

8. Vulnerable groups (adults)

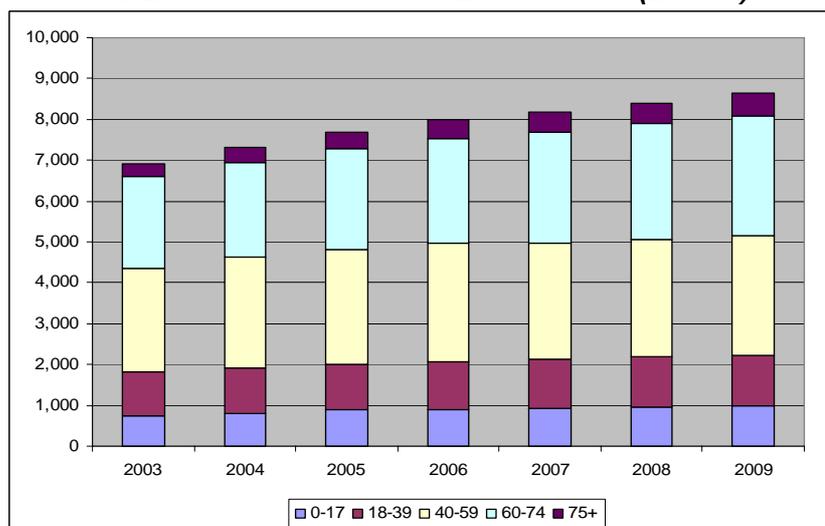
People with disabilities and mental health problems are known to experience poorer health and earlier death than other people within the community. They are also more likely to be unemployed and live in poverty. These multiple deprivations and disadvantages are often compounded by barriers that prevent access to ordinary opportunities, goods and services.

In 2001, 19.2% of North Lincolnshire residents stated that they had a long term illness or disability which “limited their daily activities”. This was just above national rate of 17.9%, and tends to increase with age.

Currently, more than 8,600 people of all ages in North Lincolnshire are in receipt of Disability Living Allowance, (a proxy measure of severe disability). This represents 5.4% of the total resident population, and includes almost 1,000 children and young people under the age of 20, and 3500 people aged 60+.

The number of benefit claimants has increased year on year and in all age groups, but is especially marked amongst those aged 60-74 years.

Figure 8.1
No. of DLA claimants in North Lincolnshire (2003-9)



Source: DWP, 2009

The highest concentration of DLA claimants is in Scunthorpe North, where 1 in 16 people of all ages are claimants.

Table 8.1
DLA claimants by locality, 2009

	Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
Number	1010	1570	1435	1535	3100
% residents	4.6%	4.8%	4.7%	6.5%	6.0%

Source: DWP, 2009

In addition to this, there are more than 7,500 people of working age in North Lincolnshire, who are permanently sick or disabled and unable to work who are claiming incapacity benefit and/or severe disablement allowance. This represents 8% of the working age population, which is lower than the national and regional rate, although rates rise to 10% in some of our most deprived wards. The largest group of incapacity benefit claimants are people with mental health problems and behavioural disorders, who represent almost 40% of the total.

The highest concentration of claimants – including people claiming on as a result of mental health needs - was in Scunthorpe North and South, where claimants represent more than 1 in 20 of all people of working age.

Table 8.2
Incapacity benefit claimants by locality, 2009

	Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
Number	610	935	770	1035	1985
% working age residents	4.6%	4.8%	4.2%	7.3%	6.5%
Number – mental health	170	360	295	440	860
% all IB claimants	28%	39%	38%	43%	43%

Source: DWP, 2009

Learning disability

People with a learning disability are at significantly higher risk of social exclusion than other population groups. They also experience poorer health and are significantly more likely than the general population to suffer physical, mental, communication and sensory impairments. The average life expectancy of people with learning disabilities is improving year on year, but is still 10 years shorter than the rest of the population.

How many people?

The precise number of adults with learning disabilities in our local population is unknown. National research estimates are in the region of 25 people in every 1,000 with a learning disability, including people with a mild to moderate learning disability, (20 per 1000 adults and 3 per 1,000 children) and 3 to 4 people in every 1,000 with severe or profound learning disabilities. Applied locally, this would equate to an approximate total of 3,200 children and adults with a learning disability in North Lincolnshire, of which between 480 – 640 will have severe or profound learning disabilities.

How many use adult services?

Not all of these adults will either require or be eligible for specialist care and support from adult services, although some may need support from time to time to help them access mainstream services, maintain independent living or to prevent a crisis. Just under 400 adults with a severe learning disability (SLD), are currently in receipt of specialist adult social care services in North Lincolnshire, including 50 adults with profound and multiple learning disabilities, (PMLD), who require continuous and specialist care, equipment and support. Slightly more adults will receive help from the learning disability nursing team or from supporting people services. Table 8.3 below shows the distribution of these service users across North Lincolnshire

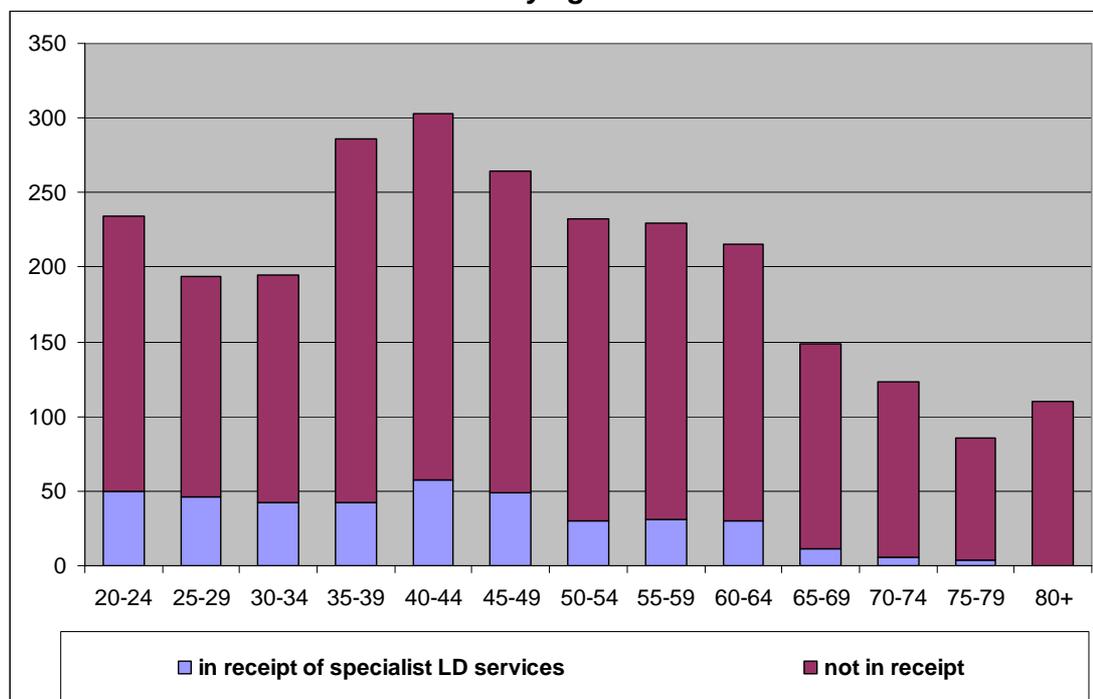
Table 8.3
Number of LD service users by locality, 2009

Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South	Postcode out of area or unknown
28	59	74	67	143	32

Source: CareFirst, 2009

Figure 8.1 illustrates the difference between the number of adults with learning disabilities who are estimated to be in the population, including people with mild to moderate learning disabilities, compared with those who are currently in receipt of adult social care services.

Figure 8.2
Estimated no of adults with LD by age in North Lincolnshire



In other words, we estimate that more than four fifths, (85%) of all adults with learning disabilities are neither known to or actively in receipt of adult social

care services in North Lincolnshire, including the vast majority of adults with mild to moderate learning disabilities. This proportion is similar to national figures.

Although we have no local information on the support needs of adults with mild to moderate learning disabilities, (MLD), national research suggests that these could be significant. For example, in a follow-up of the National Child Development Study cohort of people in their 30s, those with mild learning disabilities were significantly more likely than their peers to be still living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress. With an estimated 2,000 adults with MLD in North Lincolnshire, the number coming into contact with mainstream services and potentially in need of low level support, including advocacy, and supporting people type services, could be significant.

Health needs

'Health Care for All' (2008), highlighted some of the shortcomings of mainstream health services in meeting the additional and often complex health needs of people with learning disabilities. These additional health needs include a higher than average prevalence of:

- Cardiovascular disease and congenital heart problems – up to half of people with Down's Syndrome are affected by congenital heart problems
- Sensory impairments and physical disabilities – People with learning disabilities are between 8.5 and 200 times more likely to have a visual impairment compared to the general population and around 40% are reported to have a hearing impairment, with people with Down's syndrome at particularly high risk of developing visual and hearing loss;
- Epilepsy
- Psychiatric disorders
- Eating and swallowing problems
- Respiratory infections and urinary tract infections – respiratory disease is the leading cause of death for people with learning disabilities and is much higher than for the general population
- Diabetes
- Dental health problems
- Musculoskeletal problems and osteoporosis
- Higher levels of obesity and lower levels of physical activity
- Higher risk of Alzheimer's Disease
- Higher risk of gastro intestinal problems
- Higher risk of cancer

Learning Disability Registers and Health Checks

Although people with learning disabilities visit their GPs with as much frequency as the general population, national research has shown they are less likely to receive regular health checks. In April 2008, a Directed Enhanced Services (DES) was designed to encourage GP practices to identify those patients with moderate to severe LD as defined by the same criteria used by the local authority, and to ensure health checks are undertaken annually.

While all 21 GP practices in North Lincolnshire have a register of adults with learning disabilities, to date, only 13 have contracted to deliver the DES. This means that 8 of these GP registers remain to be validated. It also means that almost half, (227), of all adults known to adult services with a severe to moderate learning disability in North Lincolnshire are unlikely to receive an annual health check. It is too early to say how the linkages between these registers and the health action plans will develop locally.

Health Action Plans (HAPs)

Health Action Plans were first introduced by Valuing People, (2001). This specified that everyone with a learning disability should be offered the opportunity to develop a Health Action Plan, accessible to the user and supported by a Health Facilitator and in consultation with the primary care team and other relevant health professionals. The aim is to produce a living document that is updated as the person's health changes and which can act as a patient-held medical record

Health Action Plans were re-launched in North Lincolnshire towards the end of 2008, and to date more than a third of service users have completed HAPs with learning disability nurses. Work is in hand to complete HAPs with all 400 clients before April 2010, and to use the information gathered to inform the commissioning and planning of services. The data analysis exercise will focus in the first instance on take up of cancer screening, immunisations as well as on access to other preventive services such as weight management and access to mainstream health and leisure services. This work is due for completion by March 2010.

North Lincolnshire and the local Learning Disability Partnership Board have also completed a local review of health services for people with learning disabilities, in consultation with providers, service users, their families, carers and advocates. They have also submitted two voluntary self assessments of health services for people with learning disabilities to the regional Strategic Health Authority.

