Cambridgeshire County Council

NHS Cambridgeshire

Cambridgeshire Joint Strategic Needs Assessment (JSNA)

Physical and Learning Disability through the Life Course 2012-13

FINAL REPORT

28/05/13

Contents

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Executive Summary

1.1 Introduction

The aim of this Joint Strategic Needs Assessment (JSNA) is to provide information on people with a disability across the life course. Many people with learning disability will also have physical and sensory disabilities. There is less emphasis on older people and people with long-term conditions, as these are areas covered in previous and (potentially) future JSNAs. The effects of social and environmental factors are considered; of which housing is the subject of another JSNA. While the needs of carers have not been considered in this JSNA, this important group will be the subject of a future JSNA.

1.2 Key findings

1.2.1 Numbers of people with a disability

Most of us will experience some form of disability in our lives, either personally or through caring for others. There is no one source of information on numbers of people with a disability and various sources of data have been looked at for this JSNA. Various definitions of disability are used across datasets. As more detailed age-band information becomes available through the 2011 census, later this year, further information will also be available concerning long-term health problems and disability.

Children

In Cambridgeshire (information for 2012 unless stated otherwise):

- 11,066 children are estimated to meet the Equality Act (2010) definition of disability.
- 7,124 children had a Statement of Special Educational Needs (SEN) or were registered at School Action Plus, of which 76 had a visual impairment; 138 had a hearing impairment; 1,767 had learning difficulties typical of a learning disability; and 215 had a physical disability. The number of children with a Statement (SEN) or are on School Action Plus, are only an estimate of the number of children with disability. The true numbers are likely to be higher.
- In February 2013, 868 children were receiving direct social care support; these are children and young people whose needs are beyond those of a non-disabled child of the same age, meaning they are likely to require lifelong support from statutory services, in the future.

Adults

In Cambridgeshire (information for 2012 unless otherwise stated):

- 11,424 adults aged 18+ were predicted to have a learning disability and 2,376 to have moderate or severe learning disability (and therefore likely to be in contact with services). The number of adults on Cambridgeshire GP practice-based learning disability registers was 1,922 and 1,630 adults with learning disability received social care services.
- 3452 men and 374 women, aged 18-64, are predicted to have autistic spectrum disorders.

- 38,319 people aged 18-64 are predicted to have a moderate or severe physical disability, of whom 8,766 are severe. The Countywide Physical Disability Team supports 808 adults with a physical disability (January 2013), plus a further 24 with HIV.
- 246 people aged 18-64, were predicted to have a severe visual impairment while 9,341 aged 65+ were predicted to have a moderate or severe visual impairment. From April 2012 to February 2013, 251 adults were added to the Cambridgeshire County Council register for severe sight loss (blindness) or sight loss (partially sighted); with 57 of these individuals identified as having dual sensory loss.
- 59,770 people aged 18+ were predicted to have a moderate or severe hearing impairment.

1.2.2 Trends

- As the Cambridgeshire population grows and ages, the number of people with disabilities is also expected to rise. The proportion of people with a learning disability aged over 55 is expected to increase and parents caring for them are likely to have died or become frail. Social care requirements for people with learning disability in England are expected to increase by 14%, up to 2030.
- The number of children with disabilities is predicted to increase. The number of children with statements of special educational needs has increased in Cambridgeshire.

1.2.3 Key inequalities and issues for Cambridgeshire

1.2.3.1 Disability and disadvantage

- People with disability are more likely to live in poverty and be unemployed. There are differences experienced by people who have had a disability since birth and those who have become disabled later in life.
- Children with special educational needs are three times more likely to be recipients of free-school meals.
- People with Learning disabilities are more likely than their non-disabled peers to be exposed to poverty, poor housing conditions, unemployment, social exclusion, violence, abuse and discrimination.
- Those who are already disadvantaged are at a greater risk of becoming disabled later in life.

1.2.3.2 Prevention and staying healthy

- Physical disability is related to a number of chronic health conditions. People receiving support from the physical disabilities social care team at Cambridgeshire County Council are most likely to have a disability resulting from Multiple Sclerosis, spinal or skeletal injury or acquired brain injury.
- People with disabilities have similar oral diseases but significantly poorer oral health and access to oral health care services, with worse health outcomes than the general population.

- People with disabilities are subject to the same risk of chronic diseases as the population as a whole, but may be less able to access healthy choices. People with disabilities may be less able to access leisure services, and people with learning disability and their carers may have poor knowledge of healthy eating.
- People with Learning disabilities are more likely to experience ill health and to die younger. In part, this is related to a number of environmental factors, including, poverty, discrimination and unemployment. Preventable causes of death are relatively common, such as pneumonia, which can result from swallowing difficulties and seizures.
- Health checks for adults with learning disability are important to reduce inequalities in accessing healthcare. 75% of eligible adults received a health check, in Cambridgeshire, in 2012.
- People with Learning disabilities are less likely to take up screening and other health promotion activities. In Cambridgeshire, work is underway to ensure screening is signposted at health checks and to look at how information on screening uptake can be obtained from primary care.
- Identifying adults with a learning disability on information recorded during a hospital admission is important to ensure reasonable adjustments are made. This is happening less often in Cambridgeshire, than the England average for psychiatric admissions. Learning disabilities specialist nurses, based at two Cambridgeshire NHS trusts, identify when people with Learning disabilities are admitted to those trusts and advise on necessary reasonable adjustments.
- People with learning disability in England are more likely to go into hospital for conditions that could have been treated in the community. Admission rates in Cambridgeshire are not significantly different from the England average, suggesting that this may be a problem in Cambridgeshire as well. Better sharing of information on people with a learning disability across agencies would allow us to look into this further.
- Parents of children with disabilities in Cambridgeshire report a need for better emotional and relationship support for parents right from the start, and for access to skilled, knowledgeable and sensitive health workers.
- People with learning disabilities in Cambridgeshire reported certain shortcomings in the provision of health care services, in 2007. This included a lack of easy read information; poor attitudes from some health staff towards people with learning disabilities and their carers; insufficient care available whilst person with learning disability is in hospital; inadequate hospital facilities, including access and delays in referrals. Local surveys identified that people with autism have unmet needs, such as difficulties with identification and diagnosis, and lack of training amongst staff concerning people with autism with whom they came into contact.

1.2.3.3 Education and Employment

- Children in Cambridgeshire with Special educational needs have poorer outcomes at all stages of schooling and are more likely to be NEET (not in employment, education or training).
- Being in employment is associated with better health and a better quality of life. People with a disability are less likely to be in employment than their non-disabled peers. People with learning disabilities have particularly low rates of employment.
- In 2011-12, only about 6% of adults in Cambridgeshire with Learning disability, known to Cambridgeshire County Council, were in paid employment and

approximately 5% were in unpaid voluntary work. This is part of a downward trend over the past few years, possibly as a result of the economic recession.

1.2.3.4 Transition

- The term, 'Transition,' is used to describe the process of moving from childhood into adulthood. Transition can be defined as: 'A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions, as they move from child-centred to adult-oriented health care systems.'
- The transition between children's and adult social care and health services is regularly cited as one of the most difficult experiences for young people and their families. Poor transition processes are associated with poor health and social care outcomes. Carers in Cambridgeshire have described it as feeling like a 'no man's land' (2010/11), although 92% of carers felt supported in person-centred planning.

1.2.3.5 Housing and accommodation

- Most adults of a working age with a physical disability, or adults/older people with a sensory impairment, live in mainstream accommodation within the community. Some with profound needs or multiple disabilities are supported in specialist accommodation.
- 72% of people with learning disabilities, known to Cambridgeshire's social care services, live in settled accommodation; which is higher than national and regional averages.
- The recent Winterbourne Concordat placed a duty on Clinical Commissioning Groups to review out-of-county hospital placements with a view to bringing people back into the county in more local, community-based services. In Cambridgeshire the local authority as lead commissioner is required under the concordat to review the care of all people with learning disability or autism inpatient beds and agree a personal care plan for each individual, based on their and their families' needs and agreed outcomes, as soon as possible, enabling community-based care arrangements to be put in place, as appropriate.

1.2.3.6 Safety and relationships

- Children and adults with disabilities are vulnerable to abuse.
- In 2011-12, most cases of alleged abuse were for adults with learning disability, with most abuse occurring in the adults' own homes. There was an increase in safeguarding referrals for adults with learning disability, compared with the previous year, which is thought to reflect good practice in the community.
- People with learning disabilities in Cambridgeshire would like to make friends and have a partner. A recent community survey revealed that only half of all adults with learning disability knew where to access sexual health services, and less than half of those have received training on appropriate relationships.
- People with autism in Cambridgeshire have reported needing support with getting a job or with social skills.

1.2.4 Key needs for Cambridgeshire

1.2.4.1 Children with a disability

Children and young people with disabilities are a diverse group who access a range of different services, provided by both health and social care. It is therefore important that services are well joined up. The National Service Framework for Children, Young People and Maternity Services, expects local authorities, Primary Care Trusts (now Clinical Commissioning Groups) and NHS Trusts, to ensure that there are 'arrangements to encourage multi-agency strategic planning of services for disabled children… which allow for development and implementation of a locally-based, multi-agency database, containing core data on disabled children, based on shared and agreed definitions'. There is no agreed definition for children with a disability across services. It is therefore difficult to plan and improve services for children with disabilities. Although this issue is not unique to Cambridgeshire, sharing information across services is needed in order to enable understanding of whether children with complex needs are receiving optimum care, for example, whether they have a key worker.

1.2.4.2 Transition to adult services

There is a lack of flexibility in the transition age from children's to adult services and a need for joint planning across agencies in line with the Children and Families Bill 2012-13. Although work on this is underway in Cambridgeshire, there is no current strategic county overview and policy between children and adult services that describes the multi-agency approach required to support young people in transitions.

1.2.4.3 Adults with a disability

Within adult social care (physical and sensory):

- Delayed discharges from hospital have been identified as a result of delays in care packages being set up at home (this affects both adults and older people). However, it is not currently possible (using current data systems) to identify whether these individuals required re-ablement or support from the physical disabilities service, it is necessary to be able to identify this in order to understand the reason for the delay.
- Supporting those with the most complex needs requires joint working across sensory, learning disabilities, older peoples and complex care teams.

Accommodation for a Transitions/Move on Unit is needed to help those with an acquired brain injury or other disability where they need more support in their tenancy and community that enables them to move towards more independence.

A recent mapping exercise identified key gaps in the provision of services to people with hearing loss.

There will be a need to ensure good and timely community provision for adults with learning disabilities in out-of-county, in-patient settings, reviewed as per the Winterbourne view concordat.

Key to improving the health and wellbeing of people with learning disabilities is the ability for services to share information. This facilitates, for example, the delivery of the evidence-based GP Health Check. In their report on unnecessary hospital admissions, the Improving Health and Lives: Learning Disabilities Observatory recommended the following:

> *"GPs and community learning disabilities teams should collaborate in developing a local register of people with learning disabilities, identifying their NHS numbers, age and gender. This should be done on the basis of requesting explicit consent from subjects and carers, and 'best interests' agreements, where the individuals concerned are not able to understand. At a local level, this would permit proper epidemiological monitoring of condition-specific admission patterns.*

2 Introduction

2.1 Scope and Aims

The scope of this JSNA is to identify the needs across the whole life course for people with physical, learning or sensory disability. Previous Joint Strategic Needs Assessments[1] have focussed on the needs of:

- Children and young people with disabilities (section within the Children and Young People's JSNA chapter.
- Adults with a physical or sensory disability and/or long term condition (2008).
- Adults with a learning disability (2007/08) – this JSNA included a chapter on children; and the transition between childhood and adulthood.

The aim of the JSNA is to identify the current and future health and wellbeing needs of people with a physical, learning or sensory disability. By taking a life course approach, the aim is to focus on times of particular need around transitions between services. There is less emphasis on older people aged 65 and older and those with long-term conditions, as these are the focus of complementary JSNAs (including future planned JSNA chapters). The effects of social and environmental factors are considered. Further information on housing and disability will be available in a future JSNA chapter. JSNAs produced later in 2013 will outline the needs of carers and those who acquired a disability during military service.

Since the publication of the last JSNA on adults with learning disability, the Improving Health and Lives Learning Disabilities Observatory, was established to keep watch on the health of people with Learning disabilities. A wide range of information is available on the IHAL website (http://www.improvinghealthandlives.org.uk/), including a profile of health and social care indicators for Cambridgeshire: (http://www.improvinghealthandlives.org.uk/profiles/#select_area).

Two new information systems that predict needs of people with disabilities, based on available research, are:

- Projecting Older People Population Information (POPPI) http://www.poppi.org.uk/
- Projecting Adult Needs and Service Information (PANSI) http://www.pansi.org.uk/

The recently published, 'Fulfilling Potential: Building a deeper understanding of disability in the UK today' (Available at: http://odi.dwp.gov.uk/fulfilling-potential/index.php.) contains evidence on the nature of disability and experiences of disabled people in the UK.

Much of the information in this JSNA has been taken from these sources, combined with local information where available.

[1] http://www.cambridgeshirejsna.org.uk/

2.2 Definitions

2.2.1 What do we mean by disability?

The World Health Organisation (World Health Organisation and the World Bank, 2011) has identified that, "Disability is part of the human condition – almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age, will experience increasing difficulties in functioning. Disability is complex, and the interventions to overcome the disadvantages associated with disability are multiple and systemic – varying with the context."

The Equality Act, 2010, sets out the legal framework for a disabled person's rights, whereby, a person is defined as having a disability if they have, 'A physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.' (See https://www.gov.uk/equality-act-2010-guidance).

There has been increasing emphasis on the social, as opposed to medical model of disability. The social model of disability focuses on the barriers experienced by people with a disability, which impede their full participation in family, community and society. In defining disability it is not sufficient to look only at the individual impairments or conditions without reference to the wider social environment.

Figure 2.1Figure 2.1: Definitions related to disability

A Health condition is a disease, disorder, injury or trauma.

Impairment is a moderate, severe or complete difficulty with physical or mental functioning that limits day-to-day activities as a result.

Disability is the dynamic interaction between impairment and attitudinal and environmental barriers that hinders a person's full and effective participation in society, on an equal basis with others (UN Convention on the Rights of Disabled People).

Environmental barriers include all the physical and social aspects of the environment that may affect a person's experience.

Source: Department for Work and Pensions, 2013

It is important to note that two people with the same impairment may have very different experiences and needs. People may be disabled in some areas of life but not in others. Disabled people may see their conditions as being disabling but do not see themselves as 'disabled' (World Health Organisation and the World Bank, 2011).

In terms of the life course, disability may be:

- Present from birth, eg, due to a genetic condition such as Down's syndrome or a problem at the time of birth, as in cerebral palsy.
- Acquired in childhood or adulthood.

Only about 2-3% of people are born with their impairment; most acquire impairments later in life. In fact, it is estimated that the majority of us will experience disability at some point in our lives, either personally or in caring for others. Increasing life expectancy means that more people will reach an older age and so will be at risk of conditions that cause impairments and disability. In addition many people are living longer as disabled people, both those who are disabled later in life and those who are

disabled from birth. However there are different life chances for those who become disabled later in life (Department for Work and Pensions, 2013).

Different types of impairment tend to become disabling at different stages of life. For those aged 65 or over, the most common types of health condition are osteoarthritis, dementia, coronary heart disease, stroke, Chronic Obstructive Pulmonary Disease (COPD) and cancers.

For working age people, there is more variation in conditions, with increasing prevalence in middle age of depression, anxiety and back pain, in addition to most common conditions experienced by older people. Autism, ADHD or learning disabilities are the main disabling conditions amongst children in receipt of Disability Living Allowance (DLA) (Department for Work and Pensions, 2013).

Impairments are not static and people move in and out of this group over time. Nationally, over a seven year period, as many as one in four working age adults had experienced a spell of limitation in daily activities, due to a health condition (Department for Work and Pensions, 2013).

Many people experience multiple types of impairment, for example (Emerson, et al., 2012):

- People with learning disabilities are 8-200 times more likely to have a visual impairment compared with the general population.
- Approximately 40% of people with learning disabilities are reported as having a hearing impairment.
- People with Down's syndrome are at particularly high risk of developing vision and hearing loss.
- It has been estimated that between 20-33% of people with learning disabilities also have an autistic spectrum disorder (ASD), and that 55% of children aged 10-14 with ASD also have learning disabilities.

2.2.2 Definitions

2.2.2.1 Physical disability

The definition used for physical disability in this report equates to that of impairment or disability described above. This JSNA will not describe individual conditions in detail; this will be the focus of a later JSNA on long term health conditions.

2.2.2.2 Learning disability

Learning disability is a lifelong condition that affects the way a person learns new things in any area of life. It affects the way they understand information and how they communicate. This means they can have difficulty:

- Understanding new or complex information.
- Learning new skills.
- Coping independently.

Learning disability is classified by severity into mild, moderate or severe learning disabilities.

2.2.2.3 Autism

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. The three main areas of difficulty are:

- Social communication, eg, problems understanding and using verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Social interaction, eg, problems recognising and understanding other people's feelings and managing their own.
- Social imagination, eg, problems understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine.

It is a spectrum condition, so whilst all people with autism share certain difficulties, their condition will affect them in different ways. Some live relatively independent lives while others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over (or under) sensitivity to sound, touch, taste, smell, light or colour. People with Asperger syndrome - a form of autism - often have average or above average intelligence and fewer speech problems but may have difficulties understanding and processing language.

2.2.2.4 Sensory impairment

'Sensory impairment,' is a term used to encompass visual impairment (those who are sight impaired or severely sight impaired) and hearing impaired (those who are profoundly deaf, deafened or hard of hearing). Sensory impairments may be congenital or acquired at any age.

'Sight impaired,' is a term used to identify someone who has been assessed by an ophthalmologist as being 'substantially and permanently handicapped by defective vision caused by congenital (present at birth) defect, illness or injury.'

'Severely sight impaired,' is a term used to identify someone who has been assessed by an ophthalmologist as being, "So blind as to be unable to perform any work for which eyesight is essential" - Royal National Institute of Blind People (RNIB).

Action on Hearing Loss (previously RNID) defines level of deafness - whether mild, moderate, severe or profound - according to the quietest sounds measured in decibels that you can hear:

- Mild deafness: 25 - 39 decibels - difficulty in following speech in noisy situations.
- Moderate deafness: 40 - 69 decibels - hearing aid may be needed.
- Severe deafness: 70 - 94 decibels- hearing aid needed and may rely on lip-reading. British sign language may be first or preferred language.
- Profound deafness: 95+ decibels - British sign language is likely to be first or preferred language.

2.3 Sources of information: the number of people with disability

There is no single agreed measure of disability and different sources of data define disability in different ways. Sources of information include:

- National surveys: Questions about longstanding illness and its impact on daily life are included in several national surveys. Examples of these include the Census and the Family Resources survey. The difficulty with measures obtained from surveys is that they are self-reported and may therefore be subjective. Surveys are also delivered to private addresses and so may underestimate need in residential settings.

  Social surveys under-represent some groups of disabled people. People with some types of impairment, for example learning disability are likely to be excluded from surveys that do not make reasonable adjustments for people with cognitive impairments. People with learning disabilities may also be less likely to self-identify as having a disability or a long-standing illness. National prevalence estimates may not be generalised to local populations if local demographics differ substantially to the national average.

- Local data. The JSNA will discuss and present information available from local data sources. For example information on the number of children with SEN, from the School Census and service-user data, from Adult Social Care services.

3 Children with a disability

3.1 Introduction

Children and young people with disabilities are a diverse group who access a range of different services provided by both health and social care. The Children and Young People's Health Outcomes Forum, Disability and Palliative Care Subgroup, stressed that many families highlighted difficulties in accessing services, fragmentation of services (particularly a lack of join-up between health, social service and education services) and sporadic good practice, such as the provision of a key worker approach to help with joining up care. (https://www.wp.dh.gov.uk/health/files/2012/07/CYP-Long-Term-Conditions.pdf).

The National Service Framework for Children, Young People and Maternity Services, Standard 8: Disabled Children and Young People and those with Complex Health Needs (Department of Health, 2004) established that disabled children and young people with complex health needs should receive co-ordinated, high-quality child and family-centred services, based on assessed needs, that promote social inclusion and enable them and their families to live ordinary lives, whenever possible.

The Green Paper 'Support and Aspiration: A new approach to special educational needs and disability' (Department for Education, 2012) places an emphasis on early identification and intervention to improve outcomes for children and young people with special educational needs and disabilities. It includes:

- A new approach to identifying SEN through a single early years setting-based category and school-based category of SEN.
- A new single assessment process and Education, Health and Care Plan by 2014.
- Local authorities and other services will set out a 'local offer' of all services available.
- The option of a personal budget, by 2014, for all families with children with a statement of SEN or a new Education, Health and Care Plan.

Cambridgeshire County Council's Strategy for Children and Young People with Special Educational Needs and Disability (SEND) 2012-16, identifies three priorities:

- Improve outcomes for children and young people with SEND and their families.
- Collaboration with children and young people with SEND and their families.
- Ensure quality of provision and services.

3.2 Numbers of children with a disability

Measuring disability in childhood is difficult, because the notion of disability is multi-dimensional, dynamic and contested. Definitions vary across different measurement tools. The willingness of parents to identify their child as disabled may vary according to whether the definition used reflects their personal definition of disability, their perception of any difficulties their child may experience, and the implications as they understand them, of defining their child as 'disabled'.

The sources of information considered in this chapter are:

- Information from national surveys.
- Estimates of prevalence from research applied to Cambridgeshire population figures.
- Local data on service use.

3.2.1 Estimating need from national surveys and prevalence estimates

The Family Resources Survey (FRS) is an annual survey that uses the Equality Act's definition of disability (previously Disability Discrimination Act - DDA) and therefore defines disability according to the level of limitation of daily activities. This is a useful source of information as public organisations have obligations to children who meet the definition of disability in the act: http://www.nhs.uk/NHSEngland/thenhs/equality-and-diversity/Pages/equality-and-diversity-in-the-NHS.aspx).

Information from the FRS on numbers of children with disability in different age bands is not publically available. However, estimates from a secondary analysis of the 2004/05 FRS, do enable us to estimate the number of children in Cambridgeshire with a disability, who meet the DDA definition (Blackburn, Spencer, & JM, 2010). The analysis found that proportion of children with a disability (as defined by the FRS) varies by age. The 0-4 year age group has the lowest prevalence and this increases up to the 12-15 age band; then slightly decreases in 16-18 year olds. This is likely due, in part, to some conditions going unidentified until the child is older, or as their daily activities are limited.

Applying these proportions to local population projections (Table 3.1) shows that overall, the estimated number of children with a disability, as defined in the Equality Act, is predicted to rise in Cambridgeshire. However, whether the number of children with a disability is predicted to rise or fall varies by age (which reflects the projected change in the population by age band).

Table 3.1: Estimated numbers of children with a disability by age group, Cambridgeshire, 2012-2020

Year	Age group (years)				Total
	0-4	5-11	12-15	16-18	
2012	1,423	3,939	2,680	1,942	9,984
2013	1,477	4,025	2,645	1,912	10,060
2014	1,525	4,129	2,591	1,919	10,165
2015	1,569	4,226	2,562	1,905	10,262
2016	1,602	4,319	2,579	1,874	10,374
2020	1,546	4,878	2,831	1,811	11,066

Sources: Blackburn CM et al. Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey. BMC Paediatrics. 2010, 10:21. Office for National Statistics 2011-based population projections.

