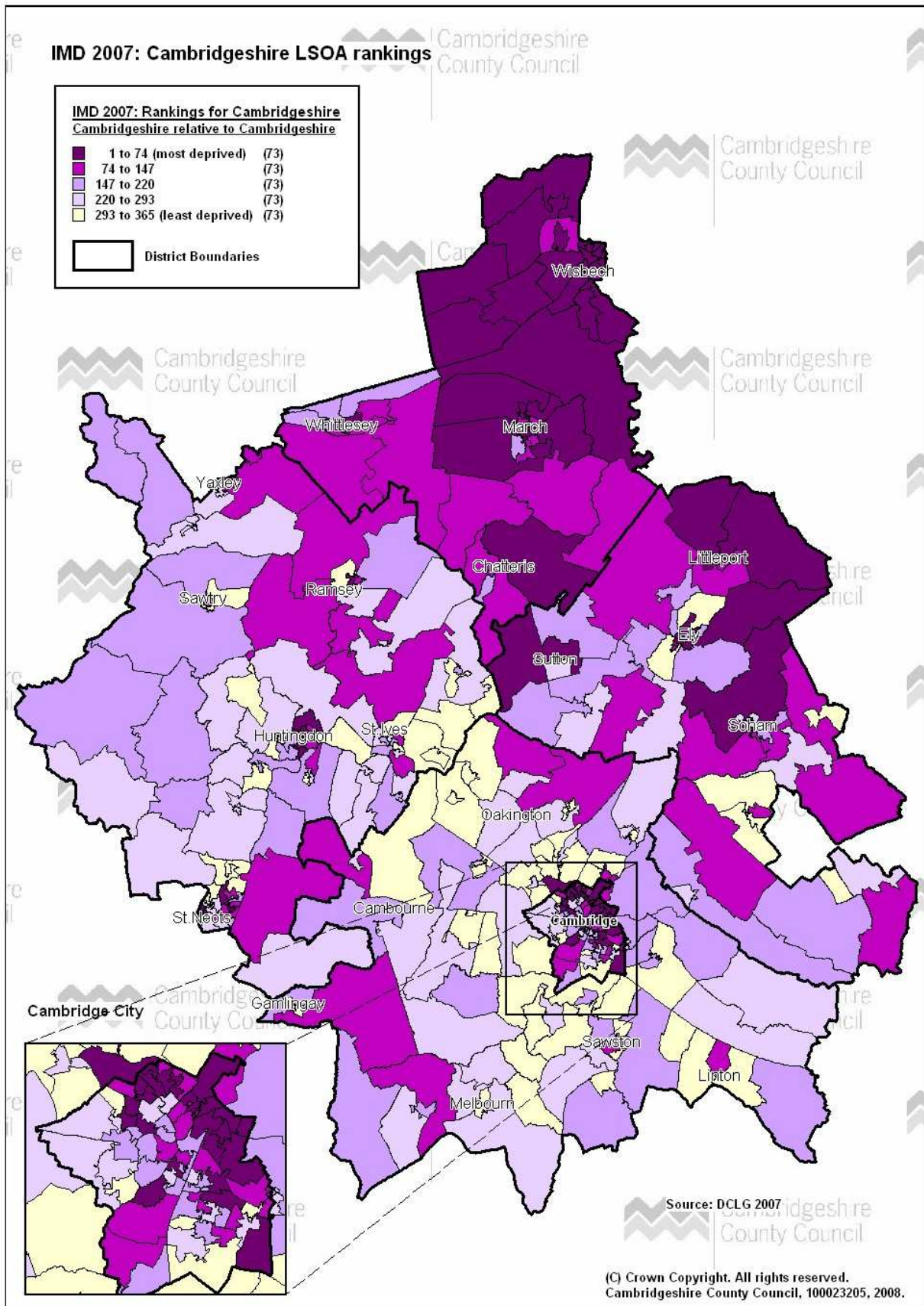
The percentage of Super Output Areas in each district, by quintile of deprivation.