The key priorities identified for the next 12 months by these exercises were:

- ❖ Completion of health checks for all those on learning disabilities GP registers by 2010, with option to record access needs on GP patient records
- ❖ All health screening and health promotion information to be provided in easy read format
- ❖ Annual patient satisfaction surveys
- ❖ Scoping of current electronic data sharing systems
- ❖ Completion of equality impact assessments
- ❖ Re-commissioning of specialist adult learning disability health services

User voice on health services

These priorities were identified through an annual 'healthcheck', or self assessment exercise. As part of this process, users and carers were invited to contribute to a local stakeholder event, known as the Big Health Day.

Key findings included:

- ❖ Most people felt they got a good service from primary and secondary health care providers and that services from GPs in particular had improved over the years.

Additional areas for improvement highlighted on that day included:

- ❖ More investment in preventive health services for people with learning disabilities, especially access to physical activity
- ❖ Easier to read appointment letters for screening and annual health checks. Many service users said these letters often made them feel 'nervous' as they did not always understand why they were being asked to attend.
- ❖ Quicker and easier access to hoists and other equipment for people attending appointments within primary and secondary care
- ❖ Better access to repeat prescriptions for people with learning disabilities. It should not be necessary to attend the surgery each time.
- ❖ Most felt that doctors were good and took time over appointments. However, people were still waiting for long periods in outpatient areas to see a consultant with nothing to do. Reasonable adjustments might include fast tracking people with learning disabilities through the hospital appointment system.
- ❖ One suggestion was to make someone responsible within LD services to act as a liaison nurse within acute services
- ❖ This should encompass people who require appointments in out of area hospitals
- ❖ Carers are not able to support their adult relatives in hospital in the same way they can children. Generic hospital staff may need more

support and training on how to support carers better when their relative needs to be admitted.

Many of these issues are already being addressed by commissioners and providers and are being monitored by the Health Action subgroup, which reports directly to the Valuing People Partnership Board

Living arrangements

Almost half of adults with severe learning disabilities in North Lincolnshire live at home with their parents and other family carers, a quarter live in their own accommodation, whilst 28%, (109) live in care homes. Most of these care homes are small local establishments. Just 14 people live in care homes outside the area, of which all but 2, are in neighbouring towns.

Table 8.4
Living arrangements of adults with SLD in North Lincolnshire

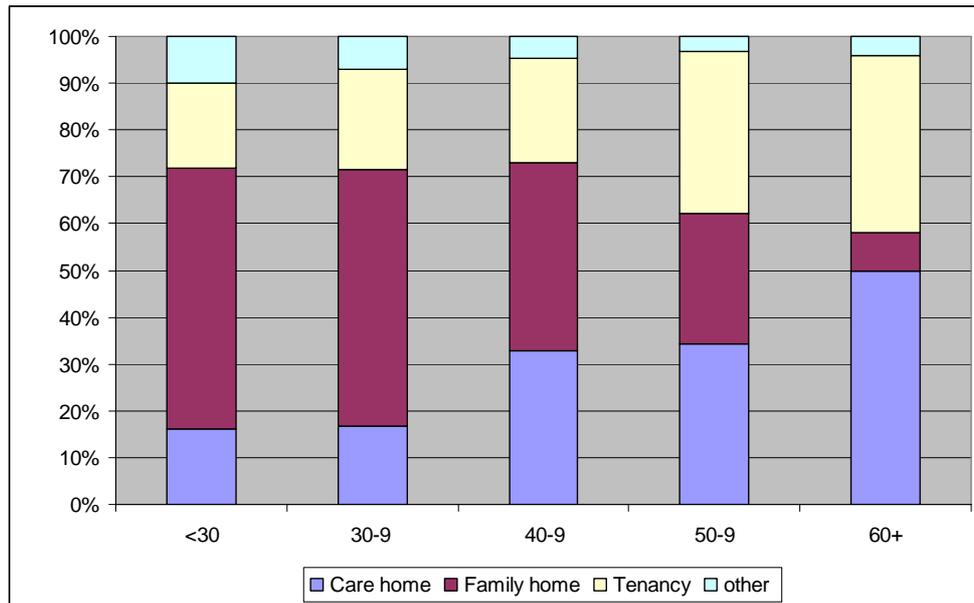
	2001	2006	2009
Care homes	34%	29%	28%
With relatives	56%	45%	43%
Supported tenancies	9%	23%	25%
Other	1%	3%	4%

Source: North Lincolnshire Council

Currently 91 adults, 1 in 4 of all service users, live in their own accommodation with support from other services. This is a higher proportion than nationally and is almost twice the number who were living in their own tenancies in 2001. Just under half of these adults live in shared accommodation, the rest in single tenancies. Two thirds of these supported tenancies are in Scunthorpe.

As the graph below illustrates, the vast majority of younger service users, (<40 years), continue to live in the family home with support from relative carers, whilst older service users are more likely to be living in care homes or in their own tenancies.

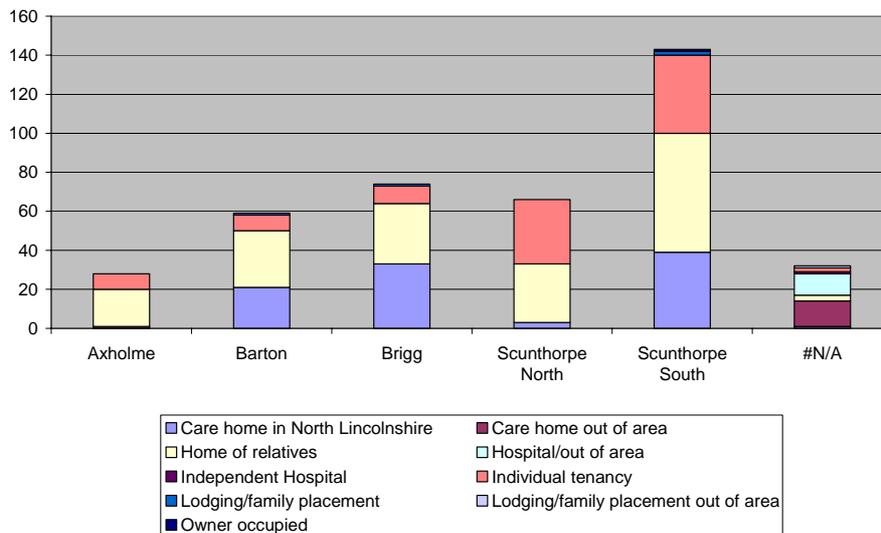
Figure 8.3
Living situation of adults with SLD in North Lincolnshire by age



Source: North Lincolnshire Council, 2009

In spite of recent developments, there is still an acute shortage of resources to fund *suitable* supported accommodation for adults with learning disabilities in North Lincolnshire, and so supported housing remains a pressing need for this group. This is likely to become even more pressing as adults with SLD live longer, more young adults move into the service and the turnover of tenancies slows down. The stated preference for many younger adults with learning disabilities in North Lincolnshire, is to live in shared accommodation in the Scunthorpe area, and this is where most of those who live in supported tenancies are based.

Figure 8.4
Living arrangements of service users by locality



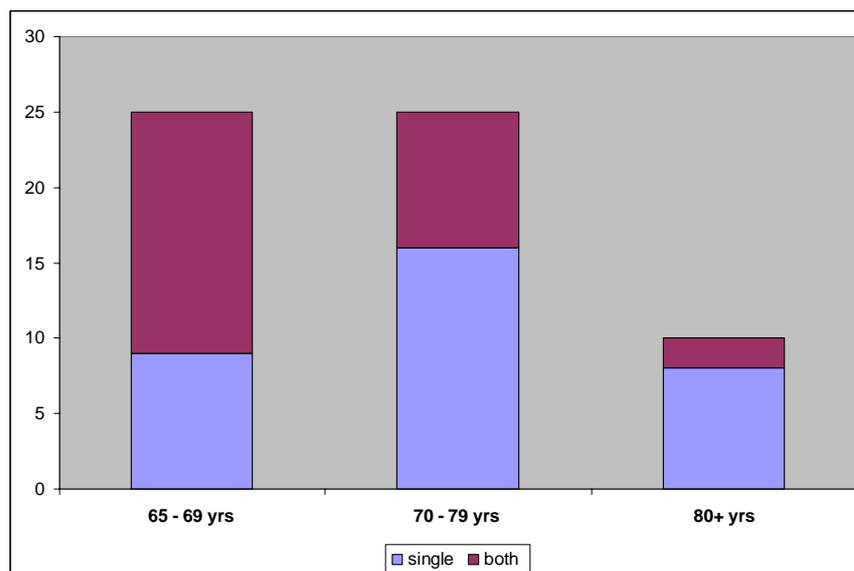
Source: North Lincolnshire Council, 2009

Older carers

Of particular concern are the future housing needs of people who are living with elderly parents/relative carers of which there are 64. Of these 64 adults, 10 are living with carers aged 80+.

More than half of these service users have high to medium care and support needs, although not all require 24 hour care. And more than half of these older carers live alone, with sole responsibility for their disabled relative.

Figure 8.5
No of adults with SLD in North Lincolnshire living with older carers



Source: North Lincolnshire Council

The age of these relative carers alone, suggests that at least an additional 10 adults with SLD per year are likely to need alternative care and accommodation, either in supported housing or, if this is not available, in local residential care, or between 60-100 adults within the next six to ten years.

As this group lives longer and the number coming through children’s services increases, this could mean developing more locality based packages of home care to enable people to remain living in their own home for longer.

Table 8.5
Locality of people with SLD living with older carers

Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
8	14	19	19	34

Source: Carefirst, 2009

Demand for supported housing is also likely to increase as a result of changing expectations. For example, it is likely that many of today’s younger

family carers will expect and want their children to have the opportunity to leave home as young adults, and may be less inclined to continue caring for them at home in the very long term.

Although we have no data on the average age at which people with learning disabilities leave home, we know that most adults with learning disabilities continue to live with their carers until at least 40 years of age.

This is likely to present a considerable challenge in the face of existing budget pressures on Social Services and Supporting People funds.

Strategic housing issues

- With more parents and service users expressing a desire for more independent living options, we can expect an increase in demand for more varied accommodation and support packages than we have currently.
- A transparent system for prioritising the supported housing needs of people with learning disabilities should be developed in conjunction with commissioners and providers of housing and support services, which recognises their preference and need for shared living arrangements. Currently, the housing allocation points system does not recognise this as a specific need.
- The development of a single access point for housing, the housing register and a place to plan alongside social services for both specialist and mainstream housing would make the process more accessible, and clarify pathways into supported housing.
- Almost without exception, both carers and service users, when consulted, identify shared living arrangements, with individualised packages of support, as their preferred option in the longer term. This could present challenges to North Lincolnshire Homes and other housing providers, as housing tenure, design and management are generally based on single household occupation. In addition, a significant number of properties will need to be single storey and adapted to meet the needs of people with physical disabilities.

Older people with a learning disability

People with a learning disability are living longer and getting older. In the last 10 years there has been a significant increase in the number of people aged 60-70 with a learning disability. Currently, there are almost 50 service users with SLD in North Lincolnshire who are aged 60+, and 94 adults aged 50+. A significant number of these will develop dementia type illnesses and are likely to require specialist assessment and support from older people's mental health services. These needs should be reflected in the commissioning strategies for older people's mental health.

As with the general population there is a significant bulge in the number of adult service users in their 40s and 50s. The greatest demand is therefore likely to come in the next 5-10 years.