Whilst this information is helpful, it is likely to contain information on children with a range of impairments and doesn't give information on the group of children with profound and complex disabilities. Table 3.2 shows the estimated number of children, in Cambridgeshire, with more severe disabilities, based on national data from the Family Fund Trust register of applicants.

This is the most extensive national data base of severely disabled children available for this type of estimate; however, it has certain limitations (Read & Spencer, 2009).

Firstly, it is estimated that only 50-70% of eligible families actually apply, and secondly, only those on lower incomes are eligible to apply. Therefore, the number of Cambridgeshire children with a severe disability is likely to be an underestimate. See **Table 3.4** for comparison, which shows the number of children who receive Disability Living Allowance in Cambridgeshire.

Table 3.2: Estimated numbers aged 0-19 years with a severe disability by age group and sex, Cambridgeshire, 2010

Age group (years)	Sex		Total
	Male	Female	
0-4	28	14	42
5-9	21	8	29
10-14	14	7	21
15-19	6	4	10
Total	69	33	102

Source: Disability Needs Assessment, Child and Maternal Health Observatory
(National prevalence estimates based on Family Fund Trust statistics applied to ONS mid-2010 population estimates)

Table 3.3 shows the estimated number of school-age children with an autism spectrum disorder in Cambridgeshire, based on national data. The table shows that ASD is more common in boys than girls. These estimates are based on 2004 data and so may underestimate the current number of children in Cambridgeshire, with ASD. By comparison, Table 3.5 shows the number of children who have a statement of special educational need or registered at school action plus with ASD.

Table 3.3: Estimated number of children with autism spectrum disorder (ASD) in Cambridgeshire, 2011

Age band	Sex	% with Autism Spectrum Disorder	Estimated number in Cambridgeshire
5-10 years	Boys	1.9	400
	Girls	0.1	20
	All	1.0	400
11-16 years	Boys	1.0	220
	Girls	0.5	100
	All	0.8	340
All	Boys	1.4	600
	Girls	0.3	120
	All	0.9	750

Source: Mental Health of children and young people in Great Britain, 2004, National Statistics and mid 2011 population estimates, Office for National Statistics.
Note: Totals may not agree, due to rounding

3.2.2 Local data on number of children with a disability

3.2.2.1 Children in receipt of Disability Living Allowance (DLA)

DLA is a benefit to help with extra costs if a child under 16 has a disability, illness or health condition that means they need much more looking after than a child of the same age without a disability, or have walking difficulties, or both.

In Cambridgeshire, there are 3,120 children and young people under 16-year-old, receiving Disability Living Allowance. Of those, 1,080 are classified as having a high level disability, in receipt of a high level disability allowance.

Table 3.4: Number of children (under 16 years) receiving Disability Living Allowance, Cambridgeshire 2012

District	Total number of children	Care Award Type		
		Higher Rate	Middle Rate	Lower Rate
Cambridge	440	140	280	20
East Cambridgeshire	390	150	220	20
Fenland	680	240	400	30
Huntingdonshire	1,010	360	590	40
South Cambridgeshire	600	190	370	20
Cambridgeshire	3,120	1,080	1,860	130

Source: Department for Work and Pensions Information, Governance and Security, Work and Pensions Longitudinal Study, Data for May 2012

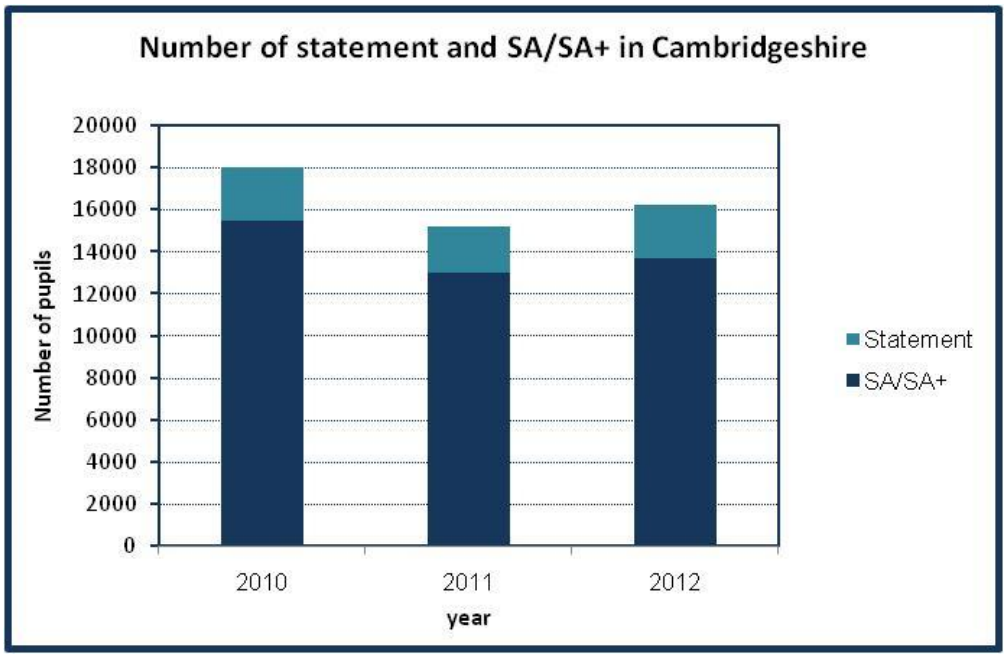
3.2.2.2 Number of children with Special Educational Needs

Local data are available on children with Special Educational Needs (SEN), as defined in the 1996 Education Act. Children have special educational needs if they have a learning difficulty that calls for special educational provision to be made for them, with three levels of SEN:

- School Action – extra or different help is provided to the child;
- School Action Plus – extra or different help is provided to the child, plus the class teacher and school's Special Educational Needs Coordinator (SENCO); receive advice or support from outside specialists, eg, an educational psychologist.
- Statement of SEN – the pupil has a statement of SEN, a legal document that specifies the child's needs and the extra help they should receive.

In Cambridgeshire, there are just over 16,000 children and young people attending Cambridgeshire schools with an SEN. Just over 2,500 have a Statement of Special Educational Need - representing 3% of the school population. This is slightly higher than Cambridgeshire's statistical neighbours (local authorities with similar demographic and geographical characteristics) and the national figure (both 2.8%). Figure 3.1 shows the number of Cambridgeshire pupils registered at School Action or School Action Plus and the number with a Statement of SEN.

Figure 3.1: Number of Cambridgeshire pupils with Statements and at School Action or School Action Plus



Source:School Census 2012, Cambridgeshire County Council

In practice, many children with SEN are also defined as having a disability under the Equality Act. However, not all disabled children have an SEN. Similarly, not all children with SEN have a disability (Russell, 2007). The Thomas Coram Research Unit, compared a range of measures used by local authorities across England, to define and record disability in childhood (Mooney, A; Owen, C; Statham, J, 2008). They estimated that the true number was likely to sit in a range, where the lower estimate was the number of children with SEN (statement and SA+) or the number of DLA claimants (whichever is higher) and the higher estimate the sum of these measures.

Table 3.5 show the primary need for pupils with statements and/or at school Action Plus. The following sections will outline the relation between this table and types of disability.

Table 3.5: Primary needs for pupils with Statement and/or at School Action Plus

Primary need	No. of pupils
Behaviour, Emotional & Social Difficulties	1,702
Moderate Learning Difficulty	1,357
Speech, Language and Communication Needs	1,149
Specific Learning Difficulty	901
Autistic Spectrum Disorder	871
Severe Learning Difficulty	305
Other Difficulty/Disability	289
Physical Disability	215
Hearing Impairment	138
Profound & Multiple Learning Difficulty	105
Visual Impairment	76
Multi-Sensory Impairment	16
Total	7,124

Source: Cambridgeshire Schools Census, January 2012

3.2.2.2.1 Learning disability

Three types of SEN, when combined are roughly equivalent to learning disabilities (Emerson, et al., 2012):

- Moderate learning difficulty (MLD).
- Severe learning difficulty (SLD).
- Profound Multiple Learning difficulty (PMLD).

We can estimate that 1767 school-aged children have a learning disability.

3.2.2.2.2 Physical disability

This category of disability includes children and young people with varying types of physical disabilities, including:

- Mobility difficulties.
- Physical impairment affecting upper limb(s) disability and/or lower limb(s) disability.
- Manual dexterity.
- Disability in co-ordination with different parts of the body.

In Cambridgeshire, there are 215 children and young people of school age classified as having a physical disability. This number may be slightly under representative of those with physical impairment due to the Top Up funding that has been available to support children and young people with physical and medical needs.

3.2.2.2.3 Sensory impairment

The children and young people that the Visual Impairment (VI) Service supports have the following difficulties:

- They cannot see well enough to read print.
- They cannot read beyond the fourth line of an eye chart, with glasses (if worn) – ie, have distance vision measurements of 6/18 (Snellen), 0.5 (Logmar) or worse.
- They have significantly reduced fields of vision.
- They have an eye condition which means their vision will deteriorate.

They are likely to have one or more of the following, visual difficulties:

- Reduced near vision.
- Nystagmus (a constant flickering of the eyes).
- A visual field defect.
- A colour vision defect.
- Photophobia (sensitivity to light).
- Monocular vision (vision in one eye only).

In Cambridgeshire, 76 school-aged pupils have visual impairment as their primary need. Additionally, there are many other pupils with other learning difficulties that also have a visual impairment.

Hearing disability includes those who are completely or partially deaf (deaf is the accepted term for a person with hearing impairment). Pupils with a significant hearing disability are those unable to access the curriculum using purely oral methods, ie, the pupil may need to use signed communication. It is also likely that these pupils and those using an oral approach – may need particular adaptations to teaching methods and appropriate modification to teaching materials. They will require greater emphasis on language development, auditory training and communication skills. The social and emotional needs of these children will also need to be taken into account more widely. Some pupils may have additional needs, for example, visual impairment, learning or physical difficulties.

In Cambridgeshire, 138 pupils have hearing impairment and a Statement of SEN or School Action Plus. The total number of pupils with hearing impairment will be higher when taking into account those with other co-occurring difficulties and may be classified with another primary need.

There are some children and young people with both visual and hearing difficulties, referred to as multi-sensory impairment. In Cambridgeshire, we have 16 pupils with this category of need.

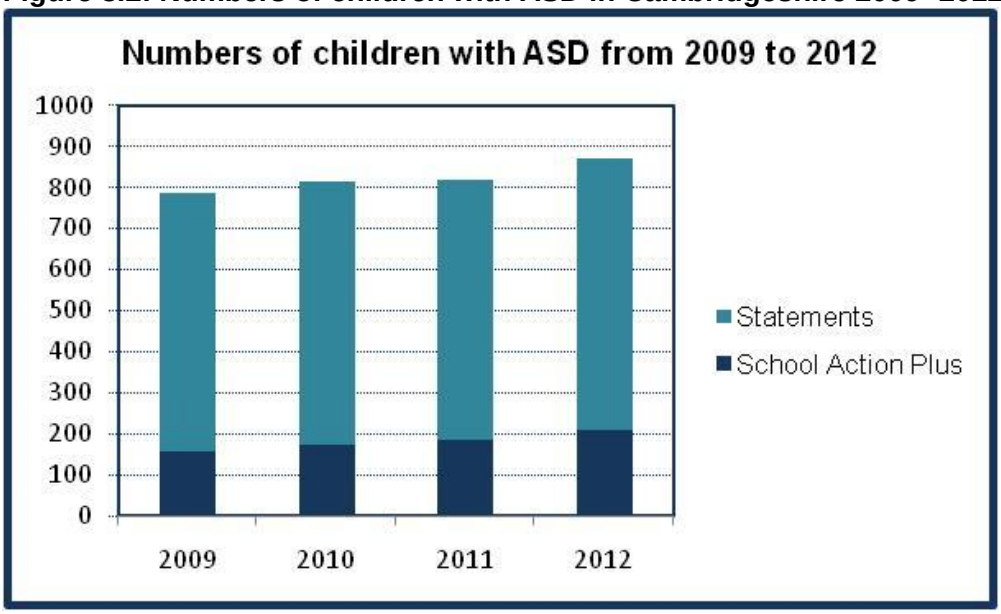
3.2.2.2.4 Autism

Children and Young People with ASD commonly experience:-

- Severe difficulties in following instructions, classroom routines and staying on task.
- A typical obsessive, challenging or withdrawn behaviours.
- Resistance to changes in routines.
- Inappropriate social behaviour, leading to social isolation.
- Severe difficulties in understanding and using language.

Figure 2.1 shows the total numbers of children and young people with ASD in the last four years, broken into two groups: those at School Action Plus and those with Statements of SEN, which shows that the number of children with SEN, related to ASD, is increasing.

Figure 3.2: Numbers of children with ASD in Cambridgeshire 2009- 2012



Source: Cambridgeshire Schools Census

Other key points on children with ASD, with an SEN, are:

- ASD is the highest primary need for pupils at special schools, in Cambridgeshire, with 29% having ASD.
- ASD is the highest primary need for pupils with statements of SEND (26%) and has remained so for the past four years.
- Pupils with ASD account for 0.7% and 0.9% of all those registered at Cambridgeshire primary and secondary schools, respectively.
- Areas with the highest proportion of pupils identified with ASD are:

  - St Neots;
  - Huntingdon;
  - Sawston and Linton.

- On average, 67 Cambridgeshire pupils are issued with a new statement of SEND every year due to their ASD (data from 2007 to 2012).
- 25% of pupils with ASD also have a secondary need identified. Two top additional needs are:

  - Speech, Language and Communication Needs.
  - Behaviour, Emotional and Social Difficulties.

3.2.2.3 Children in receipt of social services

The working definition of disability used by Cambridgeshire County Council to determine eligibility for social services is: 'The needs of the disabled child or young person are beyond those of a non-disabled child of the same age and means they are likely to require lifelong support in the future, from statutory services.' http://www.cambridgeshire.gov.uk/childrenandfamilies/specialneedsdisabilities/

A snapshot of services in February 2013, identified 868 children were receiving direct social care support as follows:

- **Short Breaks Team** (450 children)
  Short breaks give disabled children and young people enjoyable experiences away from their primary carers, contributing to their personal and social development and reducing social isolation. They also give parents and families a necessary and valuable break from caring responsibilities and disabled children and young people access to inclusive activities, in their local community.

- **Self-Directed Support Teams** (291 children)
  The teams provide named qualified social work contact.

- **Social Work Units** (127 children)
  The units support those children and families with the most complex needs and for whom a systemic unit approach is required, including intensive social work intervention, along with a consistent clinical input.

3.2.3 Trends

Understanding trends in the number of children with a disability is important for predicting future service needs. Various factors can result in changes to this number. These are:

- Changes in the proportion of children in the general population with a disability. For example, as more babies and children with disabilities survive, or the conditions that cause disability become more commonplace.

- Changes in the population - an increase in the overall numbers of children in the Cambridgeshire population is likely to result in more children with a disability.

- Other factors, for example, a change in the way disability is defined, may make it look as if the numbers of children with a disability have changed with time.

Various sources of information were considered to look at possible changes:

3.2.3.1 Applying estimates from national Surveys to population projections for Cambridgeshire

Using estimates based on the Equality Act definition of disability Table 3.1 shows that the number of children meeting this definition will increase approximately 10%, by 2020, in Cambridgeshire. This has been calculated by applying the proportion of children with a disability (as measured by the 2004/05 Family Resources Survey) to Cambridgeshire population projections.

3.2.3.2 Information on children accessing services

There is evidence at a national level that the numbers of children with special educational needs are increasing, with the total number of children with severe learning difficulties increasing by 5.1% between 2004 and 2009 (Carpenter, 2011).

Figure 3.1 shows that whilst the number of children with special educational needs (SA+ and statements) has remained stable over the last three years, the number of children with a statement (and therefore greater need) has increased. Recent data suggests that the number for 2013 will represent an increase on the previous year.

There has also been an increase in the number of children in Cambridgeshire attending special schools (for complex and severe learning needs). Recent data indicates that 4.4% of the children/young people of school age, who live in new developments/communities, attend a special school in Cambridgeshire, 3% higher than the county average.

Social care information cannot be used reliably to monitor trends, as trends reflect changes in services eligibility criteria.

3.2.3.3 Studies looking at changes in children born with a disability

It has been suggested that an increase in children with complex needs is a result of increases in survival of babies born very prematurely, yet limited evidence was found to support this. An analysis of the level of 'longstanding limiting illness' (defined in the study as illness that limits activities normal for the child's age group) at three and five years (Boyle, et al., 2012), found this to be more common, the more prematurely a child was born.

A search of the literature identified three UK studies that looked at outcomes either in children born very prematurely (Moore, et al., 2012; Rattihalli, et al., 2011), or at a very low birth weight (D'Amore, et al., 2011). Two of these studies looked at the outcome at two years old and one at three years. Two of the studies found no increase or a reduction in disability overall, despite improved survival. One found an increase in the number of children with severe disability at two years, between those born 1991-1993 and those born 2001-2003. However this difference was not statistically significant.

One of the studies described above was carried out in East Anglia (D'Amore, et al., 2011) and included some estimation of service use. Of all infants admitted to intensive care and followed-up to two years-old, 30% of infants were referred to one or more community services. 18% of these were receiving community services at the age of two and 9% children were being assessed for special educational needs.

It is important to note that these studies only included follow-up to a maximum of three years, whilst some disabilities and educational difficulties may not become apparent until the child is older. The studies also only included babies who were born very prematurely or at very low birth weight and were admitted to neonatal intensive care.

Down's syndrome is the most common congenital cause of learning disability in children. There is evidence from the North of England that the number of live births with Down's syndrome is unchanged for the period 1985-2004. A study found that the effects of the National screening programme for Down's syndrome, together with a fall in the national birth rate, balanced out any increases in Down's syndrome that might occur with rises in maternal age and increased survival of children with Down's syndrome. However they did observe that survival to one year had increased (Irving, Basu, S, J, & C, 2008).

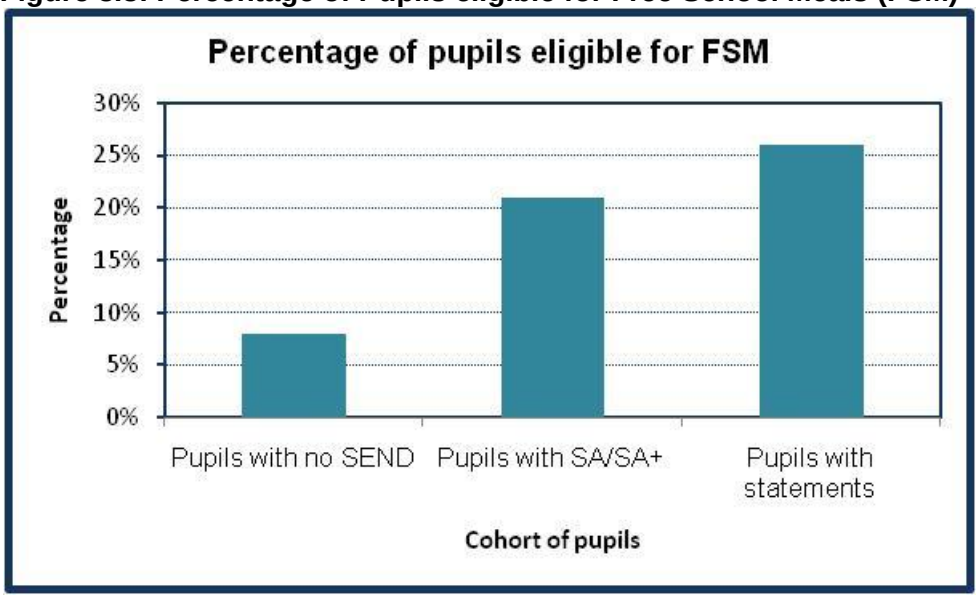
Data are available in Cambridgeshire on birth weight and on babies admitted to neonatal intensive care at various levels of prematurity. However, this needs to be linked to additional information, eg whether babies survive, in order to predict future need using estimates from research such as that described above.

3.3 Disability and disadvantage

Prevalence rates for children and adolescents with mild disabilities are higher for those from semi-skilled manual and unskilled manual family backgrounds. By comparison, the prevalence of children with mild disabilities from professional family backgrounds has been found to be lower than other socio-economic groups. The rate of severe disability is greatest amongst children from semi-skilled manual family backgrounds, whilst the lowest rates were for children from professional and managerial family backgrounds (ChiMat).

Figure 3.3 shows the percentage of children eligible for free school meals by level of educational need. In Cambridgeshire, pupils with special educational needs were more than three times as likely to be eligible for and claiming free school meals than those without special educational needs.

Figure 3.3: Percentage of Pupils eligible for Free School Meals (FSM)



Source: Cambridgeshire School Census 2012
Note: Special Educational Needs and Disability (SEND). School Action (SA).

Having a disabled child can impact on the employment of parents. Lone parents and mothers with a partner are less likely to be in paid employment (Department for Work and Pensions, 2013).

3.4 Disability and ethnicity

Learning and developmental disability has been found to be less common in minority ethnic groups in the UK, with the exception of higher rates of some forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage, and Pakistani and Bangladeshi heritage (Emerson, 2012). The special educational needs data in Cambridgeshire show a higher proportion of children from White Irish/Traveller background who have special educational needs than the general school population (although the number of children in this ethnic group is smaller).

3.5 Health

3.5.1 Facts and Figures

3.5.1.1 Community child health

Community child health services see children with a wide range of conditions. Services consist of the identification, assessment, investigation and support of children with long-term developmental problems and disabilities. Many children within this group have complex medical conditions. In 2013, an audit was carried out of children under five who had been seen for the first time in the community child health clinic, over a three-month period.

256 children were seen of whom 82 were felt to have an Autistic Spectrum Disorder; nine children had Asperger syndrome; 40 had impaired movement as a result of Cerebral Palsy; 38 had a language impairment; 19 children with a genetic disorder - 17 of whom had Down's syndrome; 32 had global developmental delay; 12 had learning difficulties; 8 had a hearing impairment; 6 had behavioural problems.

3.5.1.2 Children with Learning disabilities

A review of recent research into children with disabilities and health inequalities (Emerson, et al., 2011) analysed information collected from participants of the Millennium Cohort Study (a follow up study of over 18,000 children born in the UK, between 2000 and 2002) at age seven.
Table 3.6 shows the health inequalities found to be significant for children with learning disabilities.

Table 3.6: Health inequalities in children with learning disabilities participating in the Millennium Cohort Study

Health Indicator	LD	No LD	OR
Child health rated by parent as 'fair' or 'poor'	10%	2%	4.67 (3.31-6.69)
Parent report that child has had:			
Eyesight problems	28%	17%	1.97 (1.59-2.45)
Hearing problems	21%	13%	1.77 (1.39-2.26)
Epilepsy	4%	1%	2.98 (1.93-4.62)
Wheezing	35%	27%	1.42 (1.16-1.74)
Two or more accidents requiring medical attention	9%	4%	2.18 (1.54-3.09)
Been admitted to hospital	15%	9%	1.91 (1.45-2.51)
Been admitted to hospital more than once	3%	1%	2.25 (1.21-4.21)
Scores in abnormal range on the Strength and Difficulties Questionnaire:			
Overall	34%	7%	6.79 (5.45-8.45)
Conduct difficulties	23%	9%	3.31 (2.61-4.20)
Emotional difficulties	18%	6%	3.29 (2.52-4.29)
Hyperactivity	41%	11%	5.36 (4.36-6.59)
Peer problems	25%	7%	4.53 (3.58-5.72)
Three or more of the above health problems	52%	28%	2.72 (2.22-3.33)
Obese	9%	5%	1.72 (1.20-2.46)
Never does sport/exercise	56%	25%	3.77 (3.10-4.59)
Lived in materially poor home at more than one age	44%	20%	3.26 (2.63-4.05)
Bullied more than 'once or twice' at school	14%	6%	2.54 (1.91-3.37)

Source: Adapted from Emerson, et al., 2011
Notes: Learning Disability (LD), Odds Ratio (OR), Confidence Interval (CI)

Children were identified as having learning disability if they scored two or more standard deviations below average on tests of cognitive ability, administered at age seven (for some children health scores at age three and five were used).

