

# **An Assessment of the Health and Social Needs of Adults with Disabilities in North East Lincolnshire**



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# EXECUTIVE SUMMARY AND RECOMMENDATIONS

The aim of this work programme was to assess the health and social needs of people between the age of 16 and 64 with disabilities (learning & physical) in North East Lincolnshire. This is the first stage in the planning process to ensure the right services are commissioned to maintain the health and social well-being of our disabled residents. The following objectives were agreed by the steering group:

- To identify current health and social needs of disabled people in North East Lincolnshire
- To determine disabled people's perceptions of their needs
- To explore some needs in greater depth and to provide an opportunity for disabled people to raise other issues
- To explore the needs of carers of people with disability
- To review current services for disabled people and identify opportunities to improve services.

A broad range of methods were used in the needs assessment. These included a detailed survey of 950 people living in North East Lincolnshire with disabilities and known to services exploring the major issues of living a normal life, interviews with the carers of people with disabilities, focus groups to explore the major issues in greater depth, interviews with managers providing services for people with disabilities, analysis of available health and social service data, analysis of data on benefits and projections on future numbers of people with a range of disabilities.

Data collection began in February 2009 and proceeded until October of 2009. The survey achieved a 60% response rate and the findings of the study are broken down thematically and cover a broad range of factors that influence the health and social experience of living with disability in North East Lincolnshire. This Executive Summary identifies the main findings from the needs assessment and recommendations are made for addressing the identified needs.

## Health, Health Services and Lifestyle

Overall there was a shortage of routinely available information about the health of disabled people and the extent to which they access health services. Therefore it has been necessary to rely overwhelmingly on the self reported experience of disabled people from the survey in order to gain an understanding about their health, their use of health services and their lifestyle.

It was worrying to find that so many of the respondents reported secondary health problems in addition to their major disability given that this survey was for adults under the age of 65. 58% of participants in the survey reported a secondary condition that affected their health in addition to their primary disability and 14% of respondents identified three or more secondary conditions. Those with learning disabilities were more likely to report secondary conditions than those with physical disabilities. The most common secondary conditions were epilepsy, diabetes, arthritis, coronary heart disease, asthma, hypertension and depression. Despite this 83% of those with learning disabilities self report their health as being good or better compared to just over 34% for those with physical disabilities. This may reflect the fact that participants in the survey with physical disability tended to have quite severe physical disabilities whilst many participants with learning disability had mild learning disability. A significant proportion of the secondary conditions are lifestyle conditions such as diabetes and cardiovascular conditions which may reflect the fact that disabled people have fewer opportunities to engage in activities to support healthy living such as exercise.

Whilst on face value access to health services seems good with over 97% of respondents reporting that they had used a local health service within the last three months, over 75% of respondents

reporting that they visited their GP within the last three months and over 80% believing that they receive all the health services they need, if one delves below the surface some problems can be discerned. 13% of all respondents and 19% of those with physical disability believe they do not receive all the services they need and there appears to be a particular problem accessing dentistry for people with disability. Also over 85% had experienced difficulty accessing health services due to the need for someone to accompany them, concerns about personal safety or lack of money.

## **Recommendations**

- There is limited and conflicting information about the number of disabled people in North East Lincolnshire and the nature and extent of their disabilities. The development of a disability register would enable a much better understanding of the health needs of disabled people and is therefore recommended.
- We need to review how we manage information about disability in the NHS to make it easier to undertake needs assessments and equity audits which can identify whether disabled people are getting fair access to health services.
- We need to ensure that people with disability have easy access to health improvement services that will enable them to improve and/ or maintain their general health. At present those who attend day services appear to be much more likely to get access to these sorts of services than other disabled people and those with physical disabilities particularly appear to miss out.
- We need to ensure that disabled people have full access to dental services and that services are designed in a way that enables disabled people to access them easily.

## **Activities of Daily Living (ADL)**

The vast majority of participants in the needs assessment survey had required assistance with at least some activities of daily living in the months preceding the survey. The vast majority reported that their ADL needs were being met, usually by a friend or relative and sometimes by a paid carer. However 12 people believed that they had ADL needs related to money matters that were not being met and 26 respondents identified ADL needs related to gardening or household repairs that were not being met. In each case it was mainly those with physical disabilities who identified unmet needs. Most respondents reported difficulties shopping and preparing food, mainly because they depended on others for assistance with these tasks.