Table 8.6
No of adults with SLD aged 50+

Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
4	13	27	11	39

Source: Carefirst, 2009

People from Black and Minority Ethnic communities

The proportion of adults with a learning disability from North Lincolnshire's black and minority ethnic communities is still relatively small. According to Care First data, just 8 adult service users, (just under 2% of the total) are from BME communities – of which all but two are from the Bangladeshi or Indian communities. This number is in line with their representation in the adult population.

Over time we should expect this number to increase as our relatively young BME community ages. Currently there are 3 BME children and young people of secondary school and older with a statement of SEN where the primary need is SLD or PMLD in North Lincolnshire, and 6 BME children of primary school age.

Opportunities to enjoy leisure

National research published by the English Federation of Disability Sport shows the main barriers to participation in sport and leisure by disabled people are:

- Transport 19%
- Money 7%
- Lack of suitable clubs 33%
- Lack of information 41%

Local research suggest we also need more sports leaders and role models.

Unwelcoming attitudes as well as practical barriers such as difficult signage, changing or toilet facilities, can also make services inaccessible to people once they are in the building. Some of these issues are being addressed locally by the Bridging the Equity Gap Project (BTEG) and by the appointment of a Learning Disability Development Officer.

Education, employment and training

The Government is committed to achieving equality for all disabled people by 2025, as set out in *Improving the Life Chances of Disabled People*. This

includes the chance for all disabled people to get a job. We know that 65% of people with learning disabilities would like a paid job.

While the employment rate of disabled people in Britain overall has risen steadily, that of people with learning disabilities is much lower – just 10% nationally, for people receiving adult social services.

In North Lincolnshire the proportion of adult service users in paid employment in 2008/9 was 13%.

Adults with profound and multiple learning disabilities (PMLD)

People with PMLD are defined as having extremely delayed intellectual and social functioning. They also tend to have significant physical and sensory disabilities, in addition to complex health needs, including complex epilepsy, difficulties swallowing and feeding and respiratory problems. This group require high levels of support with most aspects of daily life and are likely to need constant support and supervision to enable them to engage with the world and achieve their potential.

Valuing People Now identified this group as in need of particular attention by local commissioners, acknowledging that those with the most complex needs may be missing out on many of the positive changes in learning disability services following the implementation of Valuing People in 2001. In particular:

- ❖ the modernisation of day services has not always considered the support needs of people with PMLD, who may require special transport and 2:1 support for lifting and handling
- ❖ delivering outreach day services in community settings may not be realistic for some adults with PMLD
- ❖ the complex health needs of some adults with PMLD may also be difficult to meet in community health settings
- ❖ the current focus on raising employment and training opportunities for people with LD may not be appropriate for people with PMLD
- ❖ What FE opportunities are available to young adults with learning disabilities are limited to those with MLD or SLD.
- ❖ Few people with PMLD take up the opportunity for self directed care because of the high cost of support packages and limited access to appropriate advocacy
- ❖ Person centred planning is not as robust as it could be with this group due to lack of staff skills in engaging people with PMLD in planning in a meaningful way
- ❖ Community based leisure services are often not accessible and so people with PMLD often spend long periods of time at home
- ❖ Many people with PMLD have significant physical disabilities and require continual access to therapeutic support including physiotherapy, hydrotherapy and postural care. However, access to these services tends to decline once children with PMLD leave school.

- ❖ The health needs of this group are often significant – yet some of their basic needs can be overlooked because mainstream health staff do not have the experience or skills to work with this group.
- ❖ People with PMLD may have limited choice about where they live, or what services they receive due to a shortage of staff with the right skills.
- ❖ People with PMLD have limited access to advocacy, because few schemes have sufficient numbers of staff with the right communication skills.
(PMLD network, 2009)

Currently, there is little local or indeed, national information available on the numbers of people in this vulnerable group, or on how well services are responding to their particular needs. This is currently the subject of a national research project commissioned from Kent University by the DoH, and will form part of a more detailed local needs assessment in North Lincolnshire. Both studies are due for completion before March 2010.

In the meantime, we can apply prevalence rates derived from national research to arrive at a local estimate of numbers. This suggests that there are likely to be 50 adults with PMLD in North Lincolnshire, with an additional 2-3 young people with PMLD approaching adulthood each year, (prevalence of PMLD is estimated to be between 0.96 and 1.6 per 1,000 children aged 5-15 years, or between 2-3 in each year group in North Lincolnshire). Currently there are 14 children of school age in national curriculum years 0-11 with statements of SEN, where the primary need is PMLD. All 14 children attend special schools in North Lincolnshire. Work is currently in hand to identify the number of adults with PMLD in North Lincolnshire.

We also know that the number of children and adults with PMLD are increasing nationally, due to improved medical technology and increasing life expectancy. Although we have no data on this locally, national research suggest an annual increase in the prevalence of PMLD amongst older children and young adults of just under 5% per year.

National projections developed by Eric Emerson at Lancaster University, suggest that we should expect a sustained and accelerating growth in the number of adults with PMLD between now and 2029, (and hence a growth in the need and demand for health and social care services for adults with PMLD), with an average annual percent increase of adults of all ages with PMLD of 1.8%. The rate of increase grows markedly toward the latter end of the forecast period due to rising birth rates in the general population in the period between 2004-2008.

Projecting future needs and numbers

'Valuing People, (2001)' estimated that the number of people with a severe learning disability requiring adult social care services would increase by 1% per annum over the next 15 years. However, this estimate was based on a relatively low assumption of eligibility for services, (where adult services were only provided to new entrants with critical or substantial needs). This estimate

would exclude most young people with mild to moderate learning disabilities, who would be unlikely to be eligible for services based on their learning disability alone. For this group it is the combination of unemployment, poorer health and other additional adversities associated with mild to moderate learning disabilities that are likely to determine their eligibility for social care.

More recent estimates, suggest a much larger growth in need for services. Assuming all of those with moderate needs were eligible for services, would result in an estimated 7.9% increase in service users per year, and a 3.2% annual increase if just 50% of those with moderate needs were eligible.

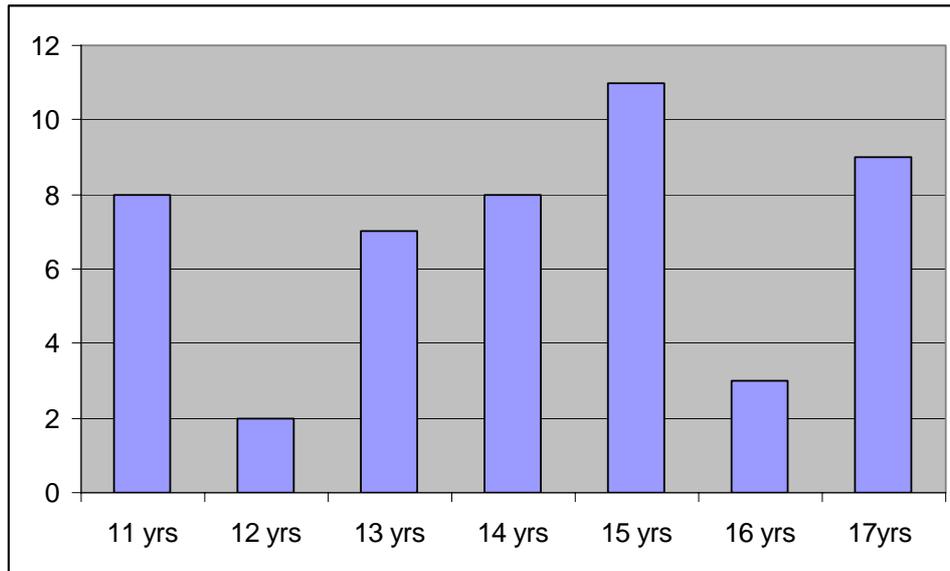
Based on these estimates we could expect an overall increase in the number of adults requiring social care services of between 10% - 79% over the next 10 years, or between 4 – 32 more adults each year using services, depending on the interpretation of Fair Access to Care eligibility criteria. Currently in North Lincolnshire, eligibility for adult services extends to those with moderate needs, although this still excludes the vast majority of people with moderate learning disabilities.

Young People with Severe Learning Disabilities

In the short term, the number of young adults with SLD or PMLD requiring adult services each year is not expected to change very much and could fall over the next five years. A recent assessment of young adults with SLD in North Lincolnshire identified between 10-12 young people aged 17-18 years of age who are likely to require support from adult services in the next 12 months, of which at least two are educated full time in out of area residential colleges.

Looking a little further ahead, the number of young adults leaving full time education who currently have a statement of SLD or PMLD is likely to be in the region of 8 a year between now and 2013, although numbers may vary from year to year.

Figure 8.6
No of young people with a statement of SLD/PMLD by age (2009)

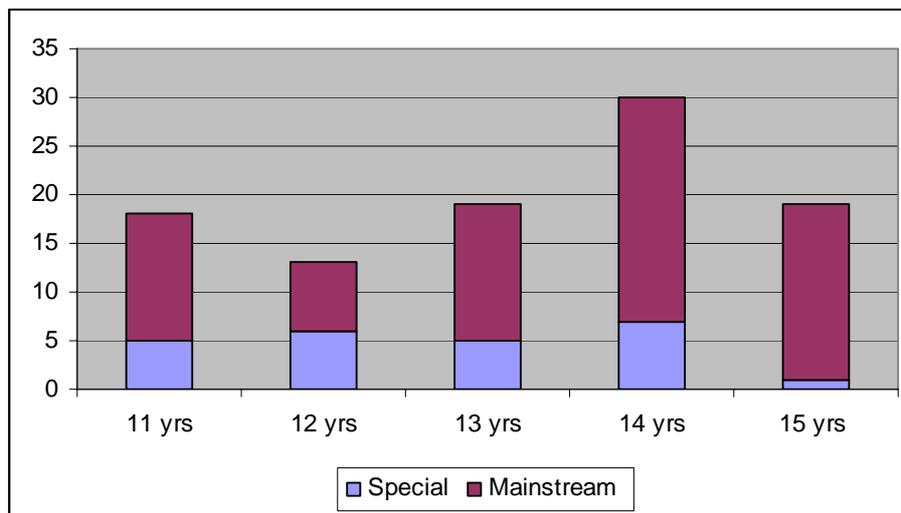


Source: North Lincolnshire Council

Young people with Moderate Learning Disabilities

There are in addition a total of 148 children and young people of all ages with a statement of moderate learning disabilities, of which 100 are of secondary school age, including 22 who attend special schools in North Lincolnshire. It is unlikely that many of these will either require or be eligible for specialist adult services post 17 years of age.

Figure 8.7
Secondary school children with a statement of SEN for Moderate Learning Disabilities , (2009)



Source: North Lincolnshire Council

People with Autistic Spectrum Disorder (ASD)

National research suggests that autistic spectrum disorders (ASDs) are more common than was previously estimated. The most recent published estimate suggests that ASD affects 116 in every 10,000 children aged 9-10 years, compared with an estimated 20 per 10,000 less than two decades ago. It is difficult to judge to what extent this represents a real underlying increase in prevalence rather than changes in diagnostic criteria or improvements in identification. However, there is much greater public awareness of autism compared with previous years.