Epilepsy is significantly more common in children with learning disability, with prevalence in moderate and severe learning disability rising to 15 and 30% respectively. Seizure control is likely to be poorer and there is some evidence that treatment of epilepsy can improve IQ scores (suggesting a bidirectional relationship) (Emerson, et al., 2011).

Particular syndromes that result in developmental and learning impairments are often related to certain behaviours. For example, William's syndrome and Down's syndrome are associated with sleep disturbance. Sleep disturbance may have negative impacts on daytime behaviour and learning (Emerson, et al., 2011).

Disabled children are less likely to take part in sport both in and out of school. The most common barriers are lack of money, ill health, unsuitability of local leisure facilities or lack of transport. The Department for Culture, Media and Sport Taking-Part Survey, 2011/12 - found that disabled children were less likely than non-disabled children to have taken part in sports, during the previous four weeks (81% compared with 90%) (Department for Work and Pensions, 2013).

3.5.2 Oral Health

3.5.3 National policy

Delivering Better Oral Health (Department of Health, 2009)[2]
This document is a reference guide on evidence-based prevention designed to be actively used by the entire primary care dental team. Subject areas include increasing fluoride availability, healthy eating advice, identifying sugar-free medicines and stop-smoking guidance.

Valuing People's Oral Health – Best practice guidance for improving oral health in disabled children and adults (Department of Health, 2007)[3]
This is a best-practice guidance document to improve oral health in disabled children and adults. It uses the evidence-based approach within Delivering Better Oral Health as a guide to assist all who provide and commission dental services for people with disabilities.

Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities (British Society for Disability and Oral Health 2012)[4]
This document provides guidance for the development of clinical care pathways and local standards for oral health care in order to raise the oral health status of people with learning disabilities to the standard of their non-disabled counterparts and address the inequities they experience.

[2] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102982.pdf
[3] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_080919.pdf
[4] http://www.bsdh.org.uk/guidelines/BSDH_Clinical_Guidelines_PwaLD_2012.pdf

3.5.4 Oral health in children with a disability

Good oral health is fundamental to general health and wellbeing. Poor oral health, despite being almost entirely preventable, can lead to pain and discomfort that people with disabilities may struggle to communicate. It also impairs a person's quality of life, ability to interact with others, attend school, and to work.

Oral diseases include tooth decay, periodontal (gum) diseases and oral cancers. Tooth decay is one of the most common chronic diseases, principally caused by exposure to dietary sugars. The burden of tooth decay lasts a lifetime as once the tooth is destroyed it will usually need restoration and maintenance throughout life. In extreme cases, this can lead to unnecessary and expensive interventions or services (Nunn et al 1995). Gum diseases result from inflammation of the gums and bone that support and anchor teeth. When severe, it can cause otherwise healthy teeth to be lost. Gum disease is more severe in children with Down's syndrome, even when a good standard of oral hygiene is maintained. Oral cancer describes all malignancies of the oral cavity and oropharynx. Almost all oral cancers are thought to be preventable (Downer 1997).

Despite substantial general improvements in the oral health of children, marked inequalities remain. Surveys show how more decayed teeth remain untreated, and teeth are more frequently extracted in children with a disability (Gizani, et al., 1997; Pope & Curzon, 1991; Nunn & Murray, 1987). In children with mild learning disabilities and children who are partly independent, prevalence of tooth decay is higher (Storhaug & Holst, 1987). It would appear that these children may have fewer dietary restrictions and are therefore at greater risk of developing dental caries. Studies uniformly report poor standards of oral hygiene and plaque control, and poorer gum health in children with learning disabilities (Nunn & Murray, 1987; Pope & Curzon, 1991; Gizani, et al., 1997; Evans, et al., 1991; Storhaug & Holst, 1987). A high proportion of children in special schools have periodontal disease (Evans, et al., 1991).

The impact of oral diseases in children is substantial, and research suggests that poor oral health in children is associated with being underweight and a failure to thrive (Sheiham, 2006; Acs, et al., 1992; Ayhan, et al., 1996).

Factors contributing to the inaccessibility of dental services include: poor information regarding available dental services and oral health; access to services including transport; gaining physical access to the premises and the surgery; the need to be accompanied or rely on a third party; negative attitudes towards caring and being cared for; anxiety and fear; cost in emotional, psychological, social and financial terms; professionals' attitudes to providing care and lack of training (British Society of Disability and Oral Health, 2006). Lack of parental awareness is a major contributory factor for low dental attendance in children who have a learning disability (Lo, et al., 1991).

3.5.4.1 Impact of poor oral health on education

Children with dental problems may not gain the full benefit of their education if they are in pain or discomfort. Research from industrialised countries, such as the USA, indicates how students with toothache are almost four times more likely to have a low grade point average (Seirawan, et al., 2012) and substantial numbers of hours are lost each year to dental-related illness (US Department of Health and Human Services, 2000). This has very significant long-term implications, as there is strong

evidence that educational attainment has a profound effect on long-term health (Singh-Manoux, et al., 2002).

3.5.4.2 Dental services

The majority of children and adults with physical and learning disabilities are able to access routine dental care in the normal way, via the General Dental Services. However, Cambridgeshire Community Services (CCS) offers specialist dental services to people with particular needs, namely, special care dentistry. This service delivers specialised treatment, often completed under sedation or general anaesthesia. CCS Dental Service sees an excess of 7,000 patient contacts per year across Cambridgeshire.

Referrals are accepted from a wide range of care professionals. Community Dental Clinics at Cambridge, Ely and Huntingdon have wheelchair reclining facilities to enable physically disabled patients to be treated within their own chairs. Additionally, the Oral Health Promotion (OHP) Team work within the local community, eg, in homes and day centres to deliver oral health education to disadvantaged groups. Clinics use easy read materials such as appointment letters, patient leaflets and explanatory picture books to engage service users and encourage self-empowerment.

3.5.4.3 Improving access to dental services

Evidence and peer practice

Good oral health and wellbeing and the reduction of oral health inequalities for the majority of disabled children and adults can be achieved by:

- Commissioning further epidemiological surveys to understand the patterns of oral health and service demand in children, adolescents and adults with learning disability, including older people in residential care or confined to home. In addition, oral health data could be collected as part of other data collection exercises, eg, GPs hold a list of adults with learning disabilities.
- Integrating oral health messages into all health promotion strategies to reduce oral diseases in parallel with other chronic diseases, such as obesity, cancers, heart disease and diabetes. The ‘common risk factor’ approach focuses on generic prevention by reducing tobacco and alcohol use, improving diet and hygiene, and minimising stress and trauma.
- Developing evidence-based programmes to improve access to care and preventive interventions, tailored to the needs of this population group. Community-based prevention programmes are generally cost-saving when compared with a treatment-focused approach.
- Ensuring that following a dental assessment, a written oral care plan is developed, providing practical information on the provision of oral health care, to facilitate communication between the service user, parents, carers and the dental team. Effective transition of care requires communication with other health care professionals and carers.
- Ensuring early referral to the dentist from child development teams and consultant paediatricians.
- Ensuring oral care is an integral part of social and health care planning, and included in national, local and residence-based learning disability strategies.

- Developing and disseminating effective referral mechanisms to encourage multidisciplinary referral of people with learning disabilities to oral health care services.
- Working as partners across disciplines in health and social care, using a multi-professional approach, will ensure consistency in oral health and general health messages. This includes maximising the role of voluntary organisations.

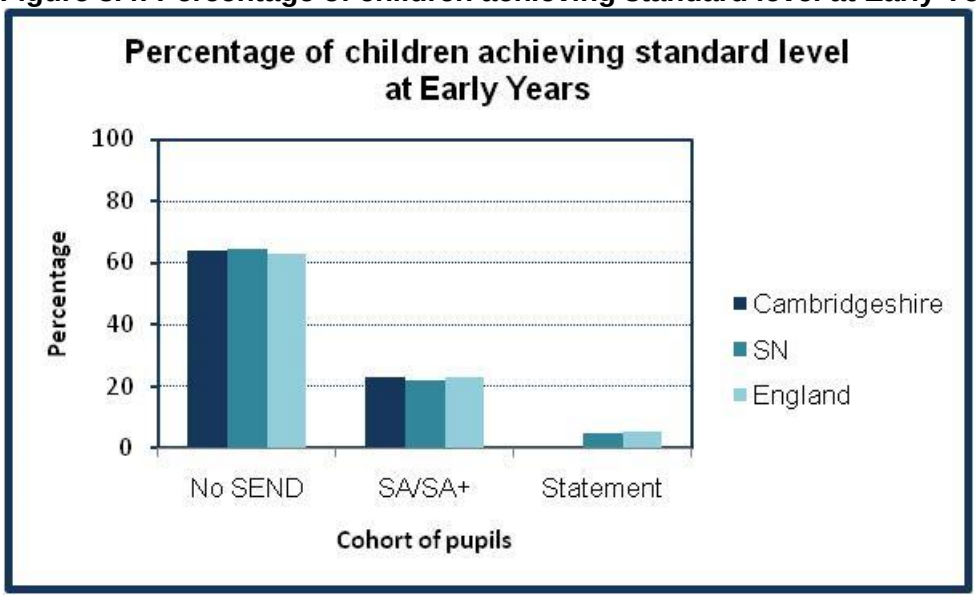
3.6 Education

3.6.1 Facts and figures

Local data show that children with Special educational needs have poorer educational outcomes compared to children without SEND.

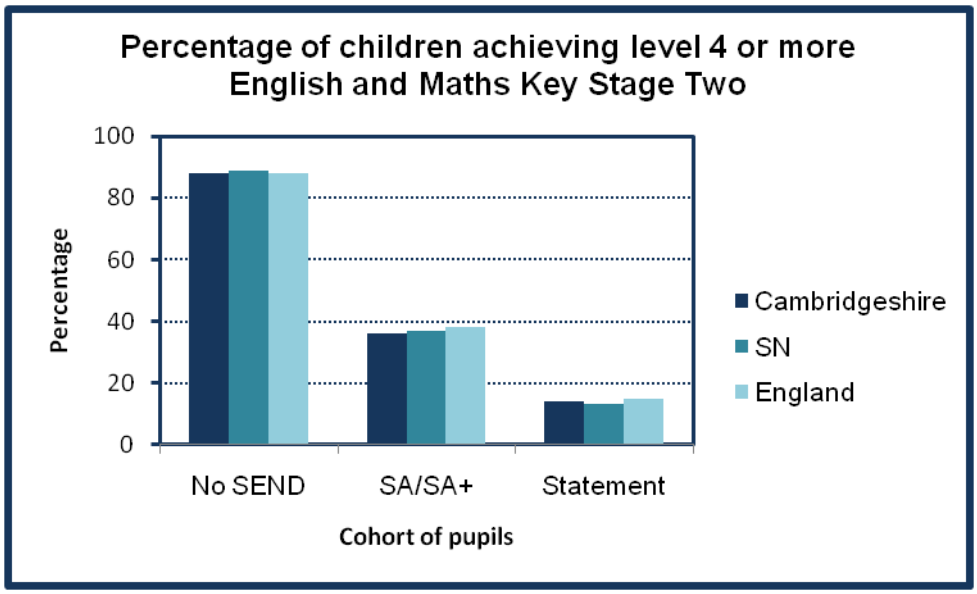
Figures 3.4 - 3.6 (below) show the comparisons in the Early Years, Key Stage 2 and Key Stage 4, between non-SEND, those pupils on School Action and Action Plus, and those with a statement, and how Cambridgeshire's performance compares with national data and its statistical neighbours (local authorities with similar demographic and geographical characteristics).

Figure 3.4: Percentage of children achieving standard level at Early Years



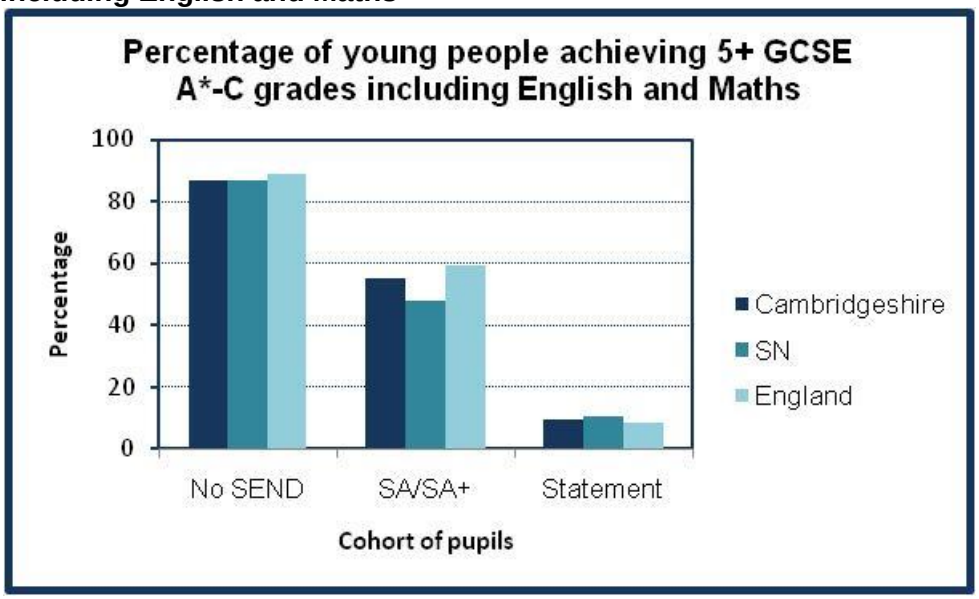
Source: Department for Education: Children with Special Educational Needs: An Analysis – 2012
Note: Statistical Neighbours (SN), Special Educational Needs and Disability (SEND), School Action (SA)

Figure 3.5: Percentage of children achieving level 4 or more in English and Maths at Key Stage Two



Source: Department for Education: Children with Special Educational Needs: An Analysis – 2012
Note: Statistical Neighbours (SN), Special Educational Needs and Disability (SEND), School Action (SA)

Figure 3.6: Percentage of children achieving five or more GCSE grades A*- C including English and Maths



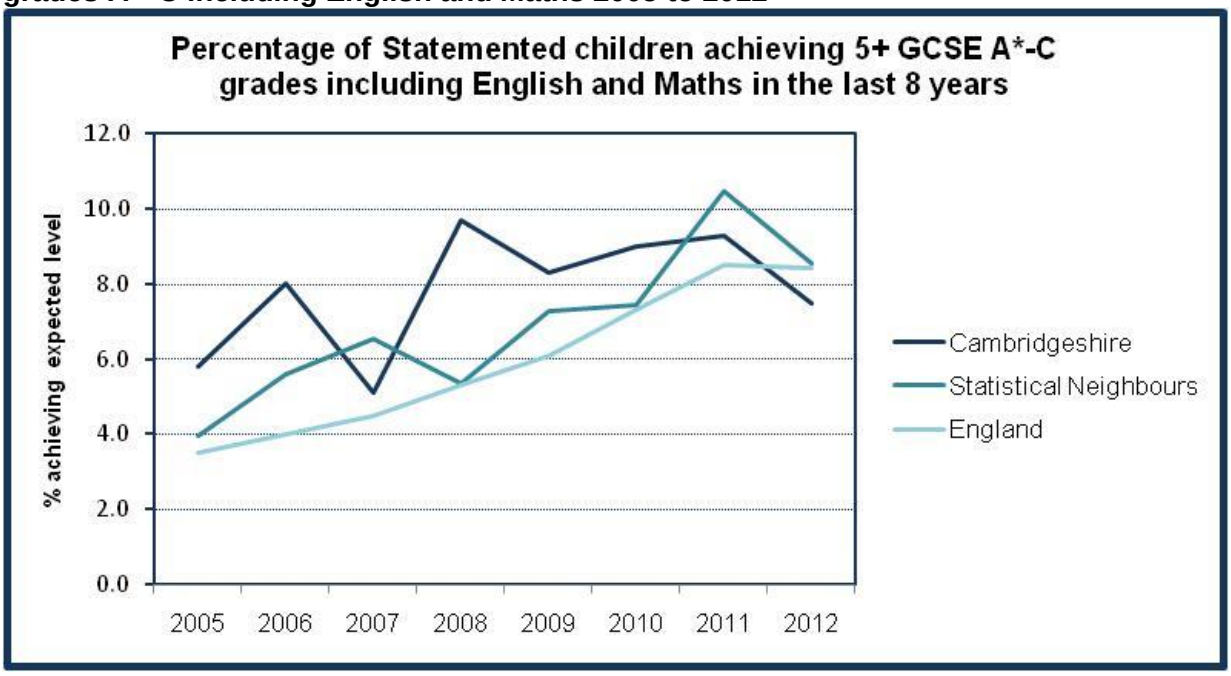
Source: Department for Education: Children with Special Educational Needs: An Analysis – 2012
Note: Statistical Neighbours (SN), Special Educational Needs and Disability (SEND), School Action (SA)

3.6.2 Trends

3.6.3

Figure **3.7** shows the trend in the performance of children with statements at GCSE level, compared with England's level and statistical neighbours. It shows that performance fell below the England average last year.

Figure 3.7: Percentage of Statemented children achieving five or more GCSE grades A*- C including English and Maths 2005 to 2012



Source: Department for Education Local Area Interactive Tool, February 2013

3.7 Choice and service provision

3.7.1 Early support

Early Support aims to improve the way services are accessed and delivered to families who have children with a disability or complex additional needs. Families and children are central to decision-making and their needs are put first. 'Team around the family' meetings avoid duplication and ensure children and families experience an integrated support package and feel supported and included.

The Early Support pathway provides:

- A care co-ordination process to work across agencies, in partnership with families using the Family Service Plan as a tool for joined-up holistic assessment and planning.
- A single point of contact for families and practitioners to co-ordinate services and information.
- A named key worker, identified in partnership with parents, to enable the family access information and services.
- Relevant information and support for parents.
- A clear understanding on eligibility and thresholds.

For more information, visit:
http://www.cambridgeshire.gov.uk/childrenandfamilies/specialneedsdisabilities/earlyyears/earlysupport.htm

Recent changes and needs:

- A new specification and eligibility criteria was recently developed for Early Support, informed by all partner agencies, Voluntary and Community Services and parent representatives. As performance monitoring of activity and outcomes has only recently been put in place, it is difficult to look at trends in number of referrals over the past years. Data is starting to be collected manually on diagnosis although there are currently no means to collate this information electronically owing to different IT systems in use by different clinicians.
- Key quality measures for Early Support are being established, including the number of children with a key worker and those with a family service plan. Recent data shows that most children known to Early Support in previous years have not had a plan or access to a key worker. However, this trend is changing with new specification in place.
- A questionnaire is being developed for parents to feedback on services received via Early Support that will provide useful information going forwards. Currently there is insufficient linkage of information across health, social care and Early Support (there is no common IT system) – enabling this linkage would support multidisciplinary working and reduce duplication.
- Developed 'Early Support' pathways that include regular Family Service Plan review meetings and early planning of transition to education services.

3.7.2 Provision for children with disabilities in children's centres

Sure Start Children's Centres provide integrated early intervention and preventative services for young children and their families. They provide services for all children (universal) as well as more targeted services for children in greatest need. Services are delivered by professionals across children's services, health and the voluntary sector. It has been recognised that, whilst all children's centres have sought to reach the parents of disabled children, families have not accessed centres to the extent needed if children's centres are to engage with families in greatest need.

A new 'hub and spoke' model is being introduced into Cambridgeshire, for children with Special Educational Needs and Disabilities. Cambridgeshire Children's Centres will be grouped into clusters, predominantly around locality boundaries for service delivery purposes. Within each cluster there will be a SEND Hub centre driving the co-ordination and facilitation of an integrated SEND service offer for the cluster.

3.7.3 Implementing a family support model for specific health needs of disabled children

Good parenting is important for a child's future health and wellbeing (Graham Allen MP, 2011). It has been recognised that Cambridgeshire's parenting programme provision should be more accessible to parents with disabled children. A specialist parenting programme, 'Stepping Stone Triple P,' will be implemented in 2013/14.

Problems with sleep are common in children with disability, including those with learning disability and autism. The 'Sleep Scotland' programme will be implemented through training of social care staff and targeted workshops at SEND children centre Hubs.

3.7.4 Self-directed support

Self-directed support involves identifying and allocating an indicative personal budget to meet the social care needs of the child. It is designed to enable choice, control and flexibility to arrange care services. It is currently taken up by around half of potentially eligible families.

3.7.5 Autism pathway

Work is underway to develop a pathway for Autism that clarifies the services and provision for children and young people with Autism, aged 0-25. This pathway is being developed with partner agencies, including health, Child and Adolescent Mental Health, and the voluntary sector.

3.8 Local views

As part of the consultation on Cambridgeshire's SEND strategy, views were sought from parents and young people. A summary of the consultation findings is available at:

http://www.cambridgeshire.gov.uk/childrenandfamilies/specialneedsdisabilities/senstrategy/

Parents and carers expressed that they would like:

- Easily accessible information, including provision of information in a one-stop shop.
- Support networks and forums.
- To be treated as equal partners who know and understand their child's needs.
- To access services close to home.
- To have a lead professional or key worker to take the lead on coordinating the services and support for their child.
- To have a 'passport' which contains information on their child's needs and includes a list of professionals involved and a chronology of events so that they don't have to keep repeating the same information.
- Schools to have high expectations for children with SEND and seek to evidence the child's strengths and achievements in a holistic way.
- Professionals to involve children and young people in decision making, informal discussions with schools were also welcomed by parents and carers.
- Professionals to receive specialist training on special educational needs and disability, including rare conditions.
- Plan for transitions and identify needs early.

Children and young people would like:

- Access to leisure activities, including after-school clubs.
- People to speak at reviews and meetings in *Plain English*.
- More work experience choices.

- Support future independent living arrangements, eg, planning their day and managing money.

A consultation carried out through the Cambridgeshire parent carer participation network of parents of disabled children, has identified support needed at the point of diagnosis.

The key themes were:

- Emotional support – a listening ear, someone to talk to in order to reduce isolation.
- Access to group support from other parents in a similar situation.
- Better signposting – easily accessible information on all support available to the whole family including statutory/non-statutory, locally and elsewhere.
- Access to on-going support – helping parents to help their child.
- Information on and about the disability or condition.
- Honest and sensitive support, from birth or point of diagnosis.
- Understanding, supportive, knowledgeable and well-trained staff.
- Early and planned access to respite.
- One person/one point of contact.