## **Recommendations**

- Additional ADL support for people with disabilities is needed around money matters and gardening/ household repairs. It is recommended that links with community groups and/ or third sector organisations be explored to attempt to meet these needs. Some services are currently available provided by Citizen's Advice and Open Door but many people are unaware of these and information about these services needs to be made more widely known.

## **Mental Health**

The needs assessment identified that 70% of respondents reported feelings of depression always, often or sometimes. There was considerable variation between the cohorts however with 82% of respondents with a physical disability and 59% of respondents with a learning disability indicating these levels of depression. A similar pattern was apparent in relation to feelings of anxiety. 77%

of all respondents reported anxiety always, often or sometimes and this varied between 80.5% of those with a physical disability and 72% of those with a learning disability.

Limited social contact appears to underpin a lot of the depression and anxiety which affects disabled people. Qualitative data suggests that fear of people often linked to bad experiences such as bullying or abuse from members of the public is impacting on a lot of disabled people's lives. Many also report a fear of crime especially after dark.

Carers of disabled people also reported feelings of depression and anxiety. For some carers, anxiety was linked to fear of the future and what would happen to the person they looked after when they were no longer able to do so. Many carers mentioned restrictions on their lives in terms of lack of freedom to come and go without planning.

## **Recommendations**

- Large numbers of disabled people report feelings of depression and anxiety. However few disabled people are accessing services to treat depression and anxiety at the present time. We need to ensure that appropriate services are available and that disabled people can access them. Where services are available it is important that disabled people are signposted to them.
- Many participants in the needs assessment reported anxiety when out in the public realm, often due to adverse experiences in their past. It is important that abuse/ bullying of disabled people is treated as a crime by public authorities and measures are taken to stop it. This may include public education as well as police action against the perpetrators.
- There appears to be a shortage of community led organisations and support groups for people with physical disability in North East Lincolnshire. The service sector should seek to facilitate the development of these groups.
- The introduction of the two posts of carer support worker within the Learning Disability service appears to have been a positive development. It is recommended that these posts receive sustained funding. We should also consider extending this service to the carers of people with physical disability
- The opening of the new Carers Centre offers the potential for a substantial enhancement in the quality of services to carers in North East Lincolnshire and this is welcomed. Carers for disabled people have significant stress factors within their lives which can easily lead to anxiety and depression. It is important that appropriate services are available for the treatment and prevention of anxiety/ depression in carers. Such services should include regular respite, access to counselling/ Cognitive Behavioural Therapy, social groups as well as financial advice/ support when appropriate.

## **Social Support and Networks**

Almost half of all respondents (48%) to the survey had a low social network score. This varied between 53% of those with learning disabilities and 40% of those with physical disabilities. By contrast 42% of those with physical disabilities lived alone compared with under 10% of the other cohorts. People with physical disabilities were also much more likely to report feelings of loneliness with 61% indicating that they feel lonely always, often or sometimes, compared with 43% of those with learning disabilities. More than half the respondents to the survey said that they did not feel part of their community.

Overall more than two-thirds of respondents with learning disabilities attended daytime activities. However less than a third of those with physical disabilities did so and this may underpin some of the additional feelings of loneliness amongst physically disabled participants. A wide range of barriers to social participation were identified. Whilst the greatest number identified factors associated with their disability as their main impediment, many also identified potentially modifiable factors such as transport difficulties or the need for a companion. Many respondents wanted more opportunities for social interaction and there was thought to be a particular lack of social opportunities for disabled people who are neither young, nor old.

## **Recommendations**

- Lack of social contacts appears to be associated with anxiety and depression for disabled people in North East Lincolnshire. We need to increase opportunities for social interaction for disabled people, especially those who at present do not access regular day time activities.
- A large number of physically disabled people live alone and are at high risk of social isolation, especially those who do not attend day services. Consideration needs to be given to how these people can be given more opportunities for social interaction given their limited mobility. Day services which support people with physical disabilities could be extended to increase the number of people able to access them and the amount of time they can be accessed for. However day services are not suitable for all and it may be more appropriate to make investments in community and voluntary organisations which provide social or vocational activities which reduce the social isolation of physically disabled residents of North East Lincolnshire.
- More consideration needs to be given to the social needs of disabled people in a middle age range, e.g. 30-60, who may be too old for social activities targeting people in their teens and twenties but too young for activities designed for older people. The Local Authorities Leisure and Culture and Libraries service should invest further in initiatives that support disabled people in this age range.
- Community and voluntary groups in North East Lincolnshire should explore opportunities to promote social integration within their local communities to reduce social isolation among people with disabilities. The provision of a development worker to support such groups should be considered.