Across all ages the most recent national research estimates suggest a population prevalence of ASD of 1%, of which 45% will be high functioning, (with an IQ below 70) and 55% high functioning, (above 70). Applied to local population estimates, this suggests almost 1500 people with ASD in North Lincolnshire, of which just over half are likely to have support needs. Almost all of this group will live at home, either alone or with family carers.

Table 8.7
Estimated prevalence of people with ASD

Age functioning group	Prevalence per 10,000	No of people with ASD in North Lincolnshire (based on 2008 mid year estimates)
Pre school (high functioning)	4.5	3
Pre school (low functioning)	5.5	4
Primary school (high functioning)	45	60
Primary school (low functioning)	55	72
Secondary school (high functioning)	45	45
Secondary school (low functioning)	55	55
Adults (18+) – high functioning	45	562
Adults (18+) – low functioning	55	688
Total		1499

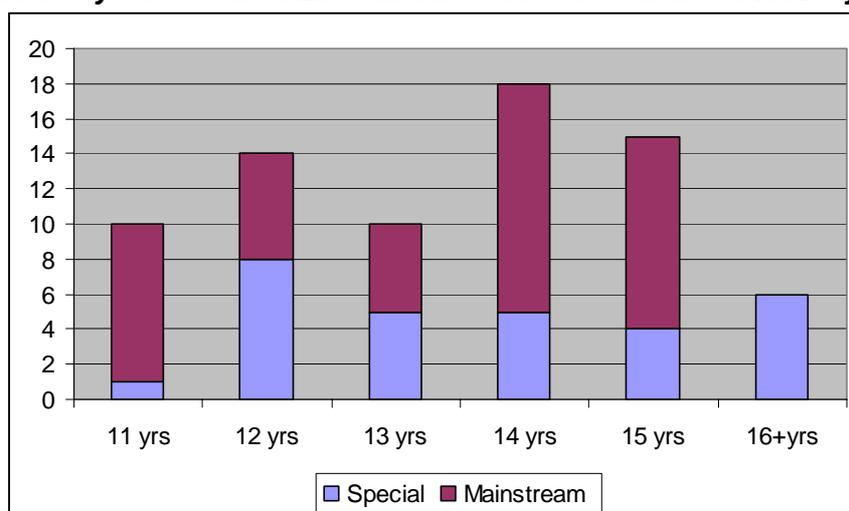
Source: 'The Economic Consequences of Autism in the UK, Knapp et al, 2007,'

A recent local audit of case files identified 60 adults with ASD who are known to adult health or social care services. This represents less than 10% of the estimated number of adults with low functioning ASD in North Lincolnshire.

Currently there are 120 children of all ages with a statement of special educational needs where the primary need is ASD, and an additional 7 on School Action Plus. This compares with an estimated 131 children with low functioning ASD in the population, according to the prevalence estimates above.

Just over half of those with a statement of ASD, (73) are attending secondary schools/colleges, of which 29 have significant learning disabilities and are attending special schools. Ten of these young people are attending independent schools for young people with ASD, 7 in North Lincolnshire, and 3 out of area. The remainder are attending local mainstream schools. The graph below shows the number of 11-17 year olds with a statement of SEN where ASD is identified as the primary educational need.

Figure 8.8
No of 11-16+ year olds in N Lincolnshire with a statement of ASD by school



Source: North Lincolnshire Council

Although adult learning disability services have historically provided a service for young people with ASD returning from out of area placements, there are no additional adult resources within learning disability services for this user group, unless they have significant learning disabilities. Family carers are therefore likely to bear a large proportion of caring for young people with ASD as they approach adulthood.

Key challenges and implications

- Conservative estimates suggest the number of adults with learning disabilities, including those with profound and multiple needs, is projected to rise by at least 20% over the next 10 years.
- In North Lincolnshire, the number of young people with severe learning disabilities and PMLD requiring specialist adult services each year is not expected to grow much over the next five years.
- Most of the projected growth is accounted for by rising life expectancy amongst this client group, with most adults with severe learning disabilities outliving their parents.
- Rising life expectancy means that more people with learning disabilities will develop long term conditions associated with ageing, including dementia, diabetes and heart disease. This will have implications for the commissioning and delivery of older

people's and mental health services, as existing models of service delivery may not be appropriate to their needs.

- It also underlines the pressing need to engage all 21 GP practices in annual health checks for this vulnerable group. To date, only 13 practices have contracted to deliver the DES for these health checks.
- The number of young people with profound and complex needs is also likely to increase, although the number in each year group (between 1-2) is small. More locality based packages of home care will be required to enable them to live in their family homes for longer.
- Unlike children's services, there are no physiotherapists, OTs, or speech and language therapists who are dedicated to working solely with adults with learning disabilities. Consequently as young people with SLD and PMLD leave school, they rely on accessing support from mainstream therapeutic services.
- Currently, there are just 8 adults with SLD from BME groups known to specialist services, although the number of BME adults with MLD may be much higher than this.
- However, the expected increase in the number of young people with learning disabilities from our Asian communities, through natural population growth, will need to be carefully planned for. In particular the need for short break services and appropriate daytime, social and recreational activities. More information is required on the needs of young BME adults with learning disabilities in order to develop appropriate services in the future.
- The number of people living in supported tenancies has grown impressively over the last five years, and is twice what it was in 2001.
- However, demand for supported housing still outstrips supply, and is likely to grow with changing family expectations and increasing life expectancy of current service users. The preferred type of accommodation expressed by service users is shared housing in the Scunthorpe area. However, this preference is not reflected in the allocation of social housing for this vulnerable group.
- Currently, more than a third of all adults with SLD who live at home, are cared for by elderly relatives. The age of these relative carers alone, suggests that at least an additional 10 adults with SLD per year are likely to need formal care and accommodation, either in supported housing or, if this is not available, in local residential care.
- This could mean finding alternative accommodation for between 60-100 adults in North Lincolnshire within the next six to ten years.
- Getting the right type of support package in place is likely to prove more of a challenge, especially with continuing pressure on adult social care budgets.
- There is likely to be a significant and growing gap in the levels of support that young people with moderate learning disabilities and with ASD receive as children, compared with those they can expect

as adults. The proportion of adults with low functioning ASD or moderate learning disabilities is estimated to be less than 10%.

- There is no single database or register with comprehensive information on the health, housing and social care needs of people with learning disabilities in North Lincolnshire.
- More information is required on people with ASD, MLD and PMLD to get a better understanding of their numbers and needs.

Areas for Action

- ❖ Ensure that the needs of people with learning disabilities are reflected in all health and social care commissioning strategies, including the projected needs and numbers of people with PMLD, ASD and MLD
- ❖ Develop more detailed information on health needs on people with LD to inform strategic planning
- ❖ Ensure that transition planning for young people with learning disabilities aged 14+ takes full account of the national framework for adult NHS Continuing Health Care
- ❖ Develop more detailed information on the needs of people with low functioning ASD and MLD to inform strategic planning
- ❖ The needs and expected increase in the number of people with SLD from our Asian communities will; also need to be carefully planned for. In particular the need for short break services and appropriate daytime, social and recreational activities.

Areas which may require further investigation

- ❖ Analysis of Health Action Plans (HAP) data
- ❖ Integrating data drawn from Health Checks in a way that informs strategic planning.
- ❖ Complete local research project investigating the needs and numbers of people with PMLD, including children and young people
- ❖ Investigate further the needs of young adults with SLD and their carers from our local BME communities

Mental health

Mental health problems are a major cause of disability in this country, and by 2020 mental ill health is projected to be the second leading cause of loss of disability adjusted life years in the world. In England, almost 1 in 4 adults meet the diagnostic criteria for at least one mental health problem – the most common being anxiety and depression. Suicide accounts for 1% of all deaths in this country and nearly two thirds of these deaths occur in depressed people. Family relationships are also frequently affected by relative's mental ill health, and parental depression, if undiagnosed and untreated, can lead to poor emotional health and well being outcomes for children.

Mental ill health is the most common reason for claiming disability and sickness benefits in this country and the third most common reason for sickness absence, accounting for 40% of all days off sick and almost 40% of all incapacity benefit claimants. Whilst work is an important part of recovery for people with mental health needs, the employment outcomes for this group are very poor compared with people with other health conditions and/or

disabilities. For people with severe and enduring mental health problems, employment rates are as low as 12%.

In 2009, just over 2,000 people of working age were unable to work and were claiming incapacity benefits in North Lincolnshire as a result of mental ill health.

Table 8.8
Incapacity benefit take up for mental ill health

	Total	Axholme	Barton & Winterton	Brigg & District	Scunthorpe North	Scunthorpe South
No	2125	170	360	295	440	860
% all working age adults	2%	1%	2%	2%	3%	3%

Source: DWP, 2009

Mental health is also the biggest spend area of the NHS, both nationally and in North Lincolnshire, and currently accounts for 9.5% of NHS North Lincolnshire's annual budget, or £23.9 million a year. Nationally the cost is Expenditure on mental health is projected to increase in years to come with rising costs and increasing life expectancy - the major drive coming from a projected increase in the prevalence of dementia amongst our older population.

The wider social and economic costs of mental ill health are even higher, with the costs to employers alone estimated at £28.3 billion nationwide, with depression being amongst one of the most costly mental health conditions in terms of service costs and loss of earnings. In 2007, the total cost of services for depression in England was estimated to be £1.7billion, whilst lost employment increased this total to £7.5billion.

Improving the prevention, early identification and management of mental ill health in the workplace and in the wider community could potentially save the economy and the public, millions. Yet mental health literacy and awareness amongst employers and the wider public can be low.

What is the level of need?

Estimates differ, according to the weight given to local socio economic factors, such as levels of unemployment, housing and environmental conditions and so on. The table below shows the prevalence rate and estimated number of adults aged 16-64 with neurotic disorders in North Lincolnshire and the likely numbers who may require or benefit from psychological therapies.

Table 8.9
Prevalence of Common Mental Disorders 16-64 year olds, (2008 based)

	Any neurotic disorder	All phobias	Depressive episode (major depression)	Generalised anxiety/depression	Mixed Anxiety/depression	Obsessive Compulsive Disorder	Panic Disorder
Prevalence per 1,000	119.8	11.7	19.7	33.8	62.2	6.4	4.1
Number	11,920	1164	1960	3363	6190	610	410

Source: National Psychiatric Morbidity Survey, 2007

This is based on a national survey of psychiatric morbidity, applied to local population estimates, which suggests that areas with a profile like North Lincolnshire should have lower than average prevalence rates of these disorders compared with more urban, and more deprived parts of the country. Indeed, according to this analysis, North Lincolnshire is likely to have one of the lowest prevalence rates of common mental disorders in the country, ranking in the bottom 10 districts nationally, (NEPHO, 2008).

An estimated 12,000 16-64 year olds suffer from common mental health disorders in North Lincolnshire. Depression is also estimated to affect between 11-15% of our older population, (2,900-4,300 people), with between 3-5% (870-1,450) experiencing depression in its most severe form. Prevalence of depression almost doubles for older people suffering ill health and disability.

Not all of these people will need or accept psychological therapies. Indeed, some common mental health problems may be resolved without seeking formal treatment. National research estimates suggest that about a fifth of this number, may require psychological therapy each year, although this proportion is likely to vary from one area to another.