More information on the results of the consultation is available at: http://www.pinpoint-cambs.org.uk/get-involved/the-pinpoint-network/for-parents-of-disabled-children

3.9 Assets

Hospital passports contain information about a child, their health and how best to support them. They can reduce the need for children, young people and carer to have to repeat this information to multiple professionals. An example of a passport in use in Cambridgeshire is available at: http://www.cuh.org.uk/resources/pdf/patient_information_leaflets/PIN2734_hospital_passport_for_children_with_special_needs.pdf

3.10 Evidence and best practice

3.10.1 Early intervention

National Institute for Health and Clinical Excellence (NICE), guidance on social and emotional wellbeing in the early years, identifies that children with physical disabilities are potentially vulnerable to poor emotional and social wellbeing. It also defines how the social and emotional wellbeing of vulnerable children under five, can be supported through home visiting, childcare and early education. Guidance is available at: http://www.nice.org.uk/nicemedia/live/13941/61149/61149.pdf

The Centre for Excellence and Outcomes in Children and Young People's Services (C4EO) knowledge review: 'Improving the wellbeing of disabled children (up to age eight) and their families through increasing the quality and range of early years interventions' identifies the state of knowledge on early intervention for disabled families. Key findings included that services are less likely to be accessed by disadvantaged families; should be seamless; consider the needs of the whole family; use key workers; that good quality early education prevents future educational need.

Available at:
http://www.c4eo.org.uk/themes/disabledchildren/increasingquality/files/c4eo_improving_the_wellbeing_through_early_years_full_knowlege_review.pdf

3.10.2 Commissioning guidance

The Strategic Network for Child Health and Wellbeing in the East of England, used a process of wide stakeholder and user involvement to develop principles for commissioning and delivering better health outcomes and experiences for children and young people, which are comparable with the best in the world. The principles are available at: https://www.eoe.nhs.uk/downloadFile.php?doc_url=1355750970.pdf

Contact a Family, has published guides for GP and Clinical Commissioning Groups, which describe the measures GPs can take to make it easier for disabled children to see their GP and the services they might need. Available at: http://www.cafamily.org.uk/professionals/supporting-your-work-with-families/our-work-with-health-professionals/

The National Children's Bureau is encouraging the delivery of Early Support, as a way of improving the delivery of services for disabled children and young people and their families. The approach has been extended to support young people aged 0-25. http://www.ncb.org.uk/early-support/about-early-support

The Department of Health document: 'NHS at Home: Community Children's Nursing Services,' includes key messages on what is effective for a safe, sustainable service, including best practice examples. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_124898.

A toolkit for clinicians developing mental health services for children and adolescents with learning disabilities is available at: www.rcpsych.ac.uk/PDF/DevMHservCALDbk.pdf

The Family Friendly Framework, offers a practical approach to enable the delivery of services for children and families. It summarises the phases of care from prevention through the care pathway to adult life. The model is currently under consultation (March 2013). Available at: http://www.bacch.org.uk/policy/position_statements.htm

The national Child and Maternity Health Observatory (ChiMat) website has information on research, guidance and other resources relating to learning disabilities. Available at: www.chimat.org.uk/ldcamhs

3.10.3 NICE guidance for specific conditions

NICE guidance on the recognition, referral and diagnosis of children and young people with autism spectrum disorders, is available at: http://guidance.nice.org.uk/CG128 .

Draft NICE guidance on the care and support of young people with cerebral palsy, is available at: http://guidance.nice.org.uk/CG/Wave22/5/PrepublicationCheck

3.11 What is this telling us?

3.11.1 What are the key inequalities?

Children and young people with disabilities are a diverse group who access a range of different services provided by both health and social care. They are therefore likely to be affected where services are not well joined up. Local consultation and national policy point to the importance of good coordination across services and the need for a key-worker approach. Educational outcomes are poorer in children with a special educational need or disability and these children are more likely to claim free school meals. Children with disability are more likely to have health problems, including epilepsy, sleep problems and poor oral health.

3.11.2 What are the key trends?

The number of children with a disability is predicted to increase in Cambridgeshire, including children with complex needs.

3.11.3 What are the gaps in knowledge/services?

The National Service Framework (NSF) for Children, Young People and Maternity Services, expects local authorities, Primary Care Trusts and NHS Trusts to ensure that there are 'arrangements to encourage multi-agency strategic planning of services for disabled children, which allow for development and implementation of a locally-based, multi-agency database containing core data on disabled children, based on shared and agreed definitions." There is no agreed definition for children with a disability across services and it is therefore difficult to monitor the outcomes of children with a disability. Although this is not unique to Cambridgeshire, sharing information across services is needed to enable understanding of whether children with complex needs receive optimum care, eg, whether they have a key worker.

Specifically within health services, the information system SystmOne collects information on a range of health indicators, including, recording information on whether a child is receiving early support. It may be possible to extract information regarding children receiving early support and benchmark this against the general child population to examine how far young children with a disability are able to access universal health services.

4 Transition from Children's to Adult's services

4.1 Introduction

The term 'transition' is used to describe the process of moving from childhood into adulthood. Transition can be defined as 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions, as they move from child-centred to adult-oriented health care systems' (Department of Health/ Department for Education and Skills, 2006). Well-planned transition improves clinical, educational and social outcomes for young people. Transition to adulthood has a legal framework in society that has an impact on a young person's right to make decisions for their future path.

As they get older, children need to be involved increasingly in decisions about matters that affect them, so that by the time they are young adults they have learned to take responsibility for their own health and wellbeing. The law and governmental guidance in regard to personal responsibility, mental capacity and the safeguarding of vulnerable young people, alters between the ages of 16 and 18 and applies into adult life. These factors must all be considered as a young person with complex needs matures into adulthood.

From a social and health care perspective within Cambridgeshire, support through this period of transition applies to all young people with a disability, who are likely to be eligible for support from Adult Services, when they reach 18 years-old. This is in accordance with Fair Access to Care eligibility criteria as defined in 'Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care - Guidance on Eligibility Criteria for Adult Social Care, England (Department of Health 2010).

However, transitions should be viewed as a process, not a single event, individuals who have high/complex needs and will require continual support through the transition process and beyond. This includes young people aged 14-25 with:

- Learning disability (including those with an additional diagnosis of Autism).
- Physical disability.
- Complex health needs.
- Sensory impairment.
- Mental health needs.
- Autistic Spectrum Disorder (ASD – high functioning).
- Social and communication disorders.

4.1.1 National Policy context

The Children and Families Bill, 2012-13, includes provision for children, families, and people with special educational needs, for example, the right to request flexible working hours. The clauses on SEN aim to reform the SEN system, including the duty on local authorities to draw up Education, Health and Care plans and to set out a 'local offer' of services available to parents and young people.
http://services.parliament.uk/bills/2012-13/childrenandfamilies.html

The Draft Care and Support Bill includes the transition from children's care and support services (clauses 39-44). It states:

> *The transition between children's and adult social care is regularly cited as one of the most difficult experiences for young people and their families. We want to use the opportunity of reforming the law for adult care and support to improve this process and the outcomes achieved. These provisions support the transition by giving local authorities powers to assess children, young carers and the carers of children under the adult statute, and so make the transition as smooth as possible.*
>
> *No young person should go without the care and support they need at the point of transition. The draft Bill provides a new protection to ensure that any service being provided under children's legislation must continue to be provided after the individual's 18th birthday, until the assessments and care planning required under the adult statute have been completed, and adult care and support is ready to meet their needs. This will ensure that there is no gap in care and support at this critical time.*

http://www.publications.parliament.uk/pa/bills/cbill/2012-2013/0131/2013131.pdf

Support and aspiration: A new approach to special educational needs and disability. Progress and next steps proposes a new single assessment process and Education, Health and Care Plan, by 2014. This will replace the current 'Statement' system by bringing together all services across education, health and social care. The Care Plan is intended to cover the full age range, from 0 to 25, and support a more child-centred assessment process, with greater focus on long-term planning that will help to achieve the outcomes that matter most to children, young people and their families.

4.1.2 Local Context

Transition processes were developed within the last few years and a multi-agency protocol was launched in 2009, for Cambridgeshire's young people, likely to meet the eligibility criteria for social care support in adult life.

http://www.cambridgeshire.gov.uk/council/depts/adultsocialcare/transitions.htm

The Enhancing Transitions in Cambridgeshire Project was commissioned by the Transitions Partnership Board to bring children's and young people's services and adults commissioning processes together. In addition to £85,000 of transitions development funding, a grant of £58,000 was awarded to the Transitions Team by the Transitions Support Programme, to invest in this work.

Local work on transitions has been informed by feedback from parents and carers of young people going through transition (given in 2010/11). Comments included that families can feel like they are in a, "No man's land," during the time of transition, where services for children and young people are drawing to a close and that it may be difficult for decisions to be made that may not be carried forward by Adult Services. Further comments included the importance of involving families and carers; and the importance of the young person being at the centre of the transition process.

Work to enhance these and other areas of transition were also taken forward by the Project Working Group, from January 2011 to January 2012. This included refining transitions processes for young people with complex health needs, sustaining the engagement of young people with disabilities and parent/carers in strategic groups, as well as promoting person-centred 14+ reviews in special schools.

A work stream began in March 2012 to take this into a wider county council, 14–25 strategy, linked to the draft national legalisation.
In late 2012, in consultation with young people and parent carers, Cambridgeshire County Council developed a vision for young people in transition.

Vision for the Transition of Young People, aged 14 to 25:

All young people, aged 14-25 and likely to require support in adult life, experience the transition to adulthood as a positive, exciting, albeit a challenging time that assists in them reaching their full potential as an adult. The transition process will be driven by the young person and their family, and not by the agencies surrounding them. It will be flexible and realistic in approach, driven by a young person's aspirations, need and personal choice.

Guiding Principles

Process

- The transition process into adulthood will be an inclusive approach that puts young people at the heart of the process and involves their families.
- Transition is more than a series of assessments and reviews; it is a clear, coherent, continuous process (not an event) that will evolve to support transitions at an appropriate time, assisted by clear, agreed decisions at significant points.
- Use meaningful person-centred planning and reviews that inform and support planning and ensure personal budgets lead to positive life outcomes for young people.
- The transition process will support access to quality further education opportunities, meaningful employment, social participation, community engagement, and levels of economic self-sufficiency.

Participation:

- Information will be developed with families and young people themselves: "Nothing about us without us."
- The young people, their parents and carers will be well supported and actively involved in any decisions about transitional arrangements.
- Ensure that the experience of young people and their families informs strategic planning and commissioning.

Working Practice:

- Professionals working with young people will focus on their ambitions for adulthood and how best to prepare for them.

- Adult services will work alongside the young person and their family, to provide good quality and timely information from agencies already working with them, to ensure coordinated and good quality decision-making, about future adult provision.
- All staff with a duty or responsibility towards this group will have a clear understanding of their role and function and of others involved.
- Staff working with young people will acknowledge the needs for a young person's privacy and confidentiality and their wish to take increasing responsibility for their own health and care.
- If a young person lacks the maturity or capacity for decision-making, we will consult people interested in that person's welfare to make decisions in their best interest.
- Raise aspirations for a fulfilling adult life, by sharing clear information about what has already worked for others.

http://www.cambridgeshire.gov.uk/childrenandfamilies/specialneedsdisabilities/supportfromsocialcare/transitionfromchildtoadultservices.htm

Feedback from Parent Carers – Talk about Transitions 5 Event, Supported by Pinpoint, October 2013

Feedback suggests there is a need for clear and simple information for parent carers (the roadmap style is popular), supported by on-going opportunities for group-style, face-to-face information sharing, linked to a clear and achievable shared (children's and adult services) vision about the future, in an uncertain financial environment.

4.2 Numbers of young people going through transition

Figure 4.1 shows the number of children likely to require/meet the eligibility for social care support at transfer point to Adults Services, by year and primary area of need.

Figure 4.1: Number of young people likely to require support at transfer to Adult Services by Cambridgeshire transitions service (meeting eligibility criteria)

Primary need	2011/12	2012/13	2013/14
Learning disability	60	44	58
Physical disability	0	<5	<5
Sensory Impairment	0	<5	0
Autistic spectrum disorder	5	7	11

Source: Cambridgeshire County Council Transitions Team Tracking System for young people referred to the service 2011 - 2013

Many young people are referred to the Transitions service but are not eligible for social care support; for transition in the year 2013/14, 96 children were referred who do not meet eligibility criteria.

4.3 Prevention and staying Healthy

Person-centred approaches to health planning with young people are critically important and (as with other areas) successful transition planning requires collaboration between children's and adult services. In order to ensure this, a shared philosophy needs to be established between adult and paediatric care.

4.3.1 Facts and Figures

The number of children in Figure 4.1 relates to the young people transitioning to adult services who will have their health needs identified as part of the Children's Health Action Plan process. This was developed as part of the 14 – 25 Strategy work in partnership with Cambridgeshire Community Services (CCS), and Cambridgeshire and Peterborough Foundation Trust (CPFT).

Thirteen young people, aged 17, attending local special schools, will have a complex Health Assessment Action Plan, developed between September 2012 and February 2013. These plans will identify both physical and mental health needs and the resulting action required for a smooth transfer to adult health support both specialist and generic. This process has been developed following the Enhancing Transitions in Cambridgeshire project and the subsequent on-going work with the 14 – 25 Strategy, which identified work priorities for the development of protocol, for transfer of health support between CYPS and Adults services.

Work has begun to identify specific groups of young people who may face barriers for gaining adult health provision. The County Transitions Health Coordinator is developing processes that support these changes, and is advising on, or has advised on, required health intervention processes, for 42 young people, in the last 18 months.

On-going work is required on the transfer of young people from Children's Continuing Care to the Adult Continuing Health Care framework. This is currently occurring on a case-by-case basis (currently less than five children).

An analysis of health inequalities in adolescents with learning disability used data from the Longitudinal Study of Young People, in England, tracking over 15,000 adolescents from mainstream school to adulthood (Emerson, et al., 2011). The study found that boys with mild to moderate learning disabilities reported significantly poorer self-rated health and mental health than their peers; were more likely to report they had ever smoked, that they had smoked in the last year, lived in a poorer household, and were more likely to be bullied on a weekly basis, at school. However, there were no significant differences in health status or health-related behaviour in girls, although they were more likely to live in a poorer household and be bullied at school.

4.3.2 Assets

A health passport has been developed in Community Child Health for children attending special schools in the area and is available on SystmOne (a clinical information system). The generic information populates automatically from records held on the system. The passport is currently being completed, led by the special school nurse and used for any child transitioning into adult services. The next stage of development will be to extend this to the time of entry to special schools, where it can be accessed and populated by the health visitor and other health professionals involved in the child's care. Further anticipated development would be obtaining parental consent to share information with social care so that it can feed into a single health and education plan.

4.3.3 Local views

VoiceAbility consulted young people with disabilities, between the ages of 15 and 17, to ask about access to leisure activities. 45% said they do not take part in leisure activities out of school; 57% said the reason they are not involved in leisure activities is that they don't know what is available; 48% said there was nothing that interested them, close to home. Where young people were involved in activities, the majority found the choices available of what to take part in, appealing, but suggested:

- Organisations promote activities within schools.
- Schools support individuals in finding out what is available.
- Schools arrange visits to organisations for taster sessions.
- It would be helpful to have someone to go with (friend, buddy or volunteer).

4.3.4 Evidence and best practice

All young people with learning disabilities who need them have effective Health Checks[5] and Health Action Plans with their GPs. These should be holistic with a focus on both health and wellbeing and engage all the relevant health professionals including specialist health care support and paediatricians.

Transition: Moving on Well - A Good Practice Guide for Health Professionals and Their Partners on Transition Planning for Young People with Complex Health Needs or a Disability (Department of Health, 19 March 2008): www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance/DH_083592

To improve the health and wellbeing of people with learning disabilities, an Evidence-based Commissioning Guide for Clinical Commissioning Groups (CCGs) is available at http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups.

On the subject of transition, the guide recommends:

- The importance of well-planned, person-centred transition, because poor transition can lead to serious health outcomes following disengagement with health services and subsequent costs to health services.
- Identifying a care coordinator or navigator is important, and is valued by families and young people. The navigator works with the young person, their family and the multi-disciplinary team (including the GP) to coordinate the plan.
- Pathways to Getting a Life http://gettingalife.org.uk/downloads/2011-Pathways-to-getting-a-life.pdf includes a health pathway but sets it in the context of holistic transition planning, personalisation and support planning.
- For young people with learning disabilities and mental health needs. No health without mental health 74, says, "Care and support should be appropriate for the age and developmental stage of children and young people, adults of all ages and

[5] In February 2009, directions were published by the Department of Health requiring Primary care trusts to offer GP practices in their area the opportunity to provide health checks for adults with learning disabilities as part of a Directly Enhanced Service.

all protected groups. Careful planning of the transfer of care between services will prevent arbitrary discontinuities in care, as people reach key transition ages. Services can improve transitions, including those from CAMHS, into adult mental health services, or back to primary care, by:

- Planning for transition early, listening to young people and improving their self-efficacy.
- Providing appropriate and accessible information and advice so that young people can exercise choice effectively and participate in decisions about which adult and other services they receive.
- Focusing on outcomes and improving joint commissioning, to promote flexible services based on developmental needs.

Useful guidance is also available at: www.ldtransitionguide.bham.ac.uk/chap5_4.pdf

4.4 Education and Employment

4.4.1 Figures and trends

Transition should be a time of creativity with great choices. Nationally, young people with a disability are more likely not to be in education, employment or training (NEET) - 37% of disabled people nationally are NEET. This represents 16% of all people NEET. The levels of aspirations among disabled 16-year-olds are similar to those of their non-disabled peers and they expect the same level of earnings from a full-time job. However, disabled young people are less likely to be in higher education than non- disabled people. This is important because having a degree-level qualification can significantly improve employment outcomes (Department for Work and Pensions, 2013).

Figure 4.2 shows the proportion of young people aged 16-19 not in education, employment and training for the past two years. By way of comparison, for Cambridgeshire as a whole, the proportion of children NEET in 2011/12 was 5.1%.

Figure 4.2: Percentage of 16-19 year olds with Learning Difficulties and Disabilities who are Not in Education Employment and Training (NEET), Cambridgeshire 2011/12

District	Dec 2011		Dec 2012	
	No.	%	No.	%
Cambridge City	30	9.6	30	12.1
East Cambridgeshire	13	7.1	16	8.7
Fenland	28	9.5	39	13.5
Huntingdonshire	29	9.7	34	9.3
South Cambridgeshire	13	5.3	13	6.4
Cambridgeshire	113	8.5	132	10.2

Source: Aspire. Trend data are only available from 2011 when the cohort definitions were changed by the Department for Education – there are 19 more young people with Learning Difficulties and Disabilities in NEET in December 2012 than 2011. Performance is variable across the county with Fenland and Cambridge City having a greater percentage of young people with Learning Difficulties and Disabilities who are NEET and East Cambridgeshire and South Cambridgeshire having less.

4.4.2 Local views

As part of the consultation on the development of the Cambridgeshire Special Educational Needs and Disability Strategy (http://www.cambridgeshire.gov.uk/NR/rdonlyres/DA8D31A8-19FA-4114-A255-77E27876681A/0/SENDStrategyConsultationSummaryDocument.pdf) young people were asked about their priorities.

The key themes were:

- Communication and equipment
  - Public information should be easy to understand.
  - I would like to be able to use Facebook, computers and mobile phones safely.
  - Information about how communication aids will be funded when I become an adult.

- Better work experience
  - I want to be able to choose my work experience.
  - Preparing me with the skills I will need for the workplace.

- Leisure and transport
  - Accessible leisure facilities that I can go to with my friends, without a parent or carer.
  - I want to be able to see my friends out of school.

4.4.3 Evidence and best practice

There are a number of barriers and enablers for young disabled people making the transition from education to employment (Department for Work and Pensions, 2013). Enablers include:

- Strong aspirations.
- Experience of voluntary work.
- Self-employment.
- Experience of work placements and work experience.
- Strong family support.
- Accurate information and encouraging support from professionals.

Barriers include:

- Lack of flexibility in education leading some young disabled people to drop out.
- Accessibility and cost of transport to voluntary work.
- Attitudes of others – young disabled people believe their abilities are doubted before they are given an opportunity to demonstrate what they can do in terms of education, work and accessing services. Employers look at what a young disabled person can't do rather than what they can do.
- Lack of awareness amongst professionals of what support services are available for disabled young people.

Preparing for Adulthood (PfA) is a two year programme funded by the Department for Education as part of the delivery support for the 'Support and aspiration: A new approach to special educational needs and disability' green paper. http://www.preparingforadulthood.org.uk/

4.5 Accommodation and Housing

There are currently 20 young people requiring housing within the next 6-12 months in Cambridgeshire, with 11 young people having had their needs met this year. The majority of young people require housing, because their parents are no longer able to offer them accommodation.

Accommodation is offered in two ways:

- Via the Home Link (Choice Based lettings) http://www.home-link.org.uk/THO/

  Young people look for their own home using the Home-Link web site or magazine. Vacant properties are entered into the Home-Link site via the housing associations and district councils and applicants are prioritized on application. The Transition Team will support young people and their parent/carers to make the application and bid as appropriate.

- Via the LDP vacancies and accommodation processes.

  The Adult Learning Disability Partnership Housing Development Manager supports young people to work with housing associations and district councils to access housing specific to their needs.

4.6 Choice and service access/ service organisation

4.6.1 Person-centred planning

100% of young people move through transitions to adult social care support through personalisation and the self-direct support process. This is known as person-centred planning.

Person-centred planning is a way of planning for the life a young person wants, and can be used for both how things are now and in the future. Planning is individualised to meet the communication needs of the young person and the young people are always at the centre of the plan. This enables young people to access flexible services that meet their needs, from purchasing of community activities, personal assistant support and more formal styles of care, such as residential respite and day services.

Cambridgeshire has a county-wide Transitions Team that helps support this move to adult style services from when a young person is 17 years of age.

4.6.2 Developing good practice

It has been recognised that there is a lack of flexibility within the development of services for young people in transitions, such as the age of transfer between services. This is the key issue for the next phase of the transitions project and process development within Cambridgeshire.

The Transitions Strategy work currently underway will:

- Review existing policy, legislative framework, business processes, protocols and guidance that support the transition of 14 to 25-year-olds between children's and adult's services and to ensure compliance.
- Specifically identify and address where there is either an absence of clarity or shortfalls in thresholds and eligibility for Children's and Adults Services.
- Re-define clear roles & responsibilities and decision-making/governance processes where appropriate.
- Develop further and continue in-house joint commissioning work.
- Deliver refresh training and a support programme to train/support appropriate professionals, covering professional, policy and process training.
- Analyse IT requirements, look to identify how the use of IT can better support the professionals involved.
- Review current funding arrangements and enhance to support new approach.
- Design and implement a process for the continuation of financial responsibility and transfer between children's and adults services.
- Develop planning mechanisms that allow the ability to plan explicitly from childhood to adulthood, group planning, early identification of need, resource requirements and practice implications.

4.6.3 Local views

Feedback on the transitions process was sought from parents and carers in 2010/11. A feedback form was completed at the handover to case responsible adult teams six weeks after a young person's nineteenth birthday. The key points were:

- Support plan:
    - 92% of carers felt supported to complete the person centred plan with 4% feeling they were not. Workers were described as being patient and supportive, with invaluable guidance. A comment was made that the system still has issues and communication between carers and services was not always sufficient.
    - 92% of carers felt the young person was at the centre of their plan with 4% feeling they were not.
    - 92% of carers felt they were given enough information about the process with 4% feeling they were not. A comment was made about the difficulty in predicting a young person's needs so far in advance and that they experienced limited flexibility with a young person's personal budget when their young person's needs changed.
    - 96% of carers felt supported to put the plan in to action.
    - However, in some cases plans were not fully established and in one case not compiled at all.