## **Dignity and Respect in Health and Social Care Services**

Almost 90% of respondents to the survey believed that they were treated with dignity and respect by health and social services. However a minority, especially amongst learning disability respondents, felt that some of the difficulties of their condition were not fully understood by service providers.

Of possibly greatest concern from this section of the report is the number of participants who described incidents when they were treated disrespectfully by the general public and/ or people within their community. This came out strongly within the qualitative elements of the needs assessment. The service review pointed to a number of initiatives which have been established to tackle community safety issues or hate crimes that can affect disabled people but the evidence from this needs assessment suggests that more needs to be done.

## **Recommendations**



- This needs assessment points to a problem with antisocial behaviour and hate crimes directed at disabled people in North East Lincolnshire. However it does not provide the necessary detail to establish whether the problem is localised to specific areas or a more widespread problem across the whole area. We therefore need a better understanding about the extent of hate crime or anti social behaviour directed at disabled people and whether it is located in specific areas or a more widespread problem. It is recommended that organisations such as the police and the Local Authority review their data about reports of antisocial behaviour and hate crime directed towards disabled people and develop initiatives to tackle identified problems.
- There is a need for disability awareness raising in the local population. For children and young people this may be possible within schools and youth clubs. For the wider population there may be an opportunity to use media communications more effectively.

## **Employment and Education**

Employment and/ or education is vital to the economic and social wellbeing of many working age adults. Exclusion from employment, either on a temporary or permanent basis can have a major negative impact on the mental health and self esteem of people who are unable to work. Only a very small proportion of the survey respondents were in paid full or part time employment with over three quarters of respondents indicating that their disability had left them unable to work. Of those that were able to work most stated that they had found it difficult to get a job because of their disability. This was particularly the case for respondents with a learning disability. Around one in eight respondents were participating in voluntary work, a similar number were in full time education and a similar number again were in part time education.

Educational opportunities were a particular concern for those with learning disability going through transition as little choice was being given about where children could continue in education. It was suggested that they were being pushed towards one institution, regardless of whether they felt it was suitable or not.

The service review showed there are a significant number of innovative organisations and initiatives within the statutory and voluntary sector working to develop employment, education and training opportunities for people with disabilities with some considerable success.

## **Recommendations**

- It was surprising and concerning that so few participants in the survey were in employment. Public sector and private sector employers need to ensure that they are taking their responsibilities for ensuring disability employment rights seriously and are supporting disabled people into employment within their organisations. As part of a Corporate Social Responsibility agenda it is recommended that the Care Trust Plus and North East Lincolnshire Council undertake an audit to identify the number of staff with disabilities working within their organisations and an audit of buildings to identify how accessible the buildings are for disabled people.
- The impressive work of the voluntary sector in North East Lincolnshire in increasing occupational opportunities for disabled people should be given maximum support from public sector organisations. Continued expansion of voluntary sector initiatives which support employment, education and training amongst disabled people is recommended. However at present most initiatives appear to be targeted at those with mental health problems or learning disabilities. It is likely to be cost effective to map and bring together the various local initiatives and ensure that they develop a broader focus in the future by providing more opportunities for those with physical disability.

- Disabled people going through transition are in a particularly vulnerable position and need to be given the maximum possible choice to improve their education and opportunities. The presence of a nationally respected educational college for people with learning disabilities within North East Lincolnshire is a great opportunity to improve life chances for disabled people locally. The Local Authority should review whether it can make more investment in this college to ensure that people with disabilities going through transition in North East Lincolnshire have access to the best possible education. Alternatively they should assess what the factors are that make this particular college so popular with the families of disabled people and explore whether these factors can be replicated within existing provision.