In 2008, NHS North Lincolnshire was chosen by the Department of Health to become an *early implementation site* for improving access to psychological therapies for adults. In the first quarter of 2009/10, 426 adults were referred for psychological therapies in North Lincolnshire – and 11 were moved off 'sick pay' and benefits.

Other mental health conditions

Despite being relatively uncommon, psychotic illness results in high service and societal costs. The World Health Organisation calculates that the burden and human suffering associated with psychosis at the family level is exceeded only by dementia and quadriplegia. The prevalence of schizophrenia is estimated to be 6 per 1,000, or an estimated 480 adults of working age in North Lincolnshire. Prevalence varies by age and is slightly higher for males.

The number of people with bipolar disorder and related conditions is higher, ranging from 4 - 39 per 1,000 adults, depending on age; the highest rates being amongst the under 45s. There is a small gender difference in prevalence. Applied to local population estimates this suggests 1900 adults of working age with bi polar disorder in North Lincolnshire, of which half will be sub threshold. This compares with 1074 adults with psychoses on GP registers in North Lincolnshire.

Table 8.10
No of adults with psychoses on GP registers

Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
58	180	176	145	515

Source: QoF, 2009

ADHD

Attention deficit hyperactivity disorder (ADHD) is a widely recognised complex developmental disorder in childhood. Prevalence estimates for childhood ADHD are thought to be in the region of between 3% to 9%.

In recent years, the persistence of ADHD characteristics into adulthood has gained some recognition and become the focus of research and clinical attention. At present, there is a lack of robust epidemiological data on the prevalence of ADHD in the adult population, particularly for England. Longitudinal studies have demonstrated the persistence of ADHD into adulthood, suggesting that 15% of adults diagnosed with ADHD as children may retain the full diagnosis at the age of 25, with a further 50% in partial remission with persistence of some impairing symptoms of ADHD.

Currently in North Lincolnshire there are 273 children with a diagnosis of ADHD, of which 69 are aged 16-17 years of age. This is well below expected numbers for under 16s, suggesting a significant level of unmet need in North Lincolnshire. Nevertheless, the number of 16-17 year olds with a diagnosis suggest that there could be a rise in demand for ADHD support amongst adults over the next 10 years.

Projected prevalence amongst working age adults

The needs, prevalence and distribution of adults of working age with mental health needs are not expected to change much in the next 5-10 years, although the current trend of rising unemployment, increasing alcohol consumption, rising levels of obesity and increasing incidence of long term conditions, such as diabetes, may result in an increasing incidence of depression and anxiety in the adult population.

However, the major impact on services is likely to come from natural population growth. Even assuming the local incidence of neurotic disorders, such as anxiety and depression, remain the same and stay below national

rates, we should be planning for potentially 10 new cases a year requiring services, between now and 2015, due to a 2-3% growth in the working aged population over this 6 year period.

Table 8.11
Projected prevalence of Common Mental Disorders 16-64 year olds, (2006 based)

	Any neurotic disorder	All phobias	Depressive episode (major depression)	Generalised anxiety/depression	Mixed Anxiety/depression	Obsessive Compulsive Disorder	Panic Disorder
Prevalence per 1,000	119.8	11.7	19.7	33.8	62.2	6.4	4.1
Year 2015	12,268	1170	2020	3460	6370	655	420

Source: NEPHO, Mental Health Needs Assessment Tool

There is some national evidence of increasing incidence of schizophrenia in the population, although the reasons for this are not yet clear. Whilst some have associated this with increasing use of cannabis amongst younger adults, further national research is required to establish a trend.

Any major changes in demand for services amongst this client group are more likely to come from the projected increase in the younger adult population (20-43 yr olds), which is projected to grow by more than 1000, between now and 2015, (a 2% increase on 2008). Local agencies may expect an additional 10 new cases presenting to services between now and 2015.

Mental health of older people

Whilst the majority of older people can expect to remain in good mental health, there are a range of mental health problems that affect people in older age, including, depression, anxiety, & delirium. Other mental health problems start earlier in life but may stay in older age, including schizophrenia, bi polar disorders and other severe and enduring mental health problems, as well as alcohol and drug misuse. Suicide, self harm and self neglect are more common in older age and are often the result of mental health problems.

A summary of national research data suggest that:

- An estimated 1 in 4 older people living in the community, (7,000 in North Lincolnshire) may have symptoms of depression that are severe enough to warrant treatment. Yet only 1 in 3 of these will ever discuss this with their GP
- Of those that do, only half are diagnosed and treated often with anti-depressants
- Depression is the leading risk factor for suicide and older men and women have some of the highest suicide rates

- Dementia costs the health and social care economy more than stroke, heart disease and cancer combined
- A third of people who provide unpaid care for an older person with dementia, have depression
- Delirium or acute confusion affects up to 20% of older people in a general hospital setting
- There are estimated to be between 70-140 older people in North Lincolnshire with an enduring mental health need such as schizophrenia
- People aged 55-74 have the highest rates of alcohol related deaths
- Two thirds of NHS beds are occupied by people aged 65+, of which up to 60% have or will go on to develop mental health needs during their admission.

Older people's mental health is thus a major public health issue and is likely to become more important as our population ages. Mental ill health amongst this older age group is an important and independent predictor of poor health outcome, and includes a greater risk of mortality, greater lengths of stay in hospital, loss of independent function and greater risk of institutionalisation post discharge from hospital. It also has a significant impact on quality of life in older age. For example, it is estimated that dementia contributes 11.2% of all years lived with disability amongst people aged 60 plus. This is more than stroke, (9.5%), musculoskeletal disorders, (8.9%), cardiovascular disease (5.0%), and all forms of cancer (2.4%).

The prevalence of depression amongst care home residents is estimated to be much higher than this, at 45% of all admissions, (Sharp, 2007). A recent national study suggests that prevalence is increasing in care homes, as older people with less complex needs are supported for longer in their own homes. Amongst general hospital patients prevalence is estimated at 29%, with only a quarter of these cases being detected, (RCP, 2005).

Table 8.12 below shows the projected numbers of older people with mental health conditions living in North Lincolnshire in 5 years' time.

Table 8.12
Projected prevalence of mental health conditions in older people

Mental health condition	Estimated no. older people affected 2010	Estimated no. older people affected 2015
Dementia	2052	2350
Severe depression	800	970
Schizophrenia	155	180
Delirium	460	538

Dementia

The expected prevalence of *severe mental disorders*, (such as dementia and psychosis) amongst our *older population* will rise significantly, simply as a result of increasing life expectancy. At the same time, the costs of providing mental health services, specifically for those with severe mental health conditions, (including dementia) is projected to increase substantially, the major drive coming from a projected increase in the prevalence of dementia amongst our older population.

Whilst the number of people affected by this disease is relatively small, (about 6% of the 65+ population), prevalence doubles with every additional five years post 65 years, and carries a significant emotional and financial cost to individuals, family, carers and to services.

Vascular risk factors such as hypertension, Type 2 diabetes, high cholesterol, dietary fat intake, obesity and stroke are all considered to be important risk factors, not just for vascular dementia, but also for Alzheimers.

Currently there are an estimated 2050 people with dementia in North Lincolnshire, of which an estimated 15% (300), will have the most severe form of the disease. This compares with 700 people with a diagnosis of dementia on GP registers in North Lincolnshire, whose condition is being treated and managed within primary care.

Table 8.13
Number of people with a diagnosis of dementia on GP registers by locality of practice

Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
122	91	173	57	258

Source: QoF, 2009

The vast majority of people with dementia live at home with relative carers. All things being equal we should expect this number to increase as our older population grows in number.

Projected prevalence

Age is the strongest risk factor associated with dementia. So we should expect the number of older people with dementia to increase incrementally over the next 10-15 years, as our older population grows. By 2015, the projections are for an additional 15% of people with diagnosed and undiagnosed dementia in the local population. This rate of increase is higher than the national regional average due to our older than average population profile. Almost half of the 2350 people with dementia projected in 2015, will be aged 85+.

Table 8.14
Projected numbers of people with dementia in North Lincolnshire
(diagnosed and undiagnosed)

People aged	2010	2015	2020	2025
Under 65	47	49	52	52
65+	2,052	2,350	2,774	3308

Source: POPPI, 2009

This growth is likely to occur fastest in our rural areas. By 2015, all things being equal, more than 58% of those older people who are projected to have dementia will live in our rural localities.

Table 8.15
Projected distribution of people with dementia in North Lincolnshire by locality

	Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
2015	12.8%	25.3%	19.2%	13%	29%

Source: POPPI, 2009, ONS population projections

Stakeholder views

One of the most important issues for older people's mental health is the delay that often occurs before they are offered support. This may happen because of people's reluctance to seek help or because of under recognition on the part of health and social care professionals. When diagnoses of dementia are made this is often too late for those suffering the disease to make choices. As a result, levels of unmet mental need amongst older people may be very high.

National research evidence suggests that early provision of support in the home for people with dementia and their carers can reduce the need for care home placements in the longer term, by up to 22%.

However, both national and local research suggest that public and professional awareness and understanding of dementia needs improving. In

a recent local consultation event, the key priorities identified by carers and other stakeholders for improvement were:

- Access to early diagnosis, information and support
- Development of professional's skills and understanding of the disease
- Raising public awareness and reducing stigma associated with the disease
- Development of a list of preferred & accredited providers who can meet local requirements for dementia care
- Development of local staff skills/provision for adults with complex needs – especially those with behaviours that may be challenging to staff

[North Lincolnshire Dementia Action Plan, 2009-11](#)

[Older People 's Mental Health Needs Assessment, 2008](#)

Suicidal behaviours

Nationally there has been a decline in suicides over the last 10 years. However, this still remains a high priority as suicide is the main cause of premature death amongst some vulnerable groups. Periods of high unemployment and severe economic recession also have a significant impact on people's mental health and have been associated with an increased risk of suicide.

The likelihood of a person committing suicide depends on a number of different factors, including physically disabling or painful conditions, mental illness, alcohol and drug misuse as well as level of support. Stressful life events can also play a part. For many people it is a combination of factors rather than a single one that is important.

In 2002, the Government launched a Suicide Prevention Strategy with a target to reduce deaths by at least a fifth by 2010/11 from a 1995-7 baseline. The number of deaths from suicide and undetermined injury in North Lincolnshire each year is relatively small – and as Figure 8.9 shows, fluctuates significantly from one year to the next. To avoid drawing undue attention to natural data fluctuations, the monitoring indicator employs three years worth of pooled data. These are reported in Table 8.16 below and show that the local suicide rate has declined since 1995-7 – and is on target for at least a 20% reduction by 2010/11.