- Outcomes for young people:

    - 93% felt that the Support Plan provided positive outcomes for their young people. Carers stated that they felt supported where changes were happening at different times between 18 and 19 years of age.
    - Comments were made about the reduction in isolation for one young person and for another that the young person had moved into her own accommodation and was progressing towards independence well.

Information on Your Life Your Choice and transition into adulthood plans, is available at: http://www.yourlifeyourchoice.org.uk/i-need-help-with/disabilities-and-sensory-loss/transitions-into-adulthood.aspx

4.6.4 Assets

The Enhancing Transitions in Cambridgeshire Project was commissioned by the Transitions Partnership Board to bring Children's and Young Peoples Services and adults commissioning processes together. Key areas of work have been:

- Refining transitions processes for young people with complex health needs.
- Sustaining the engagement of young people with disabilities and parent/carers in strategic groups, including workshops, consultations and neighbourhood forums.
- Promoting person-centred reviews at 14+ in special schools – this work will also be taken forward as part of the Single Plan.
- Joint commissioning protocols as part of the 14-25 transfer strategy.
- A Health Action Plan (HAP) for young people at Area Special Schools. Further work is required to introduce the HAP to all children and young people with complex health needs and to develop diagnostic specific pathways as part of Education, Health and Care Plans.
- Forming close working links between Children and Young People's Services (CYPS) and Adults' Support Services.

The aims of future project work are:

- To improve outcomes for young people and their families by implementing a more flexible and personalised approach to transition with fewer age barriers.
- Transparent, clear and robust 'catch-all' pathways and processes with clear roles and responsibilities.
- Achieving efficiencies by implementing a more effective commissioning strategy (better value for money).
- More effective use of key resources.
- Improved multi-agency partnership working.
- Better performance management information.
- Appropriately skilled professionals.
- Better use of IT systems that support users.
- Reduction in administrative and repetitive procedures for young people, their families and professionals.

- Processes that improve safe-guarding and the protection of vulnerable young people.
- Increased respect amongst professionals will lead to less duplication of effort (eg assessment activity).

Additional needs' advisors in Cambridgeshire provide advice and guidance service for young people, aged 13 -19, and to young people with learning difficulties and disabilities up to the age of 25. Support is provided to all young people with additional needs during their transitions to adulthood.

4.6.5 Evidence and best practice

Transition to Adulthood: A guide for practitioners working with disabled young people and their families (Cerebra 2013).
http://www.cerebra.org.uk/English/getinformation/disabilityrightslegalissues/Documents/Transitions%20guide%20for%20proffesionals.pdf

The National Development Team for Inclusion publication, 'Pathways to getting a life,' sets out current best practice on how to help young people to live the lives they really want, based on the work of Valuing People, from 'Getting a life' demonstration sites.
http://www.ndti.org.uk/uploads/files/2011-Pathways-to-getting-a-life.pdf

4.7 What is this telling us?

4.7.1 What are the key inequalities?

Adolescence can be a difficult transition for all young people, but young people with a disability face specific issues and challenges. Where health and social care needs have been delivered to families by professionals with whom the family have developed a relationship over many years, losing that contact and continuity can be difficult for the family, resulting in poor health outcomes and subsequent cost to services. There is also a risk of vulnerable young people 'falling through the net'.

Adolescents with learning disability report having significantly worse health and mental health than their peers, and would like to access leisure facilities, with their friends. Compared with Cambridgeshire as a whole, twice as many young people with disabilities are not in education, employment or training (NEET). Opportunities for work experience, preparation with skills for the workforce and information and support from family and professionals are key to improving this. Young people also want to choose their work experience, and be prepared for and attain necessary workplace skills.

4.7.2 What are the key trends?

Numbers of young people requiring social care support at age of transition are predicted to increase, as are those who do not meet the eligibility criteria for adult services. There will therefore be an increasing need for information and signposting to appropriate support.

4.7.3 What are the gaps in knowledge/services?

Where services are drawing to a close, and it is unclear how needs will be met in adulthood, Carers identified that current transitions feel like a ‘no man’s land’. There is a lack of flexibility in the transition age from children’s to adult services and a need for joint planning across agencies in line with the Children and Families Bill 2012-13. Although work on this is underway in Cambridgeshire, there is no current strategic county overview and policy between children and adult services that describes the multi-agency approach required to support young people in transitions.

5 Adults with a disability

5.1 Introduction

5.1.1 Local context

In Cambridgeshire, policy in adult social care must be seen in the context of 'Shaping Our Future – A Framework for Action.' http://camweb.ccc.cambridgeshire.gov.uk/as/ass/transform/shaping_our_future.htm - a strategy designed to promote services that fit with people's lives and do not box them into a 'one size fits all' approach, as well as meeting the pressures of an ageing population and people with complex needs.

The responsibility for social care services sits within the county council's Adult Social Care service. Cambridgeshire County Council's Integrated Plan - 2012-2013, confirms that, "*Prevention and early intervention is a crucial part of our transformation* [of Adult Social Care, in Cambridgeshire]," and commits Cambridgeshire County Council to act as early as possible to help people remain independent for longer. The plan also states that, "*Resources will be used more effectively and efficiently to ensure that these services encourage personal choice and control and prevent the need for more expensive services in the future."*

In order to support the achievement of this objective, a number of pieces of work are being undertaken to examine:

- The 'events' and 'triggers' that are experienced by individuals as they grow older and that can lead to the need for adult care services.
- The types of prevention, early intervention and support that can best tackle these 'events' and 'triggers'.
- The relationship between prevention, early intervention and support and the more 'mainstream' adult social care services.

Learning Disabilities

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 (CLDP). The CLDP brings together specialist health and social care services for people with a learning disability. The CLDP is responsible for commissioning and providing these services on behalf of Cambridgeshire and Peterborough Clinical Commissioning Group and Cambridgeshire County Council. The Learning Disabilities Commissioning Strategy, currently at final draft stage, aims to increase choice and support amongst people with learning disabilities, as well as enabling greater access to universal services and promoting prevention, progression and independence.

5.1.2 National policy

Over the past 10 years, there have been a number of government documents and policies about how health and social care services should be delivered in the future. All of these policies contain a number of common themes that are about supporting people better to enable them to live in the community; providing support and care closer to home; avoiding people going into hospital unnecessarily, and providing new alternatives to residential care and other inflexible service models. There has been a fundamental shift to giving people much more choice and control over their lives,

supported by new flexible ways of working, such as Direct Payments and Personal Budgets, rather than just offering people a limited range of services on a 'take it or leave it' basis.

The draft Care and Support Bill was published on 11 July 2012. http://careandsupportbill.dh.gov.uk/home/. It proposes a single, modern law for adult care and support that replaces existing outdated and complex legislation, as a fundamental reform of the way the law works. It places the wellbeing, needs and goals of people at the centre of the legislation to create care and support which fits around the individual and works for them. It provides a new focus on preventing and reducing needs, and putting people in control of their care and support. The draft Bill also creates a single duty for local authorities to undertake a 'carer's assessment'. This replaces the existing law, and removes the requirement that the carer must be providing "a substantial amount of care on a regular basis".

'Valuing People Now' was published in January 2009. It states that all services and support should be person-centred, personal and offer control, choices and opportunities to people. It re-stated the main conclusion of the first 'Valuing People' White Paper, which was that people with learning disabilities should expect their rights to their own home, a job, good health and freedom from discrimination to be upheld. Other government reports with relevance to people with learning disabilities are listed below:

'Our Health, Our Care, Our Say':
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453

'Putting People First':
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

'The Mansell Report' (Revised):
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

'No Health without Mental Health':
www.dh.gov.uk/mentalhealthstrategy

'Fulfilling and rewarding lives: the strategy for adults with autism in England':
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Winterbourne View investigation and concordat:
https://www.wp.dh.gov.uk/publications/files/2012/12/Concordat.pdf

5.2 Number of adults with a disability

5.2.1 Adults with a learning disability

5.2.1.1 Summary of numbers of adults with a learning disability

This JSNA used three information sources to estimate the number of adults with learning disabilities in Cambridgeshire, based on:

- Figures obtained by applying national prevalence estimates to local population data.
- The number of people using learning disabilities services.
- The number of people recorded as having learning disabilities, by their GP.

Information on these data sources is presented in the sections below, but it is useful to compare these estimates directly. Table 5.1 shows numbers for Cambridgeshire using these three estimates:

Table 5.1: Numbers of people with a learning disability (aged 18+ years) – a comparison of data sources, Cambridgeshire 2012

Data source	Number
Estimated number of adults: All severities	11,424
Estimated number of adults: Moderate or severe	2,376
Adults on GP practice-based registers	1,922
Adults receiving social care services	1,630

Sources: Projecting Adults Needs and Service Information (PANSI)/ Projecting Older People Population Information (POPPI), Institute of Public Care; Quality and Outcomes Framework, NHS Information Centre; Cambridgeshire County Council Adult Social Care 'SWIFT' data

It can be seen that the majority of adults with learning disabilities do not use learning disabilities services. There is also some discrepancy between the number of adults on GP practice registers and adults receiving social services, both of which are likely to be those with moderate/severe learning disabilities. Reasons for this may be that services use different definitions or service thresholds and that not all people known to health and social care actually use social care services in a given year. It is important to note that people with learning disabilities who are not known to specialist services may still have some significant support needs. For example, people with mild learning disabilities are more likely than people without learning disability to be living in poverty, be known to the criminal justice system and have a mental health problem (Emerson & Hatton, 2011).

5.2.1.2 Estimated current and future numbers of adults with a learning disability

It is possible to estimate the number of people with disabilities using prevalence estimates from research. Using national prevalence estimates, there were 11,424 people with a learning disability living in Cambridgeshire in 2012; the majority being people with mild learning disabilities, most of whom do not require specialist health or social care support. The number of people with a learning disability is projected to rise by 3.8% by 2016, and by 17.3% by 2030, in line with population growth and ageing (see

Table 5.2).

Table 5.2: Predicted numbers with a learning disability by age group (18+ years), Cambridgeshire, 2012-2030

Year	Age group (years)								Total
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2012	1,584	1,858	2,103	2,032	1,633	1,252	684	278	11,424
2013	1,575	1,897	2,068	2,069	1,630	1,310	703	290	11,543
2014	1,566	1,922	2,040	2,107	1,638	1,354	722	301	11,650
2015	1,549	1,945	2,029	2,133	1,659	1,394	739	314	11,762
2016	1,529	1,970	2,005	2,159	1,690	1,433	750	327	11,862
2020	1,461	2,017	2,025	2,130	1,864	1,498	885	383	12,264
2025	1,493	1,955	2,216	1,995	2,055	1,498	1,101	481	12,795
2030	1,644	1,892	2,318	2,015	2,039	1,694	1,177	619	13,400

Sources: Projecting Adults Needs and Service Information (PANSI) / Projecting Older People Population Information (POPPI), Institute of Public Care

(Based on national prevalence estimates applied to mid-2010 based ONS population projections)

Using national prevalence estimates, there were 2,376 people with a moderate or severe learning disability living in Cambridgeshire in 2012. These people are more likely to be in contact with local social care services. The number of people with a moderate or severe learning disability is projected to rise by 3.5% by 2016 and by 16.3% by 2030.

Table 5.3: Predicted numbers with a moderate or severe learning disability by age group (18+ years), Cambridgeshire, 2012-2030

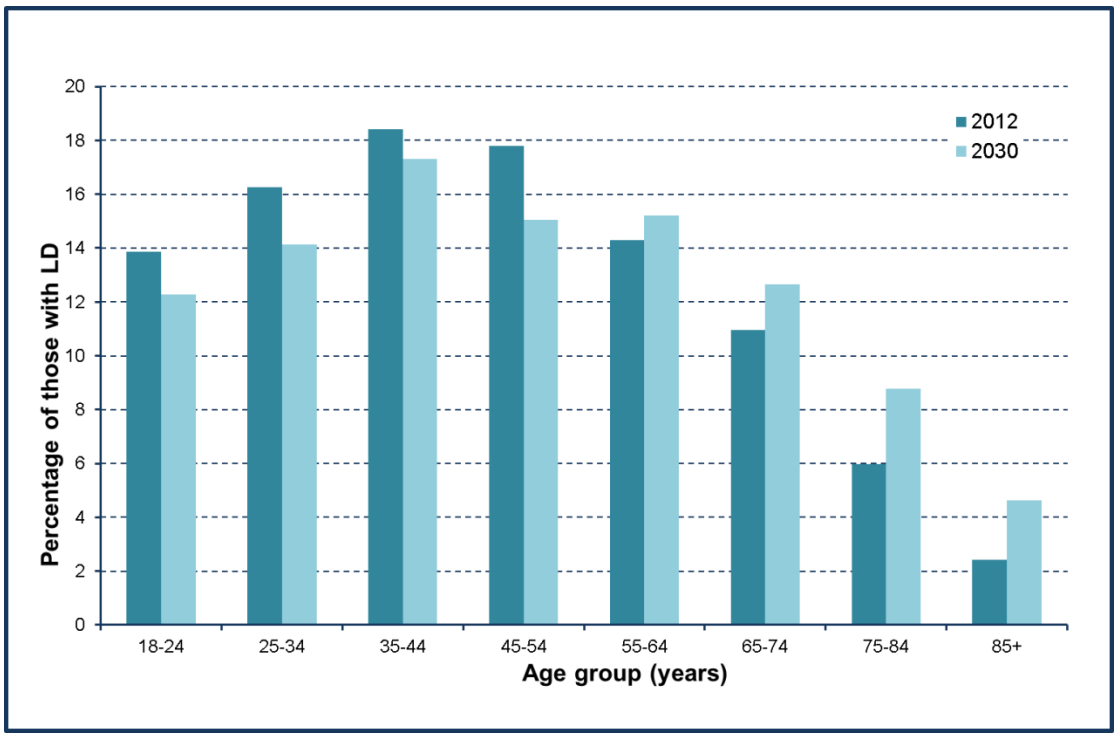
Year	Age group (years)								Total
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2012	364	369	528	458	353	205	71	26	2,376
2013	363	381	520	466	353	215	73	28	2,398
2014	361	389	513	474	355	221	75	28	2,418
2015	358	397	510	480	360	227	77	30	2,439
2016	354	405	504	486	367	233	78	31	2,458
2020	341	430	509	479	406	241	92	36	2,532
2025	352	435	558	450	445	243	114	44	2,641
2030	391	439	584	460	438	275	119	57	2,763

Sources: Projecting Adults Needs and Service Information (PANSI) / Projecting Older People Population Information (POPPI), Institute of Public Care

(Based on national prevalence estimates applied to mid-2010 based ONS population projections)

Due to the reduced life expectancy of people with learning disabilities, learning disabilities are more prevalent in younger age groups. However, the impact of the aging population in Cambridgeshire will be that there will be an increase in the percentage of people with learning disabilities who are over 55, as shown in Figure 5.1. Older people with a learning disability are less likely to be receiving care from a parent, who may have died or be very frail.

Figure 5.1: Age distribution of predicted numbers with a learning disability (18+ years), Cambridgeshire, 2012 and 2030



Sources: Projecting Adults Needs and Service Information (PANSI) / Projecting Older People Population Information (POPPI), Institute of Public Care
(Based on national prevalence estimates applied to mid-2010 based ONS population projections)

5.2.1.3 People using learning disabilities services

There were a total of 1,630 users of health and/or social care services aged over 18 in the year 2011-12. Most of the activity relates to community-based services, although the proportion of older people supported in residential care is higher.

Table 5.4: Number of people aged 18-64 with a learning disability receiving a social care service within the year

Service	2009/10	2010/11	2011/12
Community Based Services	1110	1170	1215
Residential Care	330	345	305
Nursing Care	25	30	20
Total	1435	1510	1510

Source: Cambridgeshire County Council

Table 5.5: Number of people aged 65+ with a learning disability receiving a social care service within the year

Service	2009/10	2010/11	2011/12
Community Based Services	55	65	75
Residential Care	55	55	50
Nursing Care	5	10	5
Total	110	125	120

Source: Cambridgeshire County Council

In February 2009, directions were published by the Department of Health requiring Primary Care Trusts (PCTs) to offer GP practices in their area the opportunity to provide health checks for adults with learning disabilities as part of a Directly Enhanced Service. The initial task for PCTs is that they work with their local authority to produce a register of patients with learning disabilities who are known to social services and share this information with relevant practices.

Table 5.6 shows the number of people with learning disabilities on GP practice registers, by the local commissioning group (LCG) area.

As some Cambridgeshire GP practices fall inside Peterborough LCG boundaries, and vice versa, data for the whole Clinical Commissioning Group (CCG) are included.

The recorded prevalence of learning disabilities is statistically significantly higher than the the CCG average in Peterborough and Hunts Health.

Table 5.6 and

Figure 5.2).

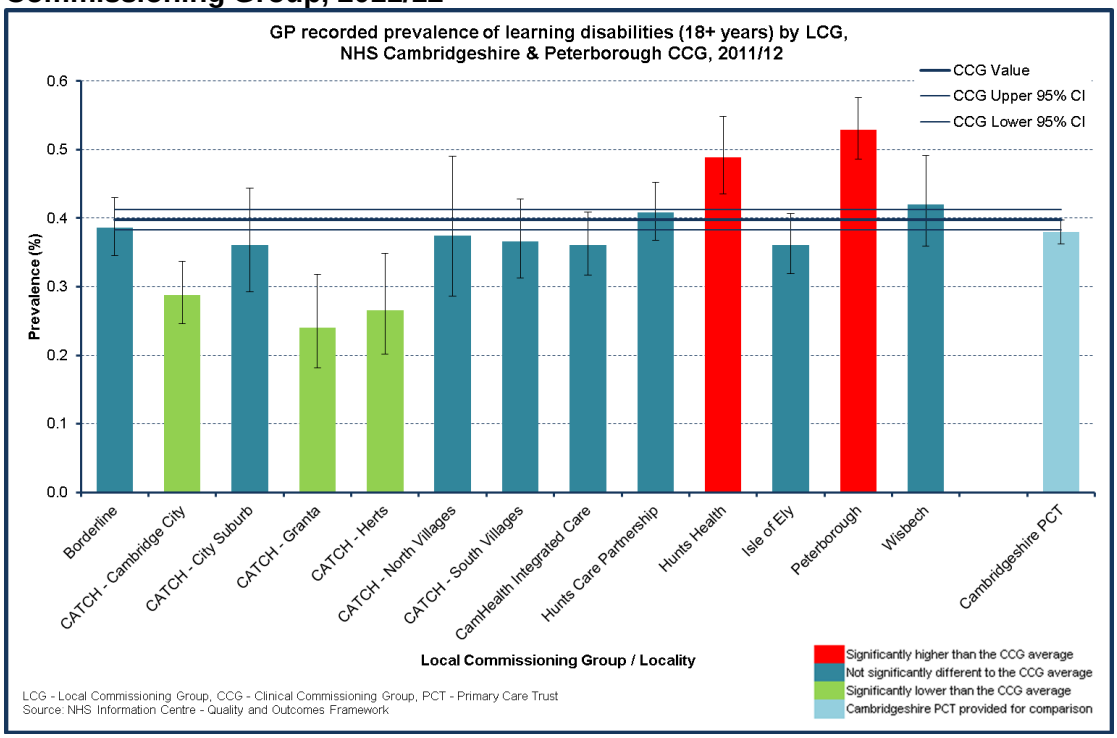
Table 5.6: GP recorded prevalence of learning disabilities (18+ years) by Local Commissioning Group, NHS Cambridgeshire and Peterborough Clinical Commissioning Group, 2011/12

Local Commissioning Group / Locality	Number	Prevalence (%)	95% CI	
			Lower limit	Upper limit
Borderline	316	0.39	0.35	0.43
CATCH - Cambridge City	152	0.29	0.25	0.34
CATCH - City Suburb	88	0.36	0.29	0.44
CATCH – Granta	48	0.24	0.18	0.32
CATCH – Herts	51	0.27	0.20	0.35
CATCH - North Villages	53	0.37	0.29	0.49
CATCH - South Villages	157	0.37	0.31	0.43
CamHealth Integrated Care	238	0.36	0.32	0.41
Hunts Care Partnership	361	0.41	0.37	0.45
Hunts Health	285	0.49	0.43	0.55
Isle of Ely	260	0.36	0.32	0.41
Peterborough	536	0.53	0.49	0.58
Wisbech	155	0.42	0.36	0.49
Total CCG	2,700	0.40	0.38	0.41

Notes: CI - Confidence Interval

CATCH - Cambridgeshire Association To Commission Health

Figure 5.2: GP recorded prevalence of learning disabilities (18+ years) by Local Commissioning Group, NHS Cambridgeshire and Peterborough clinical Commissioning Group, 2011/12



5.2.2 Physical Disability

5.2.2.1 Estimating numbers of people with a physical disability using national surveys

There is no gold standard measurement of adults with a physical disability. Two sources are the Health Survey for England, 2001 – used to predict numbers of people with disability by the Projecting Adults Needs and Service Information (PANSI). Institute of Public Care – and the national Census.

Table 5.7 shows the predicted number of adults of working age with a moderate or serious physical disability by age group. The number of adults with disability increases with age and numbers are predicted to increase, particularly in the over 55's.

Table 5.7: Predicted numbers with a moderate or serious physical disability, by age group (18-64 years), Cambridgeshire, 2012-2030

Year	Age group (years)					Total
	18-24	25-34	35-44	45-54	55-64	
2012	2,861	3,431	6,264	10,838	14,925	38,319
2013	2,847	3,505	6,154	11,023	14,883	38,413
2014	2,832	3,551	6,067	11,210	14,946	38,604
2015	2,803	3,592	6,030	11,334	15,132	38,891
2016	2,768	3,638	5,957	11,458	15,401	39,223
2020	2,651	3,726	6,000	11,247	16,974	40,598
2025	2,719	3,611	6,548	10,478	18,713	42,070
2030	3,003	3,496	6,826	10,540	18,568	42,434

Source: Projecting Adults Needs and Service Information (PANSI), Institute of Public Care
(Based on national prevalence estimates applied to mid-2010 based ONS population projections)
Totals may not equal the sums of the age groups due to rounding of estimated numbers.

Table 5.8 shows the predicted number of adults of working age with a serious physical disability. Again, the numbers rise with increasing age and overall numbers are expected to increase.

Table 5.8: Predicted numbers with a serious physical disability, by age group (18-64 years), Cambridgeshire, 2012-2030

Year	Age group (years)					Total
	18-24	25-34	35-44	45-54	55-64	
2012	467	298	1,459	2,360	4,182	8,766
2013	465	305	1,433	2,400	4,170	8,773
2014	462	309	1,413	2,441	4,188	8,812
2015	458	312	1,404	2,468	4,240	8,882
2016	452	316	1,387	2,495	4,315	8,966
2020	433	324	1,397	2,449	4,756	9,359
2025	444	314	1,525	2,282	5,243	9,808
2030	490	304	1,590	2,295	5,203	9,882

Source: Projecting Adults Needs and Service Information (PANSI), Institute of Public Care
(Based on national prevalence estimates applied to mid-2010 based ONS population projections) Totals may not equal the sums of the age groups due to rounding of estimated numbers.