The *Index of Multiple Deprivation 2007* (IMD 2007) commissioned by the Office of the Deputy Prime Minister and constructed by the Social Disadvantage Research Centre at the University of Oxford is a measure of multiple deprivation for small geographical areas. IMD 2007 scores update the IMD 2004 and have been calculated for small geographical areas known as Super Output Areas (SOAs) covering the whole of England. These individual small area IMD 2007 scores have been grouped into quintiles representing the most through to the least deprived areas of England. The proportion of each local district's SOAs that belong to each of the five deprivation quintiles produce a useful summary measure of deprivation compared with the East of England.

Summary of main findings and commentary

Numbers claiming Incapacity Benefits are significantly lower in Cambridgeshire as compared to England. However, within Cambridgeshire these are substantially higher in Fenland and Cambridge City (even higher than those in the East of England).

Map : Cambridgeshire IMD 2007 scores (showing Cambridgeshire deprivation quintiles)
 The SOAs shaded darkest represent the most deprived 20% of Cambridgeshire's SOAs



Appendix 2 Performance Management

Performance Indicators

The performance indicators listed reflect the key areas of activity and related progress. They represent both the formal Social Care Performance Indicators and a number of additional indicators that are relevant to the delivery of services to people with learning disabilities. These indicators are in line with the expectations of Valuing People, the government's strategic direction for people with learning disabilities, which the partners to the Section 75 Agreement are committed to deliver.

Clients Receiving a Review: Adults receiving a review as a percentage of those receiving services

	Target 2006-07	Performance 2006-07	Performance from April 2007 to March 2008	Target 2007-08
PI part of D40 Clients receiving a review	70%	86.6%	92.6%	70%

This indicator is cross-client and the target relates to the performance expected across all client groups. The performance to March 2008 is just for the LDP. The performance has increased month by month since April 2007 and achieved over 90%.

Direct Payments: Adults and older people receiving Direct Payments at 31st March per 100,000 population aged 18 or over.

	Target 2006-07	Performance 2006-07	Performance from April 2007 to March 2008	Target 2007-08
P1 part of C51 – number of people with an LD receiving Direct Payments	110	91	100	130

Adults with Learning Disabilities helped to live at home per 1,000 population aged 18-64.

	Target 2006-07	Performance 2006-07	Performance from April 2007 to March 2008	Target 2007-08
PI (C30) – Adults with Learning Disabilities helped to live at home per 1,000 population aged 18-64	2.1	1.97	2.17	2.3

Locality teams continue to focus on community based packages as the preferred option for supporting people with learning disabilities, rather than residential/nursing home placements,

and performance on the number of admissions of people aged 18-64 years to residential/nursing homes continues to be good. In addition, work is ongoing to identify errors in the system where people are being helped to live at home and are not recorded as such.

Service for Carers: The number of carers receiving a specific carers' service as a percentage of clients receiving community based services.

	Target 2006-07	Performance 2006-07	Performance from April 2007 to March 2008	Target 2007-08
PI (C62) – Service for Carers	12.0%	10.4%	11.28%	12%

This indicator is cross-client and the target related to the performance expected across all client groups

Person Centred Plans completed for young people in transitions: as a percentage of young people in transition

	Target 2006-07	Performance 2006-07	Performance from April 2007 to March 2008	Target 2007-08
Person Centred Plans completed for young people in transition	80%	83%	89%	80%

This year 58 out of 65 people in transitions have completed person centred plans. The long term aim is to ensure all young people in transitions are supported to develop their own person centred plans.

Health Action Plans: the percentage of people receiving a service who have a health action plan

	Target 2006-07	Performance 2006-07	Performance from April 07 to March 08	Target 2007-08
Health Action Plans	50% of service users	12% of those with a service	60% of service users	50% of service users

The target has been achieved for this financial year. Work is ongoing to continue to achieve a higher performance in accordance with the Valuing People White Paper.