Table 8.16

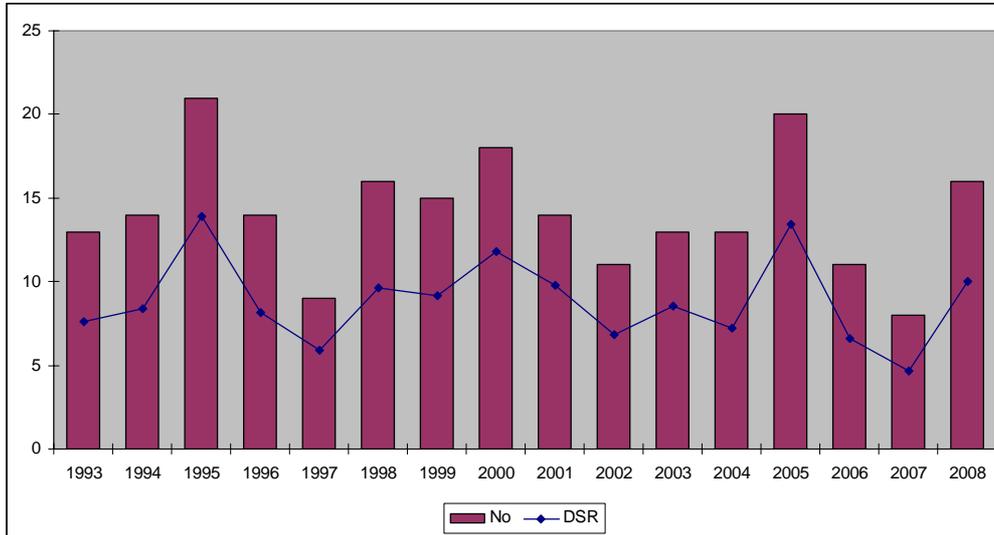
PSA Target 20% reduction in suicide rates 1995-7 – 2010/11

	North Lincs	England
1995-7	9.32	9.16
2006-8	7.10	7.76
2010/11 target	7.46	7.3

Source: National Statistics, 2009

In the three year period 2006-8 there were a total of 35 suicides, of which all but three were men. The numbers were divided almost equally by age between those aged under 45 years and those aged 45 years and older.

Figure 8.9
No of deaths from suicide and undetermined injury in North Lincolnshire and rate per 100,000 1995 – 2008



Source: NHS Information Centre, National Statistics

Physical disabilities

Definition

It is difficult to be precise about the number of adults with a physical disability in North Lincolnshire. Definitions of disability can differ considerably leading to quite different results. Disability affects all age groups and all parts of the population, although some communities may have a higher incidence of chronic conditions. Some impairments and conditions are particularly associated with ageing, while some people have a lifetime disability. Other disabilities are acquired through illness or accident. In the sections below we focus specifically on those of working age, with a physical or sensory impairment drawing on national data and research resources including some recent research conducted by the Office for Disability Issues.

Why is this important?

National survey data demonstrate that, compared with non disabled people, adults with physical disabilities are:

- ❖ More likely to live on low incomes – the income of disabled people is on average, less than half that of non disabled people
- ❖ More likely to experience feelings of isolation, loss of status, anxiety and depression
- ❖ More likely to experience problems with hate crime or harassment
- ❖ More likely to experience problems with housing
- ❖ More likely to experience problems with transport

- ❖ Less likely to feel they have control over how they live their lives and the services they receive

(‘Experiences and Expectations of Disabled People’ - Office for Disability Issues, 2009’)

National policy

In 2008 the Government set out a five year plan to improve the independence of people with disabilities, is the aim being that ‘all disabled people (including older disabled people) should be able to live autonomous lives, and to have the same choice, freedom, and control over their lives as non-disabled people’. One of the key aims of that strategy centres on the need for people to have greater choice and control over how the support they may need to help them go about their daily lives, is provided. The local authority circular ‘Transforming Social Care’ LAC (DH) 2008, describes a personalised approach to the delivery of adult social care and requires all councils to have commissioning strategies that ‘maximise choice and control’ for people, and which balance investment in ‘prevention, early intervention re-ablement and intensive care and support for those with high level complex needs’.

National Target

This includes a national target that by 2010-11, 30% of adults supported via funded care plans should receive self directed support.

The key messages from Government regarding the future shape of adult social care are:

- A common assessment of individual care needs, emphasising the importance of self assessment
- A change in the role of social workers from assessment and gate keeping to advocacy and brokerage
- A change to person centred planning in which service users can control or direct the flexible use of resources
- A personal budget for all those eligible for social care, in all care settings
- A different relationship between national and local government which enables decision making at a local level

Local implementation

The local response is outlined in North Lincolnshire’s commissioning strategy ‘Fit for the Future Your Life Your Choice’.

The local priorities for change identified in that document include:

- Development of a locality based support system with 24 hour rapid response
- Establishing an Every Adult Matters Service
- Enhancing opportunities for self assessment
- Reducing the waiting list for major adaptations and the Disabled Facilities Grant
- Ensuring that everyone has knowledge of their personal budget
- Improving engagement and self advocacy opportunities

- Establishing a fully integrated rehabilitation and re-ablement service
- Developing technologies that enable self care
- Improving the range of housing solutions
- Encouraging prevention and community development approaches
- Increasing opportunities for employment

Projects for completion this year include a commitment to

- Review and transform a local residential care home for adults with physical disabilities
- Improve the direct payments payroll and support service
- Review the local occupational equipment services
- Develop a peer support user led organisation

How many people in North Lincolnshire

There are a number of different national sources of data on the number of people with disabilities in the population, each with slightly different definitions and thus slightly different estimates of prevalence. The *Disability in Great Britain Survey* (1999) estimated that a fifth of the adult population aged between 20 - 65 years had a disability of some kind, including a mental health problem or learning disability. This survey determines the severity of disability with scores of impairment from 1-10; being the most mild form of disability and 10 being the most severe.

The survey found that of these 20% of adults:

- 34% had a severity score of 1-2
- 45% had scores of between 3-6
- 21% had scores of 7 or more.

Applied to North Lincolnshire's population this suggests that there are 18,640 residents aged 20- 64 with some form of physical, sensory or mental impairment – of which, just over 3,910 are likely to have a severe impairment.

According to official *Labour Force Survey data*, an estimated 18% of the working age population in North Lincolnshire has a long term disability, of which 9% have a long term mental health problem, and 2% a moderate to severe learning disability. Excluding these two groups results in an estimated (7%) 6,500 adults below retirement age with a long term physical disability. The major causes of physical disability identified in this age group were musculo-skeletal problems, (40%), followed by respiratory problems, (16%) circulatory diseases, (13%), diabetes (5%) and progressive illnesses, (5%).

The *Health Survey for England* is another source of data on the likely numbers of adults with physical disability in the population. According to this source, the prevalence of moderate to severe physical disability is 4.1% for 18-24 year olds, 4.2% for 25-34 year olds, 5.6% for 35-44 year olds, 9.7% for 45-54 year olds and 14.9% for 55-64 year olds. This suggests a total of 8,700 adults of working age with a moderate to severe physical disability in North Lincolnshire. This figure will include people with a learning disability.

The prevalence rates for severe physical disability in that survey are 0.8% for 18-24 year olds, 0.4% for 25-34 year olds, 1.7% for 35-44 year olds, 2.7% for 45-54 year olds and 5.8% for 55-64 year olds. This suggests a total of 1320 adults of working age with a severe physical disability in North Lincolnshire.

Our best guess is that there are between 6,500-8,700 adults under 65 years with a physical disability in North Lincolnshire, of which approximately 1300 will have a severe physical disability.

Currently, an estimated 720 adults of working age are in receipt of support financed by North Lincolnshire's adult social care services, including almost 40 who are supported in residential or nursing home care. About a quarter of these will have a neurological condition, including a third of those living in residential care.

Prevalence of Neurological Conditions

Neurological conditions are the most common form of serious disability and can affect people of all ages. Across the UK it is estimated that 2% of the population are disabled in some way by a neurological condition whilst an estimated 1% of the population are newly diagnosed each year. About a quarter of working age adults with a physical disability have a neurological condition, including a third of those living in residential care. Multiple Sclerosis is the leading cause of disability amongst younger adults, although more adults are affected by cerebral palsy and traumatic brain injury.

The table below shows the most common disabling neurological conditions affecting people of working age, (stroke and dementia will be more prevalent amongst the older adult population). There is no national register of people with these conditions, so no exact figures exist. Nor is there any indication of severity in these incidence and prevalence estimates or of the numbers who are likely to require continuing health and or social care.

Table 8.17
Incidence and prevalence of neurological conditions
Applied to North Lincolnshire's 18-64 year old population

	Incidence New cases per year per 100,000	Prevalence (%)	Approximate nos in N Lincs Incidence	Approximate nos in N Lincs Prevalence
Cerebral Palsy	N/K	0.170%	NK	165
Acquired brain injury	NK	0.183%	170	177
Early onset dementia	NK	0.085%	NK	83
Huntington's disease	N/K	0.16%	NK	16
Motor neurone disease	N K	0.008%	NK	8
Multiple sclerosis	4-5	0.18%	4-5	176
Muscular Dystrophy	N/K	0.050%	NK	48
Spinal Cord Injury	2	0.050%	2	48
Spina Bifida and Hydrocephalus	N/K	0.023%	NK	23
Young onset stroke	55	N/K	54	NK
Epilepsy	24-58	0.77%	23-56	754
Migraine	4000	13.2%	3880	13,000
Dystonia	NK	0.062%	NK	61

Source: DH, 2007, based on 'Neuro Numbers'

The annual incidence of these conditions is not expected to change in the next two decades, although the number of people living with associated disabilities could rise sharply, due to improved medical technology and general health care, increased longevity and improved diagnostic techniques.

Stakeholder views

The provision of health and social care for people with physical disabilities can easily become fragmented, especially for those with low prevalence, but highly complex conditions, where responsibility for delivering services may be shared across a range of organisations, working in different geographical areas. Hence, the need for clear lines of responsibility for those people with complex and continuing health and social care needs who require careful case management, service coordination and review, including a named key worker.

Whilst this may work well in most cases, some stakeholders who were consulted briefly as part of this JSNA summary, felt there was still room for improvement within community health services, and specifically for better coordination of community nursing, occupational therapy and other clinical rehabilitation services. Waiting times for equipment, aids and adaptations remain long – especially for wheelchairs and for housing adaptations. Access to equipment stores is also limited at weekends. This can result in serious health consequences for people with disabilities, unnecessary admissions to hospital or care, and additional costs to families and services.

We were also told that transition planning for young adults across health and social care remains problematic, leading to difficulties for patients and carers.

User views

People with physical disabilities are far less likely than the general population to describe their health as good. Nationally, only 18% of people with disabilities who participated in a recent national survey, described their health as good, 42% said it was fairly good, whilst 40% said it was not good. They are also more likely to be regular users of health services.

When asked about satisfaction with health services, the majority of people with disabilities were very satisfied with the way they are treated by staff, (94%) but far less satisfied when it came to choice over the time or location of appointments, who they saw or what treatment they received.

Younger people are less likely than older people to express satisfaction with health services than older people, with choice over appointment time and location being most heavily criticised by those in employment.

In the national survey almost half of all disabled people said they had encountered barriers, which make it harder for them to access health services. The most common one being difficulties with transport – followed by needing to be accompanied by someone else. Nationally, 1 in 4 people with disabilities questioned mentioned at least one access barrier to getting the most out of health services.

Key challenges and implications

On a more positive note, there are a number of new initiatives planned for disability services in North Lincolnshire over the next three years. This includes:

- Development of a locality based support system with 24 hour rapid response
- Establishing an Every Adult Matters Service
- Enhancing opportunities for self assessment
- Reducing the waiting list for major adaptations and the Disabled Facilities Grant
- Ensuring that everyone has knowledge of their personal budget
- Improving engagement and self advocacy opportunities
- Establishing a fully integrated rehabilitation services
- Developing technologies that enable self care
- Improving the range of housing solutions
- Encouraging prevention and community development approaches
- Increasing opportunities for employment

Delivering personalised care to people with disabilities, including a personal budget for all those eligible for social care is likely to present a challenge in North Lincolnshire. Take up of direct payments amongst this client group is well below the national average in this area, at less than 5%. This compares with a national target of 30% social care clients with self directed support by 2011.