The Census collects information on people of all ages with 'long-term health problems and disability' and the extent to which these problems limit day-to-day activities. Currently, only data on 'all ages' and 'adults of working age' are available. Further age-specific data will be available later this year to provide estimates in adults over 65.

5.2.2.2 Blue Badges

In order to enable individuals with a disability to park closer to their destination, they can apply for a blue badge. Table 5.9 shows the number of Blue Badges issued in Cambridgeshire, by age group, for the years 2008-2012.

An independent mobility assessment was introduced, in June 2011.

Table 5.9: Blue Badges issued in Cambridgeshire by year and age group

	2008	2009	2010	2011	2012
Under 19	168	211	209	189	225
20 to 64	2,169	2,402	2,840	2,635	2,683
65 and Over	8,337	8,539	9,168	8,171	7,677
Total	10,674	11,152	12,217	10,995	10,585

Source: Cambridgeshire County Council

5.2.2.3 Adults with a physical disability using social care services

Tables 5.10 and 5.11, show the total number of adults and older people in receipt of social care services. In 2011/12 there were 2,100 adults and 8950 older people receiving community-based, residential or nursing care. The number of people receiving social care in the working-age group is far fewer than the number of adults predicted to have a severe disability.

Table 5.10: Number of people aged 18-64 with a physical disability receiving a social care service within the year

	2009/10	2010/11	2011/12
Community Based Services	2,235	2,035	2,025
Residential Care	60	60	50
Nursing Care	40	35	35
Total	2,310	2,115	2,100

Source: RAP statutory data return, Table P1, Cambridgeshire County Council

Table 5.11: Number of people aged 65+ with a physical disability receiving a social care service within the year

	2009/10	2010/11	2011/12
Community Based Services	8,155	7,515	7,680
Residential Care	1,095	965	1,060
Nursing Care	600	555	655
Total	9,435	8,625	8,950

Source: RAP statutory data return, Table P1, Cambridgeshire County Council

5.2.2.4 Adults known to the physical disability team

The Physical Disability Team is countywide and works with individuals with physical disabilities (acquired or congenital), between the ages of 19 and 64, or a long-term health condition. Individuals with the most severe forms of physical impairment are eligible for adult social care support, and currently (February 2013) the team is supporting 808 individuals with a physical disability, plus 24 with HIV and 18 vulnerable adults ie those who meet overall eligibility criteria, but not necessarily the criteria for individual services.

Over half those supported are over the age of 51. Very few referrals come to the team from children's services via transitions (in contrast to referrals to the adult learning disabilities team). The overwhelming majority of referrals come via the hospitals to the Reablement Service and then if that preventative input has not sufficiently succeeded then they are referred to the team.

A recent audit showed that within the team the biggest service user groups are those with multiple sclerosis (15%), spinal/ skeletal injury (10%) and acquired brain injury (10%).

5.2.3 Sensory impairment

5.2.3.1 Estimated current and future numbers of people with visual impairment

Table 5.12 below, shows the estimated number of adults with serious visual impairment. It is thought estimates of less than serious impairments are unreliable in this age group. The estimates are based on a combination of research evidence of prevalence of those with a visual acuity less than <6/48 and RNIB estimates of those who are registerable.

Table 5.12: Predicted numbers with a serious visual impairment, by age group (18-64 years), Cambridgeshire, 2012-2030

Year	Age group (years)					Total
	18-24	25-34	35-44	45-54	55-64	
2012	38	48	56	57	47	246
2013	38	50	55	58	47	248
2014	38	50	54	59	47	248
2015	37	51	54	59	48	249
2016	37	51	53	60	48	249
2020	35	53	53	59	53	253
2025	36	51	58	55	59	259
2030	40	49	61	55	58	263

Source: Projecting Adults Needs and Service Information (PANSI), Institute of Public Care

The predictions for older people in Table 5.13 are based on those with a moderate or severe visual impairment. The overall prevalence of all causes of visual impairment in those aged 65-74 years and over with visual acuity (VA) of less than 6/18 (moderate or severe) is 5.6%, and 12.4% for those aged over 75.

A visual acuity (VA) of less than 6/18 is the approximate statutory threshold point used to qualify as 'severely sight-impaired' (registered blind), or 'partially sight-impaired' (registered as partially sighted).

Table 5.13: Predicted numbers with a moderate or severe visual impairment, by age group (65+ years), Cambridgeshire, 2012-2030

Year	Age group (years)		Total
	65-74	75+	
2012	3,265	6,076	9,341
2013	3,416	6,262	9,678
2014	3,528	6,436	9,964
2015	3,623	6,622	10,245
2016	3,718	6,758	10,476
2020	3,853	7,911	11,764
2025	3,875	9,796	13,671
2030	4,390	11,098	15,488

Source: Projecting Older People Population Information (POPPI), Institute of Public Care
(Based on national prevalence estimates applied to mid-2010 based ONS population projections)

5.2.3.2 Numbers of adults known to visual impairment services

The Sensory Services Team works closely with those aged 19 – 119. The team also works closely with colleagues in the Children's Disability Service and provide technical officer support with equipment for the deaf and Visual Impairment (VI), and rehabilitation expertise, by setting goals and reviewing commissioned VI rehabilitation training. The Sensory Services Team also works with many external partner agencies, such as Fire and Rescue, residential homes, and local voluntary organisations, to assist and support people with a sensory loss.

Social services authorities are required to maintain registers of people in their areas who have severe sight loss (blind) or sight loss (partially sighted). From April 2012 to February 2013, 251 people were registered with either a severe sight loss or partial sight loss. Additionally, 57 of these individuals were identified as having a dual sensory loss.

5.2.3.3 Estimated number of adults with hearing impairment

Table 5.14 shows the predicted number of adults in Cambridgeshire with a moderate or severe hearing impairment. Hearing impairment is much more common in older people. Population growth and aging will result in greater numbers of people with hearing loss in Cambridgeshire.

Table 5.14: Predicted numbers with a moderate or severe hearing impairment, by age group (18+ years), Cambridgeshire, 2012-2030

Year	Age group (years)								Total
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2012	86	335	1,240	4,927	8,227	11,151	21,325	12,479	59,770
2013	86	341	1,215	5,003	8,196	11,636	21,819	12,988	61,283
2014	85	346	1,196	5,082	8,233	12,066	22,439	13,498	62,946
2015	84	348	1,188	5,143	8,318	12,397	22,935	13,922	64,335
2016	83	352	1,170	5,186	8,478	12,736	23,307	14,602	65,915
2020	80	359	1,166	5,080	9,355	13,145	27,217	16,895	73,297
2025	79	351	1,264	4,753	10,304	13,245	33,731	20,971	84,698
2030	88	340	1,316	4,802	10,179	14,999	35,976	26,830	94,530

Sources: Projecting Adults Needs and Service Information (PANSI) / Projecting Older People Population Information (POPPI), Institute of Public Care
(Based on national prevalence estimates applied to mid-2010 based ONS population projections)

The Cambridgeshire Campaign for Tackling Acquired Deafness (CAMTAD) provides 'Hearing Help' sessions, home visits and support with hearing aid maintenance to around 3500 individuals per year, in four-out-of-five Cambridgeshire districts; predominantly in the 50+ age group, with coverage now also extending to Fenland.

5.2.4 Autistic spectrum disorder

Table 5.15 shows the predicted numbers of adults with an autistic spectrum disorder (ASD) in Cambridgeshire. About 1% of the population is estimated to be autistic, with higher prevalence in men than women. The number of adults with ASD is predicted to rise.

Table 5.15: Predicted numbers with Autistic Spectrum Disorders by age group (18-64 years), Cambridgeshire, 2012-2030:

Males:

Year	Age group (years)					Total
	18-24	25-34	35-44	45-54	55-64	
2012	560	707	763	783	639	3452
2013	556	725	749	794	637	3461
2014	553	736	740	806	641	3476
2015	545	745	740	815	646	3492
2016	538	756	736	819	659	3508
2020	513	778	758	797	729	3575
2025	527	749	839	751	801	3667
2030	581	724	877	772	785	3739

Females:

Year	Age group (years)					Total
	18-24	25-34	35-44	45-54	55-64	
2012	55	71	87	88	73	374
2013	55	72	85	90	73	374
2014	54	73	84	91	73	375
2015	54	73	83	92	74	376
2016	53	74	81	94	76	378
2020	51	76	80	93	83	383
2025	52	74	86	86	92	390
2030	58	72	90	84	92	395

Source: Projecting Adults Needs and Service Information (PANSI), Institute of Public Care
(Based on national prevalence estimates applied to mid-2010 based ONS population projections)

Local Authority and Health Authority data systems do not always include a separate field for autism, therefore identifying those on the autistic spectrum who are known to social care can be problematic. Those on different parts of the spectrum may have very different needs.

The National Autistic Society states that:

> *"Estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence."*

Data from the Department of Health's autism strategy, Leading Fulfilling and Rewarding Lives (Department of Health, 2010), concludes that people on the autistic spectrum generally have similar disadvantages to people with learning disabilities. This includes poor access to healthcare, social exclusion, more at risk of abuse and needing support to access and benefit from appropriate housing, employment and independent living. They are also likely to have poor outcomes from interactions with the criminal justice system.

5.3 Disability and disadvantage

Disabled people are more likely than non-disabled people to live in poverty, with issues affecting disabled people being inter-linked. For example, poor educational outcomes may result in unemployment. Those who already experience disadvantage are more likely to become disabled. Developing impairment is strongly linked to being poor, being out-of-work, or having low educational qualifications. The risk of developing a disability is two and a half times higher for those in the bottom fifth of the income distribution. Childhood experience is important, with children in the most socioeconomically disadvantaged households being more than twice as likely to develop chronic disabling conditions compared with the least disadvantaged.

Unemployment may result in social isolation and poverty. Lifestyle factors, such as smoking, drinking and poor diet are also associated, both with material disadvantage and with increased likelihood of onset of ill-health or impairment. The age of onset of disability can be important in determining experiences. For those born with impairment or disability, education and other early experiences influence the whole of their life chances (Department for Work and Pensions, 2013).

People with learning disabilities are more likely than their non-disabled peers to be exposed to a range of 'social determinants' of poorer health. These include poverty, poor housing conditions, unemployment, social exclusion, violence and exposure to overt acts of abuse, victimisation and discrimination. Learning disabilities are more common in poorer households and mild learning disabilities are also more common in poorer communities (Emerson & Baines, 2010).

We would therefore expect to see relatively higher numbers of people with learning disabilities in the more socially deprived areas of Cambridgeshire. In addition, it has been observed nationally that patterns of provision of residential care have led to considerable 'migration' of adults with learning disabilities. However, definitive information is not available on whether this is the case in Cambridgeshire.

5.4 Health, ill health and prevention

5.4.1 Facts and Figures

Many disabled people have more than one health condition and nearly a third of people with long-term physical conditions have a concurrent mental health condition, such as anxiety or depression. People with more than one health condition are likely to be at significant risk of being disabled by the interaction of their impairments with social and environmental factors (Department for Work and Pensions, 2013).

5.4.1.1 Healthy living and screening

A review of the evidence on the impact of physical activity and health by Chief Medical Officers in the four home countries[6] concluded that the array of different impairments and disabilities makes generalisation about findings from evidence very difficult. However, the expert advisory panel agreed that the report's guidelines on the benefits of physical activity, at all ages, and the harms of sedentary behaviour would be broadly applicable. They further commented that specific activities may require adaptation to individual needs and abilities and safety concerns must be addressed. Environmental barriers, social oppression and psychological challenges also need to be considered.

It has been identified that disabled people are less likely to participate in cultural, leisure or sporting activities with only 7% of disabled adults participating in at least 30mins of moderate intensity sport three-times per week (Department for Work and Pensions, 2013). However, these figures are derived from the Active People Survey, which measures participation in sport, rather than a more general measure of physical activity, and the numbers of people with a disability at a local level were very small.

Currently, there is no robust way of assessing the actual number of people with disabilities who are physically active. Information collected by Huntingdonshire District Council shows that the number of people with a disability participating in activities at local leisure facilities is increasing. The Cambridgeshire and Peterborough Ability Plus Group[7] has started work on a facility audit of all sports facilities in the county, with the primary aim to look at how accessible sports facilities are for people with disabilities; accessibility will be assessed using indicators such as building access, how staff deal with enquiries, the opportunities and provisions made to support people with disabilities to access day to day activities.

People with learning disabilities are less likely to access routine health promotion and screening activities, including vision checks, cervical screening and breast screening. (Emerson, et al., 2011). People with learning disabilities and their carers may have poor knowledge about healthy eating.

There is evidence that health checks for people with learning disabilities are effective for identifying unmet, unrecognised and potentially treatable health conditions. Health checks therefore represent a 'reasonable adjustment' in primary care services for people with learning disabilities.

In 2012, 75% of eligible adults with a learning disability, in Cambridgeshire, received a health check - significantly higher than the England average. All but three practices in Cambridgeshire provide health checks. Work has been done locally to produce materials for GPs to enhance the quality of health checks and work is on-going to increase the number of practices currently providing this service. However, there is a difference between the prevalence of people with learning disability known to Local Authorities and the prevalence of people with learning disability on GP practice lists in Cambridgeshire. This difference is significantly higher than the national average,

[6] Department of Health. Start Active, Stay Active: A Report on physical activity for health from the four home countries' Chief Medical Officers. 2011. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/152108/dh_128210.pdf.pdf

[7] The Cambridgeshire and Peterborough 'Ability Plus Group' promotes sport and active recreation for people with disabilities or additional needs. The group membership includes representatives from local authorities, governing bodies of sport, mainstream and special schools, sports colleges and local and national sporting organisations.

which suggests that we could do better in sharing information between social care and health http://www.improvinghealthandlives.org.uk/profiles/#select_area.

5.4.1.2 Acquired brain injury

The most common disability in adults receiving direct support from the adult physical disabilities social care team is Acquired Brain injury. Brain injury in England is common and can happen in a number of ways, eg, road traffic accidents, falls, fights etc. It has been estimated that 6.6% of those attending Accident and Emergency departments in any given year have a head injury and over 100,000 people are admitted as a consequence. Although a brain injury can affect all ages, those caused by road accidents, and the consequences of alcohol often impact disproportionately on the younger age groups.

5.4.1.3 Health conditions in people with learning disability

Important health conditions, more prevalent in people with learning disabilities include (Emerson, et al., 2012):

- Epilepsy – prevalence at least 20 times higher than the general population.
- Coronary heart disease – almost half of people with Down's syndrome have a congenital heart defect.
- Respiratory disease – a leading cause of death. People with asthma are more likely to be smokers.
- Endocrine disease – hypothyroidism is common in people with Down's syndrome. GP data suggests that people with learning disabilities may be more likely to have higher rates of Type 1 and 2 Diabetes.
- Physical impairments, osteoporosis, injuries and falls – with associated increase risk of death.
- Visual and hearing impairments.
- Chronic pain, sleep disorders and dementia – People with Down's syndrome are at particularly high risk of dementia, with age of onset 30-40 years younger than the general population.
- Mental ill health and challenging behaviour – Challenging behaviour (eg aggression, destruction, self-injury) occurs in 10-15% of people with learning disabilities.
- Poor oral health.
- Difficulties with eating, drinking and swallowing – which may affect 8% of adults known to learning disability services and have implications for health, safety and wellbeing.
- Gastro-oesophageal reflux and constipation.
- Issues related to women's health – women with learning disabilities may experience symptoms associated with menopause and menstruation differently. Adverse outcomes of pregnancy may be more frequent.

5.4.1.4 Life expectancy in people with a learning disability

People with learning disabilities have a shorter life expectancy than the general population.

A report that looked at the causes of death and age at death in people with learning disabilities, in the UK, between 2004-2008 (Glover & Ayub, 2010), found two preventable causes of death were particularly important:

- Lung problems resulting from solids going down the wrong way (14% of deaths where a learning disability was recorded).
- Epilepsy or convulsions (13% of deaths where a learning disability was recorded).

A confidential inquiry into the deaths of 247 people with learning disability, in the UK, (http://www.bris.ac.uk/cipold/) has recently been published. Some key findings from the report were:

> *"The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died."*
>
> *"As with the general population, the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively). The final event leading to death was most frequently a respiratory infection in the people with learning disabilities."*
>
> *"Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs."*
>
> *"People with learning disabilities had a considerable burden of ill-health at the time of their death. Key issues that appeared to be problematic were the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision."*

In addition, the review found a lack of understanding of the mental capacity act among health and social care professionals, deficiencies in record keeping, inappropriate orders not to resuscitate and poorly coordinated end of life care.

The review recommended the following low-cost and effective measures:

- Improved communication within and between agencies.
- A named health professional to coordinate care for individuals with multiple health conditions.

- Use of patient or carer-held health records.
- Proactive use of annual health checks in order to plan based on changing needs.
- The identification of advocates to help people with learning disabilities to access healthcare services.

Further recommendations related to the understanding among professionals of the mental capacity act, the appropriate use of orders not to resuscitate and the routine collection of data on the mortality of people with learning disabilities (Heslop, et al., 2013).

5.4.1.5 Sensory impairment

For information on the needs of blind and partially sighted people in Cambridgeshire, including prevention of visual loss, please refer to the JSNA for Prevention of Ill Health in Adults of Working Age. Available at: http://www.cambridgeshirejsna.org.uk/current-jsna-reports/prevention-ill-health-adults-working-age-2011.

Visual impairment is common in adults with a learning disability. Key health messages are shown below:

- People with learning disabilities are 10 times more likely to have serious sight problems than other people.
- People with severe or profound learning disabilities are most likely to have sight problems.
- People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people think the person with a learning disability they know can see perfectly well.
- Six in 10 people with learning disabilities need glasses and often need support to get used to them.
- People with learning disabilities need to have a sight test every two years, sometimes more often. Regular sight tests and wearing glasses helps people stay healthy and get the most from life.

Source: RNIB

For information on a review of services available to people with a hearing impairment (including health) see Section 5.7.4.4.

The Deaf Services Technical Officers in the Cambridgeshire Social Care team aim to assess and install appropriate alerting equipment in one visit wherever possible. 316 clients received this service in Cambridgeshire in 2011/12 – around 80% of people receiving equipment were over 60.

5.4.1.6 Autism

NICE guidance on autism in adults (NICE, 2012) states:

> *"Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication, and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities. People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances."*

People with autism are more likely to have coexisting physical and mental disorders and other developmental disorders. They are also at risk of experiencing delays in diagnosis and subsequent difficulties in accessing appropriate services.

5.4.1.7 Oral Health

The dental health of most people in the UK has improved dramatically during the past 50 years, due largely to the widespread use of fluoride toothpaste. However, individuals with disabilities generally experience more oral disease, and have fewer teeth than the general population. It has long been recognised that the poorest oral health is found among the socially disadvantaged (Locker, 2000). People with intellectual disabilities have been found to have poorer oral hygiene, more gum disease and more untreated tooth decay than the general population (Anders & Davis, 2010). They also have greater unmet dental needs (Waldman & Perlman, 2002), as they have more difficulty in accessing dental care (Glassman & Miller, 2003). Furthermore, when oral diseases are treated they are more likely to have resulted in extractions than fillings, crowns and bridges, particularly for those living in residential care (Gallagher & Fiske, 2006).

For a number of reasons, an increased risk of oral health problems is evident among people with special needs. Some congenital conditions and syndromes may adversely affect dental development and compromise oral health. When people's ability to care for themselves is reduced, their diet and exposure to fluoride may not be under their personal control.

5.4.2 Local views

During 2007, the Cambridgeshire Learning Disabilities Partnership Board and Speaking Up Council (Self- Advocacy organisation; now the 'Speak-out' council), sought the views and experiences of local people with learning disabilities, and their family carers regarding their experience of primary and acute care. Issues raised and comments made by participants of the consultation reflect the national picture. They provide a stark picture of what the experience is like in Camridgeshire. Locally reported issues include:

- Lack of easy read/accessible information.
- Poor attitude from some Health staff/Difficult to trust staff when needs were not understood/met.

- The views of carers and/or paid staff are often ignored, resulting in reports of ill-health, or symptoms incorrectly assumed to be the result of the disability.
- Insufficient available care 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 overnight.
- Appointments not long enough (due to complex needs).
- Inadequate disabled toilet facilities, preventing people moving in a 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.

The Speak-Out council has recently expressed a need for people with learning disabilities and their carers to be able to access clear information on healthy eating.

In 2011, an Adult Autism Development Project Report produced on behalf of Red to Green, surveyed the needs of 50 people on the autistic spectrum. It found several unmet needs, which were particularly acute amongst those who were not accessing social care services. These needs overlap a number of areas relevant to other chapters to this report, but as they are wider determinants of health, they are summarised in this section:

- Difficulties with identification and diagnosis of the condition.
- Lack of social integration including access to support groups.
- Lack of training amongst staff they came into contact with.
- Lack of practical life skills such as shopping, travelling, management of money and access to benefits.
- Few employment opportunities and a lack of support once in employment.
- Difficulties in accessing appropriate housing; conflict with parents for those still living at home and a lack of supported living opportunities.

A recent 2013 report, by Cambridgeshire self-advocacy group, Speak-Out Spectrum, summarised the situations of 13 people on the autistic spectrum. More than two thirds still lived with their parents; over half were in receipt of benefits and most wanted additional support with getting a job or with social skills.

5.4.3 Assets

5.4.3.1 Cambridgeshire physical activity and sport

London 2012 - the Olympic and Paralympic Games - were a huge success for Britain. Cambridgeshire hosted a variety of local activities, where the Paralympics was the motivational theme. One of the most successful projects was Cambridgeshire Competes - a partnership between museums and sports centres across Cambridgeshire and Peterborough, inspired by *London 2012*. An exhibition trail highlighted local sporting champions and the county's connections to the past and

present Olympic and Paralympic Games. Opportunities were provided to take part in a range of activities and the memories of athletes and spectators were collected to be stored in perpetuity within the Cambridgeshire Archives.

Cambridgeshire Paralympians

Jody Cundy MBE, born in Wisbech, won the bronze medal in C4 category 4km pursuit. "London was my fifth Paralympics Games and it was the best Paralympics I've ever been to, I've never known anything like it… London 2012 was an amazing spectacle of sport… It's the first time I've seen the Paralympics represented on such a massive scale… I was so glad to be a part of it and I hope from now on that that's now put Paralympics on the map"

Dominique Bizimania, President of Rwandan National Paralympic Committee, coaches and plays seated and standing volleyball. "We use sports to show that even people with a disability, they can represent Rwanda, they can be top athletes"

Georgina Bullen represented GB in goalball, a specially designed sport for blind and visually impaired athletes. "When I found out I was selected for the Paralympics, I was so excited, it felt amazing, it was kind of pretty surreal as well actually because something you've been focused on for so long and been hoping for, that when it actually happens you really have to pinch yourself.

Dan Gordon is Principal Lecturer of Exercise Physiology at Anglia Ruskin University, Cambridge and was on the national squad with British Cycling from 2003-2005. "..to be in the venues and to walk into the stadium behind the flag, you know, I can openly admit I had tears rolling down my face as I was walking in behind the flag. It was just… you just cannot explain the fact that, you walk in, there's a cacophony of sound, and yes, absolutely extraordinary feelings….And if you do the hard work and you persevere and everything falls into place….then you'll get the chance to do it"

The 'You Can' project enables people with learning disabilities to cycle (a physical activity chosen by people with learning disabilities). Find information about You Can! at: http://www.youcanbiketoo.org/ and: http://theyoucanhub.org.uk/.