Number of People with a Learning Disability supported into employment in this current year

	Target 2006-07	Performance from April 07 to Mar 08	Target 2007-08
Number of people with a learning disability supported into employment in year	27 people	15 people	15

Workforce Development: percentage of front line staff who have achieved NVQ2/LDAF

	Target 2006-07	Performance 2006-07	Performance from April07 to March 08	Target 2007-08
Workforce Development percentage of front line staff should have achieved NVQ2/LDAF qualification	50%	40%	66%	50%

Additional Data: Assessments

Table: Number of completed assessments for new clients by primary client type and age group 2006/2007

Client Type	16-64	65-74	75+	All ages
Physical disability, frailty and sensory impairment	780	383	2918	4081
<i>Physical disability, frailty and/or temporary illness</i>	627	252	2373	3252
<i>Hearing/visual impairment or dual sensory loss</i>	56	40	249	345
Mental health	78	51	273	402
<i>Dementia</i>	-	32	194	229
Vulnerable people	10	9	24	43
Learning disability	61	-	-	64
Substance misuse	-	-	-	6
Total	932	446	3218	4596

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Table above shows that over 70% of first assessments for new clients are for people with physical disability, frailty and/or temporary illness. In total, 81% of all first assessments are in people aged 65 or over.

Table : Number of completed reviews for existing clients by primary client type and age group 2006/2007

Client Type	16-64	65-74	75+	All ages
Physical disability, frailty and sensory impairment	1452	808	4851	7111
<i>Physical disability, frailty and/or temporary illness</i>	1093	624	3591	5308
<i>Hearing/visual impairment or dual sensory loss</i>	150	77	522	749
Mental health	253	133	694	1080
<i>Dementia</i>	9	60	455	524
Vulnerable people	70	35	53	158
Learning disability	974	49	23	1046
Substance misuse	10	7	-	20
Total	2759	1032	5624	9415

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Table above tells us that over 56% of completed reviews for existing clients assessments for new clients are for people with physical disability, frailty and/or temporary illness. 80% of these are in people aged over 65 years. In total, 78% of all reviews of existing clients aged 65 or over.

Table : No of completed reviews for existing clients by primary client type and age group. 2006/07
 The numbers of completed assessments for new clients and the number of completed reviews for existing clients by primary client type and age group 2006/2007

Client Type	16-64	65-74	75+	All ages
Physical disability, frailty and sensory impairment	1452	808	4851	7111
<i>Physical disability, frailty and/or temporary illness</i>	1093	624	3591	5308
<i>Hearing/visual impairment or dual sensory loss</i>	150	77	522	749
Mental health	253	133	694	1080
<i>Dementia</i>	9	60	455	524
Vulnerable people	70	35	53	158
Learning disability	974	49	23	1046
Substance misuse	10	7	-	20
Total	2759	1032	5624	9415

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Provision of services

Table below shows that 69% of new clients with learning disabilities who have had an assessment, some or all services intended or already started. For 26% of new clients with learning disabilities who have had an assessment, no services were offered or are intended to be provided. The proportion of new clients with learning disabilities who have had an assessment, 5% were offered services but declined or are subject to other sequel to assessment.

Table : Number of new clients for whom assessments, by primary client type, with known or anticipated sequel to assessment, age group 18-64, 01/04/06-31/03/07

Client Type	Some or all (new) services intended or already started	No (new) services offered or intended to be provided	(New) service(s) offered but declined	Other sequel to assessment
Physical disability, frailty and sensory impairment	673	85	21	-
<i>Physical disability, frailty and/or temporary illness</i>	539	69	18	-
<i>Hearing/visual impairment or dual sensory loss</i>	52	-	-	-
Mental health	43	33	-	-
<i>Dementia</i>	-	-	-	-
Vulnerable people	7	-	-	-
Learning disability	42	15	-	-
Substance misuse	-	-	-	-
Total	768	136	26	2

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Table shows that the majority, or 70%, of people with learning disabilities are receiving community-based services in their own home. Note that each client may receive services from different service type simultaneously

Table : No of clients receiving services during period provided or commissioned 01/04/06-31/03/07.

Client Type	Total of clients	Community-based services in own home	LA Residential Care	Independent sector residential care	Nursing care
Physical disability, frailty and sensory impairment	2025	1936	-	59	55
<i>Physical disability, frailty and/or temporary illness</i>	1377	1295	-	51	52
<i>Hearing/visual impairment or dual sensory loss</i>	273	250	-	9	7
Mental health	937	854	-	69	19
<i>Dementia</i>	19	13	-	3	5
Vulnerable people	58	58	-	-	-
Learning disability	1137	801	5	346	24
Substance misuse	29	25	-	-	-
Total	4186	3674	5	477	99

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Table: Number of clients receiving community-services during period, provided or commissioned by the CSSR, by components of service, primary client type, age group 18-64, 01/04/06-31/03/07.