Looking ahead – a wide range of support models, including telehealth and remote care may be required to deliver person centred care to adults with physical disabilities and sensory impairments. Such services are still relatively under developed in North Lincolnshire and national research suggests that public awareness of aids and equipment of all kinds is still quite limited.

A number of service reviews are due for completion by March 2010, including a review of occupational therapy, equipment and community rehabilitation services. A review of the local Disabilities Facilities Grant process is also underway. Both review teams may wish to consider the role of health promotion, primary prevention and early intervention services in reducing the burden on services. They might also consider the views and experiences of service users.

Health and social care agencies might also wish to consider how data coding and data sharing across agencies could be improved to allow for routine analysis of need and more effective forward planning for this client group, including key points of transition between child and adult services, adult and older people services, as well as transition between different service providers.

Prevalence of sensory impairments

The term sensory impairment encompasses visual impairment (including blind and partially sighted), hearing impairment, (including those who are profoundly deaf or hard of hearing), and dual sensory impairment (combined visual and hearing problem, or deafblind).

Again, the national data on prevalence of these impairments in the population are inconsistent, due to different research methods, different definitions and different measures employed for measuring population need. The following data should therefore be regarded as best estimates.

Sight loss

Sight loss is a major health issue. Nationally, it is estimated that up to two million people have significant sight loss, and that this will rise by 2% over the next 30 years. The majority of people with a sight problem are aged 60+. An estimated 4% of the adult population aged 50+ have some form of visual impairment, including almost 1 in 3 of those aged 85+.

The National Eye Epidemiological Model gives the following percentages of adults aged 50+ with a visual impairment, based on the best available prevalence estimates.

Table 8.18
Visual Impairment* in the adult population (aged 50+)

	Impaired vision	Low Vision	Severe impairment
No in N Lincs	2,344	2,007	342
% aged 50+	3.83%	3.28%	0.56%

Source: National Eye Epidemiological Model

* applied to local 50+ population

Applied to local population estimates, we would expect just over 2340 adults aged 50+ in North Lincolnshire with a visual impairment of which less than half will be of working age. Of these an estimated 342, will have a severe impairment, of which most will be aged 65+. Currently, there are 105 adults, of working age, on the blind and partially sighted register in North Lincolnshire, of which 21 are in receipt of packages of social care.

The leading causes of sight loss are age related macular degeneration, (AMD), glaucoma and diabetic retinopathy. The age specific incidence of all three conditions has increased significantly over the last decade, with changes in diabetic retinopathy being the most marked, particularly amongst the older population, where figures have almost doubled since 1991.

Data extracted from the National Eye Epidemiological Model give some idea of the likely prevalence of the most common conditions in the North Lincolnshire 50+ population. This modelled data were calculated using 2001 census population data, and so are likely to underestimate current numbers of older people with these conditions in the population. As our population grows and ages, we should expect these numbers to grow year on year.

Table 8.19
Prevalence of common eye conditions in the adult (50+) population

	AMD	NV- AMD	Geographic Atrophy	Drusen
%	2.31%	1.63%	0.81%	10.9%
No	1272	897	446	5993

Source: <http://www.eyehhealthmodel.org.uk/mainapplication/default.aspx#>

Glaucoma is second to age related macular degeneration as the most common cause of blindness in adults in the UK. Estimated prevalence of Open Angle Glaucoma (OAG), in a predominantly white population aged 40+ is 2.1%, with a lower estimate of 1.7% and a higher estimate of 2.5%. An estimated 67% of cases are not currently detected; and a prevalence rate of 1.4% is estimated for those with previously undiagnosed disease. Prevalence increases steeply with age from 0.3 per 100,000 in people aged 40 years to 3.3% in people aged 70 years. The risk of onset for people with diabetes is almost twice that for people without diabetes.

Table 8.20
Prevalence of glaucoma in the 40+ population

	Glaucoma (OAG) Mean	Highest estimate	Lowest estimate	<60	60+	Ocular Hypertension
%	2.1%	2.5%	1.7%	5.68%	7%	3.2%
No.	1800	2140	1450			2740

Source: Health Technology Assessment, 2008

Cataract is an important cause of visual impairment in the later years of adult life. Whilst cataract is a very common eye condition that develops as people get older, people with diabetes may develop cataracts at an earlier age than someone without diabetes. Estimates of the prevalence of cataract are variable but show that it increases with age.

Table 8.21
Prevalence of cataract (in 50+ population)

	Cataract high estimate	Cataract low estimate
%	6.63%	1.80%
No.	4060	1100

Source: <http://www.eyehalthmodel.org.uk/mainapplication/default.aspx#>

Currently, surgical rates for cataract removal in North Lincolnshire exceed the national average significantly, with 661 per 100,000, cases in 2007/8, compared with 605 per 100,000 nationally.

Based upon the surgical workload for 2008/9, the number of cataract operations in 2010/11 is likely to be in excess of 1200, with an additional 20 more cases a year between now and 2015.

Diabetic retinopathy is the most common cause of blindness in working age people in the UK and is associated with Type 1 and Type 2 diabetes. At any one time up to 10% of people with diabetes will have retinopathy requiring medical follow up or treatment. This equates to at least 800 people in North Lincolnshire with diagnosed diabetes. Currently just under 800 adults have a diagnosis of diabetes which is being managed within primary care.

Both the incidence and prevalence of diabetes are forecast to rise, as a result of rising adult obesity and demographic changes. We should therefore prepare for at least a 1% annual increase in the number of people requiring screening and potentially further treatment by 2015.

Hence the importance of the national screening and early treatment programme, which is offered annually to all people (aged 12 and older) newly diagnosed with diabetes.

Table 8.22
% prevalence of Diabetic Retinopathy in patients with diabetes

	Background DR	Non prolifer DR	Prolif DR	Diabetic Maculopathy
	28%	2.5%	0.7%	7%
Expected nos in 2010	2400	215	60	602
2015	2680	240	70	670

Source: *Future Sight Loss, UK, 2009, based on expected prevalence of diabetes type I and II.*

Table 8.23
Projected prevalence of AMD in 2010 and 2015

	AMD	NV- AMD	Geographic Atrophy	Drusen
2010	1480	1045	520	6988
2015	1655	1170	580	7800

Based on current prevalence applied to population projections

Table 8.24
Projected prevalence of OAG in 2010 and 2015

	Glaucoma Mean	Highest estimate	Lowest estimate	<60	60+	Ocular Hypertension
2010	1885	2245	1525	5095	630	2870
2015	2015	2398	1630	5550	670	3070

Based on current prevalence applied to population projections

Table 8.25
Projected prevalence of Cataract in 2010 and 2015

	Cataract high estimate	Cataract low estimate
2010	4250	1150
2015	4750	1290

Source: ONS, 2009 *Based on current prevalence applied to population projections*

Hearing impairment

It is estimated that 1 in 5 adults in this country has a bilateral hearing problem which affects their hearing and communication. Amongst older people the prevalence of hearing loss is estimated to be much higher at 50%, making it the third most common age related long term condition, after arthritis and hypertension (high blood pressure).

A national research study published in 2007, found that 12% of people aged 55–74 have a hearing problem that causes moderate or severe worry, annoyance or upset, 14% have a bilateral hearing impairment of at least 35 dB hearing level. This compares with 3% of that age group who were receiving intervention, through the use of hearing aids, although good amplification was shown to benefit about one in four of this 55–74 year-old population.

Applied to local population estimates this suggests

- 4,465 55-74 year olds in North Lincolnshire with a hearing problem
- 5,210 with a bilateral impairment of at least 35 decibels hearing level
- 1,120 receiving intervention
- 4090 adults of this age who may benefit from a hearing aid but do not have one.

Source: Davis A, Smith P, Ferguson M, et al. Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models. Health Technology Assessment. 2007; 11.

The older that people are when they present for assessment and intervention, the more difficult they find adaptation to and care of their hearing aids. It often takes 10 years for an individual to recognise that they have a hearing problem (but a shorter time for significant others).

People with hearing impairment are also likely to have other problems, such as tinnitus and balance disorders which can increase the risk of falls and other accidental injury. Imbalance and falls in older people are frequent causes of loss of independence, avoidable illness and mortality.

Table 8.26
Projected Prevalence Hearing Impairment in North Lincolnshire 2010 -2015

	Hearing problem	Bilateral impairment >35 db
2010	4670	5450
2015	5110	5960

Source: ONS, 2009

User views

A recent national survey of people with hearing loss conducted by the RNID, 2008, found high levels of satisfaction with audiology services, with 79% of respondents either quite or very satisfied with the service provided. However, there were some issues with audiology services:

- 71% of respondents with hearing aids had some kind of problem with them and for one fifth of these, the problem was not resolved to their satisfaction.
- Only 23% of respondents were given information about other equipment that might be useful and 21% were given information regarding services and organisations which might be helpful when first receiving their hearing aids.
- 19% of hearing aid wearers find it difficult to get to their hearing aid dispenser.
- 84% of hearing aid users believe they should be called back automatically for a check up. Currently, many are not.

It is not known whether or to what degree these concerns are reflected locally. However, in a recent consultation exercise with profoundly deaf people in North Lincolnshire, other barriers mentioned were poor signage in health and social care facilities, as well as an over reliance on auditory rather than visual prompts when attending appointments in community and secondary care services.

Key challenges and implications

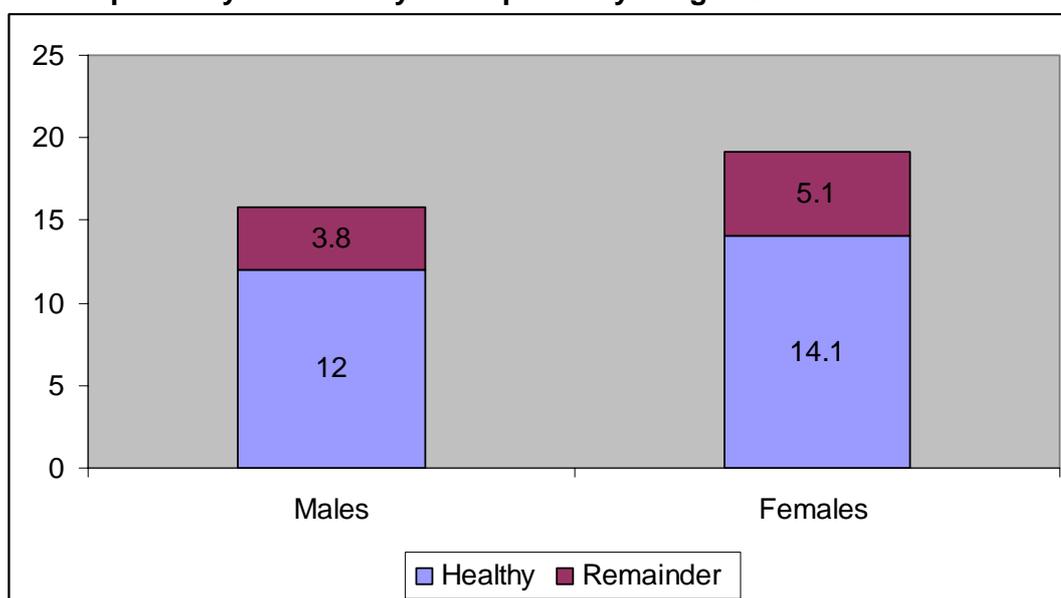
- Demand for both specialist ophthalmology and audiology services is likely to grow as our population ages.
- Both hearing and visual impairment is closely correlated with age, so those areas of North Lincolnshire with a high proportion of older people are likely to have higher levels of need.
- Recent NICE guidance which has lowered the threshold for referral to specialist secondary care services for glaucoma, is also placing increasing pressure on local services.
- Currently, day case admission rates to hospital for ophthalmology services in North Lincolnshire are the highest in the Yorkshire and Humber region and are well above national rates. The level of retention within these specialist services is also above the national average.