As a case study for leisure services provided around the county, Huntingdonshire District Council delivers a range of disability-specific activities for juniors, families and adults, including:

- Active and Able Multi-Sports Clubs for Adults.
- School Holiday Activities for Juniors and Adults.
- Support for School Sports Partnership SPRINGBOARD programme.
- A Gym Buddy scheme across the One Leisure sites where volunteers have been trained to assist disabled users.
- The lottery funded programme, Delivering Activity and Sport in Huntingdonshire (DASH), delivers sport and play sessions to various care settings in the district. Participants are from a range of disability classifications, with the majority on the autistic spectrum or have a learning disability.

5.4.4 Evidence and best practice

In addition to the recommendations made by the confidential inquiry into premature deaths of people with learning disabilities (see section 5.4.1.4), the following key areas have been recommended for reducing inequalities in health, experienced by people with learning disabilities (Emerson, et al., 2011):

- Reducing the exposure of people with learning disabilities to common social determinants of (poorer) health, such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.
- Improving the early identification of illness among people with learning disabilities by, for example, increasing uptake of annual health checks, and for women, cervical and breast screening. Knowledge of the health risks associated with specific syndromes is of value in targeting the content of health checks.
- Enhancing the health literacy of people with learning disabilities and of family carers and paid carers/supporters who play a critical role in promoting healthy lifestyles among many people with learning disabilities.
- Enhancing healthcare workers' knowledge and improving their skills for working with people with learning disabilities.
- Making 'reasonable adjustments' in all areas of health promotion and healthcare in light of the specific needs of people with learning disabilities and acting within the legal framework of the Mental Capacity Act 2005 (eg, through providing more accessible information and longer appointment times).
- Monitoring progress towards the elimination of health inequalities faced by people with learning disabilities.

An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs) to improve the health and wellbeing of people with learning disabilities is available at http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups. It includes links to key resources, including improving accessibility to healthcare, health check good practice guidance and good practice/pathway examples.

National Institute for Health and Clinical Excellence (NICE) guidance on epilepsy make clear that people with learning disability should be offered the same services, investigations and therapies as the general population. Available at: http://guidance.nice.org.uk/CG137

NICE guidance on adults with autism is available at: http://guidance.nice.org.uk/CG142/. The guidance includes recommendations on the membership and responsibilities of local multi-agency autism strategy groups, including managing and evaluating local care pathways.

Guidance on the management of adults with learning disability who have dysphagia is available at: www.nrls.npsa.nhs.uk/resources/?EntryId45=59823

An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs) to improve the health and wellbeing of people with learning disabilities, is available at: http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups. It includes links to key resources including on improving accessibility to healthcare, health check good practice guidance and good practice/pathway examples.

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Guidance on the management of adults with learning disability who have dysphagia is available at: www.nrls.npsa.nhs.uk/resources/?EntryId45=59823.

Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities is a joint report by the Improving Health and Lives Learning Disabilities Observatory and SeeAbility that brings together a number of examples of reasonable adjustments that can be used to make eye care services more accessible for people with learning disabilities. http://www.improvinghealthandlives.org.uk/publications/1167/Making_Reasonable_Adjustments_to_Eye_Care_Services_for_People_with_Learning_Disabilities

NICE have produced guidance (CG85) and quality standards on the diagnosis and management of chronic open angle glaucoma (COAG) and of ocular hypertension, which includes the monitoring of appointments and keeping a register of patients (National Institute for Health and Clinical Excellence, 2009). There is also a NICE commissioning guidance (CMG44) for services for people at risk of developing glaucoma. http://www.nice.org.uk/usingguidance/commissioningguides/glaucoma/glaucoma.jsp and http://www.nice.org.uk/guidance/qualitystandards/glaucoma/Home.jsp

5.5 Accommodation and Housing

5.5.1 Figures and trends

5.5.1.1 Physical and visual impairment

Generally, individuals of a working age with a physical disability or adults/older people with a sensory impairment tend to live in mainstream accommodation in the community. A proportion of those with more profound needs or multiple disabilities are supported by the PD and sensory teams in specialist accommodation. Of those supported by the PD team, February 2013, 65 are in residential homes, 38 are in nursing homes, and 27 have their 24-hour care needs met in their own accommodation.

Disabled Facilities Grants (DFGs) are available through Home Improvement agencies/ district councils following an occupational therapy assessment to make necessary adaptations to their homes to enable disabled people to remain in the community.

It has been recognised that some people do need specialist support in the community and the acquired brain injury project is aiming to meet the needs of some of those known to the team with a brain injury, by providing skilled staff and appropriate accommodation. A need has been identified for an additional transitions/move-on unit in the south of the county, to assist people to relearn skills in a supported environment, with the aim of moving into their own tenancies, in the general community.

5.5.1.2 Learning disability

Access to housing and support is one of the priority areas in *Valuing People Now* (Department of Health 2008). Generally, people with learning disabilities are more likely to live in poor quality housing, are less likely to be home owners and often have to share their living space with others. They are also likely to live in housing that is not well adapted to needs arising from their physical disability or sensory impairment.

In Cambridgeshire, 72% of people with learning disabilities known to social care (CCC), are in settled accommodation which is above the county's comparator group (64.1%) and also above England's average (69.9%).

Table 5.16: Numbers of adults with Learning Disability known to Cambridgeshire County Council living in Settled or Unsettled accommodation

Learning disabled people known to the council (aged 18-64) by accommodation category	2009/10	2010/11	2011/12
Total non-settled	**310**	**300**	**330**
Rough sleeper/Squatting	0	0	0
Night shelter/emergency hostel/direct access hostel	5	0	0
Refuge	0	0	0
Placed in temporary accommodation by Local Authority	0	0	0
Staying with family/friends as a short-term guest	0	0	0
Acute/long stay healthcare residential facility or hospital	10	10	10
Registered Care Home	255	275	295
Registered Nursing Home	10	5	10
Prison/Young Offenders Institution/Detention Centre	0	0	0
Other temporary accommodation	30	5	10

Total settled accommodation	**945**	**1,025**	**1,175**
Owner Occupier/Shared ownership scheme	**15**	**5**	**10**
Tenant - Local Authority/Arms Length Management Organisation/Registered Social Landlord/Housing Association	**235**	**260**	**325**
Tenant - Private Landlord	**20**	**30**	**35**
Settled mainstream housing with family/friends	**400**	**485**	**540**
Supported accommodation/Supported lodgings/Supported group home	**250**	**225**	**240**
Adult placement scheme	**15**	**15**	**15**
Approved premises for offenders released from prison or under probation supervision	**0**	**0**	**0**
Sheltered Housing/Extra care sheltered housing/Other sheltered housing	**15**	**10**	**5**
Mobile accommodation for Gypsy/Roma and Traveller community	**0**	**0**	**0**
Total number of Learning Disabled people (aged 18-64) known to the council within the period	**945**	**1,025**	**1,175**

Source: Cambridgeshire County Council: numbers rounded to a base of five.

There are still just over a quarter (28%) of people with learning disabilities known to social care currently living in 'unsettled' accommodation, primarily residential care but also including people in temporary accommodation. Current demand for both housing and support outstrips available resources. The high cost of property in Cambridgeshire, especially in Cambridge City and South Cambridgeshire, makes it difficult for people in low incomes to exercise choice about where they live.

A recent report found that Cambridgeshire is spending higher amounts on social care per person than other similar authorities. This is particularly the case in housing where Cambridgeshire has a fairly high proportion of high cost cases. For example, the gross cost of support for 30% of 409 residential/nursing placements is more than £1500 per week. One of the main reasons for this is the high proportion of service users living in out-of-county, residential care, whose needs may be complex and where there may be less control over costs. The report also found that many people were living in residential care and 24-hour supported living schemes, when they did not necessarily need that level of support. It proposed a more dynamic approach to housing services, where people should be encouraged to progress to more independent living.

The recent Winterbourne concordat has placed a duty on Clinical Commissioning Groups to review out-of-county hospital placements, with a view to bringing people back into the county in more local, community-based services. In Cambridgeshire, as lead commissioner, the local authority is required under the concordat to review the care of all people with learning disability or autism, occupying inpatient beds, and to agree a personal care plan for each individual, based on their and their families' needs and agreed outcomes as soon as possible, to enable community-based care arrangements to be put in place wherever appropriate.

Those with a learning disability, who are not eligible for social care, may be able to access floating support, which provides visiting support to people in their own homes.

5.5.2 Local views

Results from both national evidence and local consultation show 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.

5.5.3 Assets

Adult placement scheme

- There is a successful Adult Placement Scheme in Huntingdonshire that places people with learning disabilities in families where they are cared for and supported within a family environment.

In-house services changing to supported living

- Some of the residential care services provided by the Learning Disability Partnership are changing to supported living, which offers a greater degree of independence and security to residents.

Respite care for family carers

- Family carer's of people with learning disabilities can access high-quality respite services provided by the Learning Disability Partnership. This enables family carer's to have a short break from caring, in the knowledge that their 'cared-for' adult is well looked after.

Out-of-county project

- A project is currently in place to review 'out-of-county' placements, starting with some of the most expensive placements. This exercise is being conducted by a project team led by the Contract and Negotiation Manager in the Learning Disability Partnership, and includes a team manager, two care managers, two community nurses, a psychologist and a psychiatrist.

Winterbourne Action Plan

- The Cambridgeshire Learning Disability Partnership has developed an action plan to implement the concordat agreed following the investigation of abuse of people with learning disabilities at Winterbourne View hospital in Bristol. This includes keeping a register of placements, reviewing the care of everyone on the register by June 2013 and developing services to enable people to return to local community- based services in Cambridgeshire by 2014. It also developed an out-of-county policy statement, describing the circumstances in which people will be enabled to return.

Assistive Technology/Telecare

- Assistive Technology, Telecare and Telehealth supports people to remain independent in their own homes while reducing avoidable admissions to hospital and residential care.

5.6 Employment

5.6.1 Figures and trends

- Nationally, 3.2 million disabled people are in work; 11.5% of all employed people are disabled; only 9% of working-age people have never worked; 55% of disabled people play an active role in civic society, by formal volunteering, civic activism, civic participation and civic consultation (Department for Work and Pensions, 2013).

- National data highlights an approximate 30 percentage point gap between the number of non-disabled and disabled people in employment - a gap that has remained stable for the last two years. Whether a person with a disability is in employment also varies widely according to educational qualifications and the level of difficulty, frequency of limitation, number and type of impairments. Employment rates are particularly low for people with certain impairments, eg, those with learning disabilities or a mental health condition. Disabled people are also more likely to work part-time and earn less per hour (Department for Work and Pensions, 2013).

- Adults with an impairment reported that the most common barrier to work is their health condition, illness or impairment. Other barriers are family responsibilities, and a lack of job opportunities or qualifications/experience/skills (Department for Work and Pensions, 2013).

- There is some evidence that employment can enhance the quality of life of people with learning disabilities and that loss of supported employment can have negative effects on health (Emerson, et al., 2011).

- A significant number of people in the working age group, 40-65, will find their hearing deteriorate, which is commonly difficult to acknowledge or manage. Equality and diversity policies focus on the more extreme cases, with less attention given to the much more prevalent problems of people with partial hearing. This will become increasingly common as people are expected to work longer. Some may fail to reach their potential or be excluded from job opportunities (CAMTAD, 2012).

As most people who are known to the Cambridgeshire County Council Physical Disabilities team have an acquired disability or impairment, the majority have had the experience of mainstream education and employment. Where health and employment opportunities permit, individuals can be supported to remain in work, or gain employment through the flexibility of direct payments and the Access-to-Work Scheme can assist those people in employment (including self-employment) meeting the necessary criteria. Unfortunately not many people who have reached eligibility for Adult Social Care support and are known to the team are in employment and in Cambridgeshire the Physical Disabilities Team are only supporting a limited number of individuals in employment or education.

Of the 1570 adults of working age with learning disabilities known to Cambridgeshire County Council, in 2011-12, only about 95 (6%) were in paid employment and 75 (about 5%) were doing unpaid voluntary work (CCC). This is part of a downward trend over the past few years, possibly as a result of the economic recession.

Table 5.17: Number of working age (18-64) learning disabled clients known to Cambridgeshire County Council by employment status, gathered or confirmed during the financial year

	2009/10			2010/11			2011/12		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Working as a paid employee or self-employed (30 or more hours per week)	5	5	10	10	0	10	10	0	10
Working as a paid employee or self-employed (16 to less than 30 hours per week)	5	10	15	10	5	15	10	5	15
Working as a paid employee or self-employed (4 to less than 16 hours per week)	25	25	50	30	20	50	30	20	50
Working as a paid employee or self-employed (more than 0 to less than 4 hours per week)	15	20	35	10	10	20	10	5	15
Working regularly as a paid employee or self-employed but less than weekly	0	0	5	0	0	0	0	0	5
Voluntary work (unpaid) and paid employee or self-employed	0	0	0	0	0	5	0	0	0
Voluntary work (unpaid) only	50	40	95	50	30	80	45	25	75
Total	815	645	1460	890	685	1580	900	670	1570

Source: Cambridgeshire County Council: Numbers rounded to a base of five.

Lower paid employment means that people with learning disabilities generally experience lower incomes than most of the population, and miss out on the other benefits of work such as improved health and wellbeing and greater opportunities for social interaction. In Cambridgeshire people with learning disabilities often go out-of-county as children, for educational purposes, and then stay there as adults. This may have an impact on employment figures within the county.

5.6.2 Local views

Cambridgeshire is generally regarded as a relatively prosperous county with higher levels of employment than neighbouring counties. However, this prosperity tends to be located in pockets, such as Cambridge City, and as it is largely a rural county people have to travel quite long distances in order to get to work. Recent cutbacks to public transport services have impacted disproportionately on people with learning disabilities who are less likely to have access to a car. As disabled bus passes can only be used after 9.30am, this financially disadvantages people who are in lower paid or part-time jobs due to the additional expenditure.

Where work is safe and accommodating, it is generally good for physical and mental health and wellbeing. At a recent meeting of the Cambridgeshire Speak-Out Council, participants identified that work was important for social relationships

5.6.3 Assets

Some large private sector employers are positive about employing people with disabilities. Cambridge itself is home to several large public sector organisations that are well placed to employ more people with disabilities. In addition, an Adult Placement Scheme in Huntingdonshire, which is part of the Learning Disability Partnership, has been successful in supporting people with learning disabilities into employment and this is reflected in a higher percentage (11%) of this group being employed compared to the county average. The modernisation of day services in the county and a renewed focus on supporting people to take part in more meaningful day- time activities has provided the opportunity to support more people into both paid and voluntary work. Some providers of social care and advocacy services in the county are also directly employing people with learning disabilities.

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

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

These could be encouraged to work with groups of people who are the most marginalised, for example those who are on the autistic spectrum or have other complex needs.

5.6.4 Evidence and best practice

The success of the Adult Placement scheme indicates that this may offer an opportunity to improve the employment prospects of people with learning disabilities through the expansion of the scheme beyond Huntingdonshire. Other opportunities may arise through the modernisation of day services and also by encouraging both public and private sector employers, as well as those funded by the county council to employ more people with learning disabilities.

National surveys of people with disability report that enablers can play an important part in helping disabled people stay in work. These include:

- Modified hours.
- Building modifications for people with mobility or dexterity impairments.
- A job coach or personal assistant for people with a mental health condition.
- Flexible working.
- Work-focused healthcare.

Evidence considered by the Department for Work and Pensions (2013) points towards a focus on work capacity rather than disability, a range of employment-related support and work-based learning or experience.

5.7 Choice, service access and delivery

5.7.1 Accessing health care

5.7.1.1 Evidence from the Life Opportunities Survey

Evidence from the Life Opportunities Survey shows that in the UK, adults with moderate to severe impairments are more likely than non-disabled adults to experience difficulties in accessing health services, including accessing GP surgeries. Experienced barriers Include:

- Difficulty in getting an appointment.
- Anxiety/ lack of confidence.
- Not providing a home visit.
- Lack of help with communication (particularly for those from minority groups).
- Transport.
- Difficulty in getting in and out of the building.
- Difficulty in using facilities.

There is also evidence that people find health and social care systems to be fragmented and often have to explain their needs to multiple people or organisations. (Department for Work and Pensions, 2013)

5.7.1.2 Preventable hospital admissions in people with Learning disability

A national study of hospital admission data (Glover & Evison, 2013) investigated whether adults, given a diagnosis related to learning disability, differed compared to adults without any such diagnosis with regard to:

- The number of admissions.
- The associated bed use.
- Whether the cause of admission was potentially avoidable (ie the admission was for an 'ambulatory care sensitive condition (ACSC)' – one which given 'effective management' at the primary care level, should not normally result in an admission to hospital).

The key findings were:

- People in the learning disabilities group were 25%more likely than other people to be admitted to hospital as an emergency and 70% more likely to be admitted as an emergency for an ACSC.
- Emergency admissions for ACSCs were, on average, much longer than elective admissions for other causes.
- Admissions for the learning disabilities group were spread more evenly across the adult age spectrum; other adults tended to be admitted more frequently at older ages.
- Convulsions and epilepsy accounted for more than 40% of all emergency admissions for ACSCs for people with learning disabilities.
- Other ACSCs which led to higher proportions of emergency admissions for people in the learning disabilities group were constipation, complications of diabetes and influenza/pneumonia.

Data on changes in admission patterns over time were difficult to interpret because of the possibility of a change in the way information is entered, however, these data suggested that the inequity between those with learning disabilities and those without was increasing.

The report points to an opportunity to improve primary care services for people with learning disabilities, particularly with regard to medication review for people with epilepsy. A key conclusion was the need for GPs and community learning disabilities teams to collaborate in developing a local register of people with learning disabilities, identifying their NHS numbers, age and gender. This would permit better monitoring of admission patterns at a local level and help to ensure that secondary care services become aware of people with learning disabilities in their care. Further recommendations point to the introduction of routine Emergency ACSC notification procedures on discharge of a patient with learning disabilities to advise the GP and the community learning disabilities team that the person had been discharged with a condition suggestive of a requirement for review of their Health Action Plan

Information on potentially unnecessary admission rates for Cambridgeshire suggests that these rates are no different from the England average, with emergency admissions as a proportion of the total admissions being similar. However, whilst

unnecessary admission rates for psychiatric conditions were lower than the England average, Cambridgeshire was significantly poorer at identifying people with learning disability in information held about psychiatric admissions. See http://www.improvinghealthandlives.org.uk/profiles/#select_area. Being able to identify when people with learning disability are admitted into hospital is important to ensure that reasonable adjustments are made and that doctors and nurses take learning disability into account in assessing symptoms and progress. In Cambridgeshire, Addenbrookes and Hinchingbrooke hospital have specialist nurses who identify when someone with a learning disability is coming into hospital and gives advice on necessary adjustments.

5.7.1.3 Services for Physical disability

Many people with a physical disability require physiotherapy, occupational therapy and speech therapy. A cornerstone of services' responses to the problem of disability is the provision of quality rehabilitation services. Rehabilitation aims to increase independence and improve quality of life, therefore potentially reducing need for social care.

Rehabilitation services have a number of functions. Firstly, they must undertake a full assessment of the disabled person, ideally in their own home or other place of residence. This will enable functional capacity to be assessed and the scope for restoration of lost functions and acquisition of new skills to be identified. It will also identify the need for special equipment to be supplied or for adaptation to the person's day-to-day living environment. Secondly, rehabilitation services will set out to establish a clear care plan, agreed with the person concerned and their carers (if any). Thirdly, the service will implement measures and services to deliver the care plan. The circumstances vary greatly. In some cases, rehabilitation will begin following an acute hospital admission; for example, a stroke or traumatic injury. In other cases, rehabilitation services will be offered to those who have never previously had help of this sort, eg, those with a long-standing problem, such as multiple sclerosis.

It is important to recognise that people with disabilities often have long term care needs which will continue to benefit from rehabilitation services and the notion of rehabilitation as a single course of therapy is increasingly outmoded. Consequently rehabilitation services will not exclusively be provided on a hospital site, but will be delivered on a community basis. Local rehabilitation teams are multi-professional, using skills such as physiotherapy, occupational and speech therapy, in addition to those of medicine and nursing.

Specialist services are also required for the rehabilitation of people with acute traumatic injury of the spinal cord and people who have sustained head injuries. In Cambridgeshire, people who have sustained head injuries can receive assessment and rehabilitation from a number of providers, depending on need. For example, The Oliver Zangwill Centre for Neuropsychological Rehabilitation (http://www.ozc.nhs.uk/default.asp?id=).

Many disabled people require specialist medical, surgical and nursing treatment to deal with locomotor and bladder problems.

Specialist services can include the following:

- Disabled living centres
- Continence services
- Stoma care services
- Pressure sore services
- Counselling services
- Driving assessment services
- Prosthetics and orthotics
- Wheelchair and special seating services
- Communication aids
- Technical aids and medical physics services
- Aids for sensory disabilities.

5.7.1.4 Dental Services

Physical access to dental services is a major barrier for a large number of people with learning disabilities (Finger & Jedrychowski, 1989). There may also be significant costs in terms of physical effort, emotional effort and financial outlay, to gain access to oral care (Griffiths, 2000). The majority of children and adults with physical and learning disabilities are able to access routine dental care via the General Dental Services in the normal way. However, CCS offers specialist dental services for people with particular needs.

The branch of dentistry concerned with adults and children with additional needs is the specialism of special care dentistry. This Service delivers specialised treatment, often completed under sedation or general anaesthesia. CCS Dental Service sees in excess of 7,000 patient contacts per year, across Cambridgeshire. Referrals are accepted from a wide range of care professionals. Community Dental Clinics at Cambridge, Ely and Huntingdon have wheelchair reclining facilities to enable physically disabled patients to be treated within their own chairs.

Additionally, the Oral Health Promotion (OHP) Team work within the local community, eg, in homes and day centres, to deliver oral health education to disadvantaged groups. Clinics use easy-read materials, such as appointment letters, patient leaflets and explanatory picture books, to support and engage service users and encourage self-empowerment. CCS NHS Trust Dental Service's Brookfields Clinic in Cambridge, recently received 'The Way To Be' award from Cambridge City Council, for improving access and attitudes to disability. The Service was nominated by an anonymous user who particularly recognised the specialised chair that tilts wheelchair users into a reclined position for dental treatment, and the disabled toilet.

5.7.2 Self-directed Support

Self-directed support is an initiative introduced following the 'Putting People First' concordat, in December 2007. It aims to allow people to direct their own support through individual budgets and direct payments, so people eligible for care are in control over how that care is provided. The national target is for 70% of all service users in the community to be on self-directed support, by April 2013.

For all Adult Social Care services Cambridgeshire promotes the personalisation agenda, and of giving people the choice and control over their lives wherever possible. Eligible needs are met as flexibly as possible. Table 5.18 shows a reduction in the use of more traditional forms of support, such as day care and an increase in the use of assistive technology, enabling more independent living. These changes have considerable implications for the care market, with purchasers of care looking for more innovative and less traditional care services, as well as greater access to other more universal services as described above.