Client Type	Total of clients	Home Care	Day Care	Meals	Overnight respite - not clients home
Physical disability, frailty and sensory impairment	1936	459	201	48	77
<i>Physical disability, frailty and/or temporary illness</i>	1295	411	164	18	74
<i>Hearing/visual impairment or dual sensory loss</i>	260	19	14	-	7
Mental health	854	176	643	-	-
<i>Dementia</i>	13	7	-	-	-
Vulnerable people	58	-	-	-	-
Learning disability	801	379	518	-	192
Substance misuse	25	5	6	-	-
Total	3674	1020	1368	52	272

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Table : Number of clients receiving community-services during period, provided or commissioned by the CSSR, by components of service, primary client type, age group 18-64, 01/04/06-31/03/07.

Client Type	Short term residential not respite	Direct Payments	Professional support	Equipment & adaptations	Other
Physical disability, frailty and sensory impairment	-	266	193	1180	82
<i>Physical disability, frailty and/or temporary illness</i>	-	198	149	719	73
<i>Hearing/visual impairment or dual sensory loss</i>	-	14	34	223	9
Mental health	-	22	42	57	16
<i>Dementia</i>	-	-	-	-	-
Vulnerable people	-	32	-	24	-
Learning disability	9	100	-	62	97
Substance misuse	-	-	8	8	-
Total	9	421	248	1331	197

Note: '-' denotes where there are less than 5 individuals

Source: RAP return 2006/2007

Data analysis of the breakdown of community based services by client type, aged years 18-64 shows that people with learning disabilities are most likely to receive day care services (65%), home care services (47%) and overnight respite outside their home (24%). Note that each client may receive services from different service type simultaneously.

Appendix 3

Eligibility criteria

Needs	Degree of Risk			
	LOW (1)	MODERATE (2)	SUBSTANTIAL (3)	CRITICAL (4)
A Physical safety of individual and others			Abuse or neglect (including self-neglect) has occurred or will occur.	Life is threatened or will be. Serious abuse or neglect (including self-neglect) has occurred or will occur. Cannot be left alone.
B Physical health/ disability of individual and others	Concerns about physical health but unlikely to deteriorate in the next six months.	Concerns about physical health and may deteriorate in the next six months.	Significant concerns about physical health and likely to deteriorate in the next six months. Carer under severe stress.	Significant health problems have developed or will develop. Carer at risk of collapse.
C Mental health of individual and others	Concerns about mental health but unlikely to deteriorate in the next six months.	Concerns about mental health and may deteriorate in the next six months.	Ability to care for self or relate to others limited by mental state. Mental health is likely to deteriorate.	Likelihood of self-harm or harm to others. Mental health is likely to deteriorate or is deteriorating.
D Independent living skills	Is, or will be, unable to carry out one or two personal care and domestic routines	<i>Is, or will be, unable to carry out several personal care and domestic routines</i>	There is, or will be, only partial choice and control over the immediate environment. Is, or will be, unable to carry out the majority of personal care and domestic routines.	There is, or will be, little or no choice and control over vital aspects of the immediate environment. Is, or will be, unable to carry out vital personal care and domestic routines.
E Involvement in work, education or learning	Involvement in one or two aspects cannot or will not be sustained.	Involvement in several aspects cannot or will not be sustained.	Involvement in many aspects cannot or will not be sustained.	Vital involvement cannot or will not be sustained.
F Social roles, relationships and responsibilities	One or two social support systems and relationships cannot or will not be sustained. One or two family and other social roles and responsibilities cannot or will not be undertaken.	Several social support systems and relationships cannot or will not be sustained. Several family and other social roles and responsibilities cannot or will not be undertaken.	Majority of social support systems and relationships cannot or will not be sustained. Majority of family and other social roles and responsibilities cannot or will not be undertaken.	Vital social support systems and relationships cannot or will not be sustained. Vital family and other social roles and responsibilities cannot or will not be undertaken.

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