- Both audiology and ophthalmology services are under review locally with a brief to consider how local services can be remodelled to help manage this increasing demand.
- To understand the level of met and unmet need locally these reviews would benefit from the inclusion of qualitative information on people's experiences of services locally.

Older People

Getting older does not necessarily mean getting sicker. In fact, many people in their eighties and older, are active and independent and regard themselves as in good health, accepting loss of physical function as a natural and inevitable part of the ageing process. However, as people age, the frequency of ill health and disability tends to increase. So, as our population lives longer it is likely that a significant proportion of these additional years will be spent managing a long term condition, such as such as arthritis, diabetes, hypertension, stroke, heart disease and dementia. Whilst cancer is less common than some of these other conditions, the incidence of some cancers tends to increase as we reach older age, the most common being non-melanoma skin cancer, lung cancer, bowel cancer, breast cancer in women and prostate cancer in men. For more information on local trends in some of these long term conditions (LTCs) see [Burden of disease](#)

Figure 8.10
Life expectancy and healthy life expectancy at age 65 in North Lincolnshire

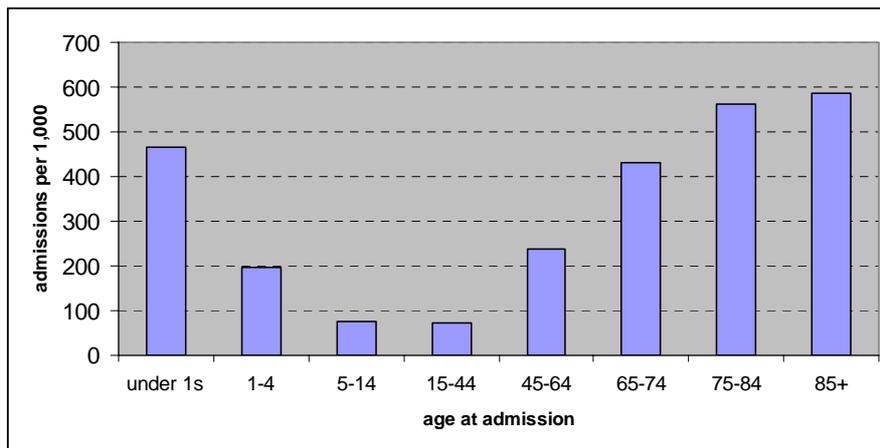


Source: ONS, 2007

Again many of these conditions share common lifestyle related risk factors, including a fatty diet, smoking, low levels of physical activity and alcohol misuse. Others are caused by a more complex interplay of factors, including our genetic make up, as well as the ageing process itself. Those people on lower incomes, who live in our more deprived areas are much more likely to suffer from LTCs than their wealthier neighbours. They are also less likely to access care that might help them manage these conditions effectively.

Across the country as a whole, it is estimated that more than two thirds of people aged 85 years and older have one or more long term condition, (LTC), compared with 20% of 16-44 year olds; with more than a quarter of this older age group having three or more LTCs. As a result, older people are the most intensive users of health services. People aged 85 years and older represent just 2% of the population, and yet account for an estimated 80% of all GP consultations, and more than a third of hospital bed days.

Figure 8.11
Hospital Admission Rate by Age Group (per 1,000 population)



Source: NHS North Lincolnshire

Population estimates

The table below shows the distribution of our older residents by locality. The vast majority of those aged 85+ are older women living on their own. Many of them are dependent on means tested benefits and are at risk of fuel poverty. Few will have access to their own, private means of transport.

Table 8.27

	Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
65-69	1119	2463	1740	1152	3533
70-74	993	1960	1445	949	3280
75-9	757	1483	1126	720	2683
80-4	533	1083	791	561	1989
85+	494	942	737	539	1478

Source: OND mid year estimates, 2008

Care Home Residents

Most older people live at home – with only a small minority cared for in specialist care homes or in various forms of supported accommodation. It is not known precisely how many of our oldest residents are living in these types of arrangements, although it is likely that most of these residents are aged 85+.

GP register data suggest there are just over a 1000 care home residents on GP practice lists in North Lincolnshire. The highest concentration of care home residents is in the Brigg locality, which has the highest number of specialist beds and sheltered accommodation, per head of population. As this older population grows the demand for 24 hour care is likely to increase.

Table 8.28
Number of Registered Beds in Care Homes and Sheltered Housing by Locality 2009

Locality	Care home residents (on local GP registers)	Residential Care Home beds	Nursing Home beds	Sheltered Housing units
Axholme	129	69	79	0
Barton & Winterton	215	140	112	164
Brigg & Wolds	329	234	162	263
Scunthorpe North	66	176	112	138
Scunthorpe South	341	236	93	257
Total	1090	855	558	822

Source: North Lincolnshire Council

Population projections

The most recent population projections for North Lincolnshire suggest a sustained increase in the number of older people in the local population, with most of the growth expected in 2015 and beyond. Between now and 2020, we should expect an average 2-3% annual growth in the overall number of 65+s in the population in North Lincolnshire; which includes an annual 2% growth in those aged 75-84 years, and an annual 4% growth amongst those aged 85+.

Table 8.29
Population projections amongst older people in North Lincolnshire % change from 2009

People aged	2009	2010	2015	2020
65-69 (number)	8,700	9,000	11,400	10,700
% change	-	3%	31%	23%
70-74	7,400	7,500	8,600	10,800
% change	-	1%	16%	46%
75-9	5,700	5,900	6,700	7,700
% change	-	4%	18%	35%
80-4	4,100	4,100	4,700	5,600
% change	-	0%	15%	37%
85+	3,700	3,800	4,400	5,300
% change	-	3%	19%	43%
Total 65+	29,600	30,300	36,700	40,100
% change	-	2%	21%	35%

Source: ONS, 2006 based population projections, 2008

Substance Misuse

National prevalence data suggest an estimated 1,308 problem drug users in North Lincolnshire. Over the last two years, 859 problem drug users have had some contact with structured treatment services in North Lincolnshire, whilst a further 26 have had contact with Tier 2 arrest referral services only. This leaves an estimated 444 drug users, 34% of the total, who are not known to services.

For every problem drug user, it is estimated that 2 family members are affected – including an average of 1 child per user. Of those users in treatment the vast majority are white males aged 24-35 years of age. All are opiate users, with 30% also using crack. 42% of these users inject their drugs.

Whilst North Lincolnshire has an excellent record of retaining clients in treatment, the local partnership has a poor record of planned discharges. Recent consultation with stakeholders, including service users suggest that 98% of service users are on a methadone maintenance script. Whilst for some this may be part of the process of recovery, many people felt that alternatives to maintenance were seldom explored, and that too few users had a planned discharge from treatment.

A recent substance misuse needs assessment identified the following key issues to be addressed in 2010/11:

- A shift in culture towards abstinence focussed treatment, including more staff training on abstinence methods.
- Key to the success of planned discharges are clients' support networks, including support from and for their families, client's access to housing, and to employment.
- Firmer strategic and operational links should be established between all agencies working with families.
- Geographical analysis suggest a large cohort of this vulnerable target group live in estate based social housing. Forging stronger strategic links with housing is therefore a major priority.
- Consideration may also need to be given to placing satellite services in some of these communities.
- There has been no change in the number of people from our minority ethnic communities accessing services. More work needs to be done to ensure that their needs are being met appropriately.

Areas in need of further exploration include

- the reasons behind the low numbers accessing vaccination for Hepatitis B and testing for Hepatitis C in North Lincolnshire.

[North Lincolnshire Substance Misuse Needs Assessment, 2010](#)

Carers

Many of our most vulnerable residents rely on the day to day care and support of relative carers to help them maintain their independence. In 2001, an estimated 1 in 10 of our population were unpaid carers, including 1 in 8 who combined this with full or part time paid work.

Many of these informal carers are older parents and spouses. Older carers are of particular concern as they are more likely to be suffering from ill health themselves. In 2009, an estimated 3,330 people aged 65 years and older provided unpaid care for others in North Lincolnshire, of which more than a third said they carry out more than 50 hours of unpaid care a week. This figure is likely to understate the actual number of older carers in our population. Caring varies between ethnic groups. Bangladeshi and Pakistani men and women are three times more likely to provide care compared with their white British counterparts

The financial costs of caring can be significant. Research by Carers UK found that 72% of carers were worse off financially as a result of becoming carers. The reasons cited for this include the additional costs of disability, giving up work to care, the inadequacy of disability benefits and the charges for services. The same research found carers reporting financial hardship in a number of areas. More than half (54%) were in debt as a result of caring and 32% of those paying rent or a mortgage say they cannot afford to pay it.

Those providing care over a long period of time are at particular risk of poor health and both mental and physical health are likely to deteriorate the longer the carer has been caring. Analysis of the British Household Panel Survey demonstrated that the health of carers is more likely to deteriorate over time than the health of non-carers and many of the detrimental changes can be attributed to the caring role. Carers in the younger adult age group were particularly at risk of poor health, compared with their non caring peers. The research also identified spouse carers and mothers looking after a disabled child as being most at risk of psychological distress and the period immediately after caring ends as a period where ill health is most likely to occur.

In 2008, the Government published its first national cross government Carers' Strategy. The main aims are to ensure that carers have increased choice and control and are empowered to have a life outside their caring role. The 2009 NHS Constitution also specifically mentions carers and the need to respect their role as expert care partners.

A local research report was commissioned in 2009, to inform the local implementation of this national strategy. This research was based on interviews and meetings with over 200 carers, and highlighted the day to day experience of carers in North Lincolnshire. It also highlighted some of the difficulties carers and those they support often face in dealing with local health and social care agencies.

They included:

- Information about support and services – carers said they either received too little information, too late, or were overwhelmed by a range of different materials from different sources. They wanted a single point of access, which would give them accurate and up to date information about what support services were available to them and the person they cared for.
- Lack of consistency and choice in the availability of short breaks services and confusion about how to access these services
- Impact of caring on their own health and well being - Carers felt they would benefit from an annual health check , as many of them feared what would happen if they became ill and were no longer able to care for their relative
- Not being listened to – whilst carers are often experts in the care needs of their relatives, some lacked the confidence and energy to make their views heard when engaging with health and social care staff. Carers wanted to be valued and listened to – and to have an opportunity to influence decisions about the care of their loved ones.

This research has informed North Lincolnshire's Commissioning Strategy for Carers, which was published in 2009. ([hyperlink to Carers Strategy](#))