Table 5.18: Packages of care provided by social care services by year, Cambridgeshire 2009/10 to 2011/12

Package of care	2009/10	2010/11	2011/12
Physical Disability Total number of service users, of which:	2235	2035	2025
Home Care	495	465	470
Day Care	155	110	90
Meals	15	10	5
Short Term Residential - not respite	10	15	25
Direct Payments	485	465	385
Professional Support	760	570	475
Equipment & Adaptations	1235	1240	1295
Other Community-Based Services	60	50	50
Learning Disability Total number of service users, of which:	1110	1170	1215
Home Care	550	475	525
Day Care	550	520	500
Meals	0	0	0
Short Term Residential - not respite	20	30	35
Direct Payments	435	645	370
Professional Support	330	270	230
Equipment & Adaptations	130	155	175
Other Community-Based Services	115	205	240

Source: Cambridgeshire County Council – Numbers rounded to a base of five

As well as giving more control over the provision of care, directing one's own support allows the potential to access a wider range of services in the community. These can include libraries, leisure centres, cinemas, theatres and a whole host of other facilities which offer inclusion, improve health and wellbeing and give access to more varied social contact. Promoting access to these services in the community also helps others with a disability but who may not be eligible for social care.

Self-directed support, choice and independence can also be beneficial in terms of enabling people to develop personal relationships. More people with learning disabilities are choosing to have children and becoming parents and consequently may need appropriate support to enable them to fulfil their parental role.

Cambridgeshire has built on its past reputation as a leading authority in the introduction of self-directed support and direct payments, by offering them as widely as possible. Preparation for the introduction of integrated care, support and education plans and the existence of a pooled health and social care budget also puts Cambridgeshire in a good position to implement personal health budgets, which combined with self-directed support will increase individual choice even further

5.7.3 Assistive technology

Standard 7 of the National Service Framework for people with long term conditions (2005)[8] highlights the use and importance of assistive technology for people with long-term neurological conditions. There is evidence that providing up-to-date and appropriate assistive technology/equipment, and home adaptations can help people to live with their condition, and promote social inclusion and independence. The Cambridgeshire Assistive technology strategy: Shaping *our* Future: Assistive technology strategy, 2012 – 2014, sets out the commissioning intentions for 2012-2014, relating to the development and provision of all aspects of Assistive Technology (AT) to the people of Cambridgeshire.

Table 5.18 shows that the use of assistive technology (equipment and adaptions) by people known to adult social care is increasing. More information on Assistive technology is available in the Prevention of ill health in older people JSNA 2013 – Housing Chapter.[9]

5.7.4 Services planning in Partnership

5.7.4.1 Learning Disability Partnership

The Cambridgeshire Learning Disability Partnership (LDP) Board has a broad oversight of the services the Learning Disability Partnership provides or commissions. Membership includes service users, carers and representatives from voluntary and independent organisations.

5.7.4.2 Physical Disabilities Partnership

Involving individuals in their support plans and decisions about their life is fundamental to adult social care. Additionally, service users, carers and other Disability Groups are engaged in assisting the work that the service offers, by being critical friends and promoting change. The board for physical disabilities and sensory impairment ceased to function some time ago and as per the commissioning strategy work is underway with the Cambridgeshire Alliance to restart this vital partner role.

5.7.4.3 Autism Consortium

Cambridgeshire County Council set up the Autism Consortium in 2010. This is a county-wide strategic group which aims to improve the life experience of people on the autistic spectrum in Cambridgeshire. It aims to address many of the issues that are important to local people, such as how to get diagnosed; how to get involved in improving services; how to have greater choice and control; how to have better dealings with the criminal justice system, and how to get better access to health, housing and employment.

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8 http://webarchive.nationalarchives.gov.uk/20130107105354/
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4105369.pdf

9 http://www.cambridgeshirejsna.org.uk/

The work of the consortium has included:

- Establishing a sustainable diagnostic clinic.
- Creating a diagnostic pathway.
- Creating a non-diagnostic, mainly social care pathway for those who have been diagnosed or await diagnosis.
- Increased awareness of autism amongst health and social care staff and the wider public and private sector by having a series of awareness days.
- Involving people with autism and family carers.
- Ensuring health and social care data fields include autism.
- Establishing a project to collect information from GP's, about people on the spectrum who are known to them.
- Developing a 'centre for excellence' in Cambridgeshire called 'The Gatehouse' to house the diagnostic clinic and provide additional support for people with autism and family carers. It is being developed as an area 'hub' which can provide a focus for many of the services that people need access to, as well potentially collecting valuable data on the needs of people on the spectrum and the effectiveness of particular services on achieving beneficial outcomes. It is planned to provide on-site support for people on the spectrum and their carer's as well as a 'signposting' function for additional services.
- It is important to assist people to gain access to universal services and the consortium is carrying out work to enable access to mainstream health, employment and housing.

5.7.4.4 Cambridgeshire Deaf Partnership

In late 2011, the Cambridgeshire Deaf Partnership was established to give local deaf service providers a forum for discussing their work and exploring the potential for closer partnership working. The group is currently comprised of Cambridgeshire Deaf Association (CDA), Cambridge Campaign for Tackling Acquired Deafness (CAMTAD), Cam Sight (comprising the Supporting Deaf People Project (SDPP)), Our Voice (OV) and representatives from Cambridgeshire County Council (CCC). A mapping exercise of all services provided to deaf people in Cambridgeshire has been carried out, through interviews with key stakeholder organisations, in order to identify gaps and overlaps in service provision. No overlapping services were found. The key findings were:

- Key gaps and opportunities for joint working:
    - Campaigning on the issues of deaf people's rights and needs, as well as an understanding of deafness.
    - Awareness-raising and publicity of the services already available. Nationally, it is thought that people take an average of ten years from onset of hearing loss to take action. Action on hearing loss statistics show that 45% of GPs fail to refer people when they first present with a reduction in hearing.
    - Targeted support for the 18-35 age range, who rarely access existing services, but may experience difficulty as they transition into University, further education or the workplace or those who feel socially isolated.
    - Targeted support for deaf people in the workplace.

- Tackling rural isolation.
- Services that build confidence and offer social opportunities.
- Access to mental health services, emotional support for those newly diagnosed and their families, appropriate and accessible therapies.
- Our Voice provides specialist advocacy to all deaf people, but is about to close. This will create a serious gap within services for deaf people in Cambridgeshire.
- This document will now provide a basis for future discussion and service development both within the Cambridgeshire Deaf Partnership and with external partners.

- Specsavers, Addenbrookes and Hinchingbrooke NHS hospital audiology services and CAMTAD, have formed a unique partnership called the Cambridgeshire Adult Hearing Service, which brought together public, private and voluntary sector organisations to allow easy access to services across a wide geographical area, aimed at people aged 50 and above who have non-complex hearing impairments. The Emmeline Centre is a nationwide centre of excellence in hearing implants, and Cambridge is also fortunate to have one of four nationwide outreach teams for the National Deaf Child and Adolescent Mental Health Service based there.

5.7.4.5 Cambridgeshire Vision Partnership

Cambridgeshire Vision Partnership is a multi-agency partnership that aims to develop a Cambridgeshire Vision Strategy and Action Plan in line with the aims of the UK Vision Strategy. Further aims are to promote a fair service across the county and to lead the planning and development of high quality, partnership-focussed and locally led eye health and sight loss support services that are centred on the needs of the individual.

5.8 Safety and relationships

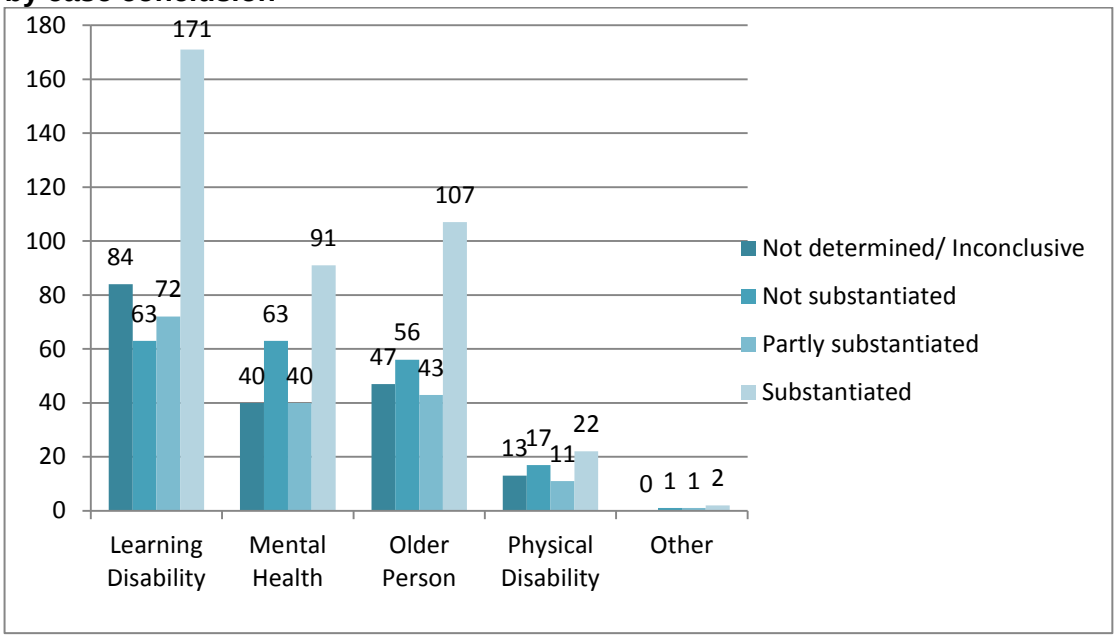
5.8.1 Safeguarding Vulnerable Adults

A vulnerable adult is defined as ‘A person aged 18 years or over, who is in receipt of or may be in need of community care services, by reason of mental or other disability, age or illness and who is unable to take care of him or herself or unable to protect him or herself from significant harm or exploitation.’

In 2011-12, most cases of alleged abuse were for adults with learning disability and most abuse occurred in the adults’ own home. There was an increase in safeguarding referrals for adults with learning disability compared with the previous year, which is thought to reflect good practice in the community.

Figure 5.3 shows the number of cases of alleged abuse in 2010/11.

Figure 5.3: Cases of alleged abuse reported between April 2010 and March 2011 by case conclusion



Source: Cambridgeshire County Council

5.8.2 Relationships and parenthood

The majority of individuals known to the Physical Disabilities Team acquired their disability in later life. Others, however, have a lifelong disability, or suffered traumas, such as road accident-related head injury, or developed illness in their thirties or forties, for example, multiple sclerosis, and therefore may have a family with children.

The Guidance for Enabling Disabled Parents to Fulfil Parenting Roles, jointly developed between Adults and Children's services, sets out guidelines for supporting parents in their parenting role as well as clarifying the roles and responsibilities for the teams where both children's and adult services are involved.

The policy aims to ensure that parents with disabilities or substantial illnesses, and their children have:

- A right to family life.
- Access to appropriate support, based on assessed need.

One of the major challenges of hearing impairment is the loss of intimacy, as people can no longer hear the sound of a whisper or quietly expressed conversation. Many people with hearing loss will say that the most difficult situations they have to cope with involve close family members and friends. The loss of intimacy is experienced by all people in the relationship or social group but it is viewed as the 'problem' of the person with the hearing loss. Hearing loss can be a significant factor in relationship breakdown, but because it isn't always acknowledged by the parties to the relationship, it can remain a persistent, tacit cause of family stress.

Conversely, it is known that people manage their hearing loss better if it is treated as a family issue.

Adults with learning disabilities surveyed by the Cambridgeshire Speak-Out Council said that they would like to make friends and have a boyfriend or girlfriend. In the survey only half of adults with learning disability knew where to access sexual health

services and less than half had received training on appropriate relationships. Work led by Cambridgeshire County Council public health team has started on identifying the sexual health needs of high risk groups.

5.9 Transition to Older People's Services

As people with learning disabilities are living longer, there are greater numbers transferring to older people's services, which happens when they reach 65 years of age. This can cause difficulties if older people's services lack the specialist skills or knowledge to care for people whose primary need may still be a learning disability. The Learning Disability Partnership has agreed a transition process to help smooth the path into older people's services.

Growing numbers of people experience a mid-life transition when their parents or family carer's who they have lived with since childhood become too ill to care for them or they die. As they have been cared for within the family, this group may not be known to social care and therefore, their housing and other circumstances may also not be known. This results in a 'hidden' demand for housing and other services that may place significant pressure on social care services in future.

A protocol exists between the Disability Service and the older people's teams, relating to the transfer of case responsibility, when the individual reaches 65. The relevant finance officer for each service provides annual information to their counterpart in the older people's services on individuals, aged between 60 and 64, who are known to the teams.

However, individuals with physical disabilities aren't necessarily known to the service so far in advance, and they may only become ill or disabled and be referred for support in the months prior to their 65th birthday. Additionally, the protocol sets out the requirement for a joint review of the individual and their support plan before they transfer across to the older people's teams.

5.10 What is this telling us?

5.10.1 What are the key inequalities

- People with disabilities are more likely than non-disabled people to live in poverty, and developing an impairment is strongly linked to being poor, out-of-work, or having low educational qualifications. The age of onset of disability can be important in determining experiences.

- Generally, people with learning disabilities are more vulnerable and more at risk of being marginalised than the general population. They are more likely to:

    - Be socially excluded.
    - Have poorer physical and mental health.
    - Have difficulties in accessing healthcare.
    - 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.

- Many people with disabilities experience a range of impairments and are less likely to access cultural, leisure or sporting activities (actual participation in physical activity is hard to measure.

- People with learning disabilities are less likely to access routine health promotion and screening and may have poor knowledge of healthy eating.

- Many health conditions are more common in people with learning disability, including epilepsy, swallowing difficulties, poor oral health and challenging behaviour.

- People with learning disability have a shorter life expectancy than the general population and a recent confidential enquiry suggests that nearly half of these deaths are premature.

- There is evidence that people with learning disabilities are more likely to be admitted to hospital unnecessarily.

5.10.2 What are the key trends?

The number of working age adults with physical, sensory and learning disabilities is predicted to increase, as is the number of older people with sensory and learning disabilities. The age distribution of people with a learning disability is predicted to change so that a greater proportion of adults with a learning disability will be over 55. Growing numbers of people with learning disability will experience a transition later in life when elderly parents die or become too frail to care for them. Social care requirements for people with learning disabilities are expected to increase by 14% to 2030. Life expectancy in people with mild learning disabilities and Down's syndrome is increasing.

5.10.3 What are the gaps in knowledge/services?

Within adult social care (physical and sensory):

- Delayed discharges from hospital have been identified as a result of delays in care packages being set up at home (this affects both adults and older people). However, it is not currently possible (using current data systems) to identify whether these individuals required re-ablement or support from the physical disabilities service, it is necessary to be able to identify this in order to understand the reason for the delay.
- Supporting those with the most complex needs requires joint working across sensory, learning disabilities, older peoples and complex care teams.
- Accommodation for a Transitions/Move on Unit is required to help those with an acquired brain injury or other disability where they need more support in their tenancy and the community to enable them to move on to more independence.
- A mapping exercise identified Key gaps in the provision of services available for people with hearing loss.
- There will be a need to ensure good and timely community provision for adults with learning disability in out-of-county in-patient settings reviewed as per the Winterbourne view concordat.
- Key to improving the health and wellbeing of people with learning disabilities is the ability for services to share information. This facilitates, for example, the

delivery of the evidence-based GP Health Check. In their report on unnecessary hospital admissions, the Improving Health and Lives: Learning Disabilities Observatory recommended:

> *GPs and community learning disabilities teams should collaborate in developing a local register of people with learning disabilities, identifying their NHS numbers, age and gender. This should be done on the basis of requesting explicit consent from subjects and carers, and 'best interests' agreements where the individuals concerned are not able to understand. At a local level, this would permit proper epidemiological monitoring of condition-specific admission patterns.*

5.10.4 References

Acs, G., Lodolini, G., Kaminsky, S. & Cisneros, G., 1992. Effect of nursing caries on body weight in a pediatric population. *Pediatr Dent,* Volume 14, p. 302–305..

Anders, P. & Davis, E., 2010. Oral health of patients with intellectual disabilities: a systematic review. *Special Care in Dentistry,* Volume 30, pp. 110-117.

Ayhan, H., Suskan, E. & Yildirim, S., 1996. The effect of nursing or rampant caries on height, body weight and head circumference. *J Clin Pediatr Dent ,* Volume 20, p. 209–212.

Boyle, E. et al., 2012. Effects of gestational age at birth on health outcomes at 3 and 5 years of age: population based cohort study. *BMJ,* Volume 344, p. e896.

British Society of Disability and Oral Health, 2006. *Commissioning Tool for Special Care Dentistry.* [Online]
Available at:
http://www.bsdh.org.uk/misc/Commissioning_Tool_for_Special_Care_Dentistry_FINAL_MARCH_2007.pdf
[Accessed March 2013].

CAMTAD, 2012. *Long Term Conditions Outcomes Strategy (response to consultation).* s.l.:s.n.

Carpenter, B., 2011. *The Complex Learning Difficulties and Disabilities Research Project. Developing pathways to personalised learning,* s.l.: Specialist Schools and Academies Trust.

CMOs for Northern Ireland, S. W. a. E., 2011. *Start Active, Stay Active – A report on physical activity for health from the four home countries' Chief Medical Officers,* s.l.: s.n.

D'Amore, A., Le Fort, W. & Curley, A., 2011. Two year outcomes from very low birthweight infants in a geographically defined population across 10 years, 1993-2002: comparing 1993-1997 with 1998-2002. *Arch Dis Child Fetal Neonatal Ed,* Volume 96, pp. F178-F185.

Department for Education, 2012. *special educational needs and disability,* s.l.: s.n.

Department for Work and Pensions, 2013. *Fulfilling Potential. Building a deeper understanding of disability in the UK today,* s.l.: s.n.

Department of Health, 2004. *The National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs ,* s.l.: s.n.

Department of Health, 2010. *Fulfilling and rewarding lives: the strategy for adults with autism in England,* s.l.: s.n.

Emerson, E., 2012. Deprivation, Ethnicity and the prevalence of intellectual and developmental disabilities. *Journal of Epidemiology and Community Health,* Volume 66, p. 218.

Emerson, E. & Baines, S., 2010. *The Estimated Prevalence of Autism Among Adults with Learning Disabilities in England,* s.l.: Improving Health and Lives: Learning Disabilities Observatory.

Emerson, E., Baines, S., Allerton, L. & Welch, V., 2011. *Health Inequalities and People with Learning Disabilities in the UK: 2011,* s.l.: Improving Health and Lives : Learning Disabilities Observatory.

Emerson, E., Baines, S., Allerton, L. & Welch, V., 2011. *Health Inequalities and People with Learning Disabilities in the UK: 2011,* s.l.: Improving Health and Lives: Learning Disabilities Observatory.

Emerson, E., Baines, S., Allerton, L. & Welch, V., 2012. *Health Inequalities and People with Learning Disabilities in the UK: 2012,* s.l.: Improving Health and Lives: Learning Disabilities Observatory.

Emerson, E. & Hatton, C., 2011. *Estimating the future need for social care among adults with learning disabilities in England: An update,* s.l.: Improving Health and lives: Learning Disabilities Observatory.

Emerson, E. et al., 2012. *People with Learning Disabilities in England 2011,* s.l.: Improving Health and Lives: Learning Disabilites Observatory.

Evans, D., Greening, S. & French, A., 1991. A study of the dental health of children and young adults attending special schools in South Glamorgan. *International Journal of Paediatric Dentistry,* Volume 1, pp. 17-24.
Gallagher & Fiske, 2006. *Commissioning Tool for Special Care Dentistry,* s.l.: British Society of Disability and Oral Health.
Gizani, S. et al., 1997. Oral health condition of 12-year-old handicapped children in Flanders (Belgium). *Community Dental Oral Epidemiology,* Issue 25, p. 352.
Glassman, P. & Miller, C., 2003. Preventing dental disease for people with special needs: the need for practical preventive protocols for use in community settings. *Spec Care Dentist,* 23(5), pp. 165-7.
Glover, G. & Ayub, M., 2010. *How people with learning disabilities die,* s.l.: Improving Health and Lives: Learning Disabilities Observatory.
Glover, G. & Evison, F., 2013. *Hospital Admissions That Should Not Happen. Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disability in England,* s.l.: Improving Health and Lives: Learning Disabilities Observatory.
Graham Allen MP, 2011. *Early Intervention: The Next Steps. An independent report to her Majesty's Government.,* s.l.: s.n.
Heslop, P. et al., 2013. *Confidential Inquiry into premature deaths of people with learning diabilities (CIPOLD): Final report,* s.l.: Norah Fry Research Centre.
Irving, C. et al., 2008. Twenty year trends in the prevalence and survival of Down Syndrome. *European Journal of Human Genetics,* p. 1336.
Locker, D., 2000. Deprivation and oral health: a review. *Community Dent Oral Epidemiol,* Volume 28, p. 161–9.
Lo, G., Soh, G., Vignehsa, H. & Chellappah, N. K., 1991. Dental service utilization of disabled children. *Special Care Dentistry,* Volume 11, pp. 194-6.
Mooney, A; Owen, C; Statham, J, 2008. *Disabled Children: NUmbers, Characteristics and Local Service Provision,* s.l.: Department for Children, Schools and Families.
Moore, T. et al., 2012. Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies. *British Medical Journal,* Volume 345, p. e7961.
National Institute for Health and Clinical Excellence, 2009. *CG85 Glaucoma: diagnosis and management of Chronic Open angle Glaucoma and Ocular Hypertension,* s.l.: http://www.nice.org.uk/CG85.
NICE, 2012. *Autism in Adults (CG142),* s.l.: s.n.
Nunn, J. & Murray, J., 1987. The dental health of handicapped children in Newcastle and Northumberland.. *British Dental Journal,* Volume 162, pp. 9-14..
Pope, J. E. & Curzon, M. E., 1991. The dental status of Cerebral Palsied children. *Pediatric Dental Journal,* Volume 13, pp. 156-62.
Rattihalli, R. et al., 2011. Neonatal intensive care outcomes and resource utilisation of infants born <26 weeks in the former Trent region: 2001-2003 compared with 1991-1993. *Archives of Disease in Childhood Fetal and Neonatal Edition,* pp. 1359-2052.
Read, J. & Spencer, N., 2009. Disabled children in the UK: a quality assessment of quantitative data sources. *Child: care, health and development,* 36(1), pp. 130-41.
Russell, P., 2007. *Improving access and inclusion in early years services,* s.l.: Department for Education and Skills.
Seirawan, H., Faust, S. & Mulligan, R., 2012. The Impact of Oral Health on the Academic Performance of Disadvantaged Children. *Am J Public Health,* 102(9), pp. 1729-34.
Sheiham, A., 2006. Dental caries affects body weight, growth and quality of life in preschool children. *British Dental Journal,* Volume 910, pp. 625-626..
Singh-Manoux, A., Clarke, P. & Marmot, M., 2002. Multiple measures of socioeconomic position and psychosocial health: proximal and distal effects. *Int J Epidemiol,* Volume 31, pp. 1192-1199.
Storhaug, K. & Holst, D., 1987. Caries experience of disabled school-age children. *Community Dental Oral Epidemiology,* Volume 15, pp. 144-9..
US Department of Health and Human Services, 2000. *Oral Health in America: A Report of the Surgeon General-- Executive Summary ,* s.l.: Rockville, MD: US Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Ins.
Waldman, H. & Perlman, S., 2002. Dental care for individuals with developmental disabilities is expensive, but needed. *J Calif Dent Assoc,* 30(6), pp. 427-32.
World Health Organisation and the World Bank, 2011. *World Report on Disability,* s.l.: World Health Organisation.