## **Finance and Benefits**

Ensuring adequate benefits is vital to the health and social wellbeing of disabled people as the majority are unable to work. The needs assessment identified that there are over 8000 adults in receipt of Disability Living Allowance in North East Lincolnshire, including over 6000 under the age of 65. There are almost 2000 people in receipt of carers allowance, around three-quarters of whom are women. The majority of people in the survey reported that they had received advice about benefits that they are entitled to, however more than one in five had not. Around one in five overall and more than one in four physical disability respondents thought that they required further advice about benefits.

Over 80% of respondents were happy with the current care package they received. This varied between 85% in the learning disability cohort and 76% in the physical disability cohort. The two most common responses from those who were not happy with the current package were that they believed that they did not have a care package at present or they had anxieties about future care. This was expressed most often by respondents currently going through transition.

## **Recommendations**

- Financial advice about benefit entitlements is vital for disabled people and should be readily available and targeted if necessary. The provision of welfare rights advocates within the Disability Services may be one way of achieving this.

## **Housing and Adaptations**

Most respondents with learning and physical disabilities live in houses. However 40% of those with physical disability live in a bungalow or ground floor flat. Unsurprisingly the needs assessment identified the fact that disabled people are much less likely to own their own home than the general population. Once again there were considerable differences in housing arrangements between those with learning disability and those with physical disability. Whereas almost half of physically disabled people own their home, only a single person with learning disability indicated that they did so. By contrast almost a third of people with learning disabilities pay a landlord for their accommodation, slightly less than this live with family and around a quarter are in residential accommodation, compared to around one in 40 of those with physical disabilities. More than a quarter of respondents who live with their parents are over the age of 40, which raises concern for future caring arrangements as their parents become too old to look after them. Around a third of people with physical disabilities live in the 20% most deprived parts of North East Lincolnshire.

Around one in six respondents believed that their accommodation was unsuitable for their needs. The main reasons for this were the presence of stairs, unsuitable bathrooms or the property was

too small. The vast majority of respondents (97%) had central heating in their home but, worryingly, just under 40% of respondents with physical disability said they could not afford to heat the home adequately. 44% of all respondents indicated that they had had adaptations carried out to their home. 17% indicated that adaptations were needed.

## **Recommendations**

- We must take account of the ageing profile of adults with disabilities and the impact that care arrangements may be having on parents who may be quite elderly. Currently around 33% of carers of people with learning disabilities are over 65 years old and it is likely that additional provision will be needed once these parents become unable to look after their disabled children. In the meantime it is important that additional support is available for elderly people carrying out caring responsibilities.
- The tendency for so many people with physical disabilities to report difficulty heating their home is of major concern. With so many living in the deprived parts of North East Lincolnshire either in their own home or rented accommodation they are particularly vulnerable to poverty which may be exacerbated by their physical condition and social isolation. We need to link with Strategic Housing to review housing quality for disabled people exploring fuel poverty issues. Based on this appropriate investments should be made to improve the energy efficiency and quality of heating in the homes of people with disabilities.
- Around a fifth of respondents indicated that their home was not suitable for their needs at the present time. We need to ensure that information that services have about the housing needs of disabled people is up to date and appropriate adaptations are carried out as soon as possible where unmet need is identified.
- Strategic Housing should consider opportunities to increase the provision of Housing with Care for people with disability, i.e. housing which provides the opportunity for independent living but which has care provision located close by if the need arises.

## **Transport**

Transport is a key enabler to participation in society and without the ability to travel disabled people are denied access to education, employment, social activities, healthcare and shopping. Transport inevitably poses significant challenges for people with disabilities and it is vital that public authorities do whatever they can to mitigate these difficulties. The survey found that overall most disabled people used cars to get around North East Lincolnshire. It was found that those who had access to their own car had higher social network scores which reduces the risk of social isolation and possibly also reduces the risk of depression and anxiety. Public transport is the main form of transport for those with learning disability, especially the bus, and concessionary bus passes have increased the freedom of disabled people to travel this way. For some however, public buses are not a good option because not all buses are disability friendly, the attitude of bus drivers and passengers has put the person off using the bus or the person is unable to travel alone. Many disabled people use taxis but fares were considered expensive and therefore limited the frequency that they would be used.

Walking is also common amongst disabled people as a form of transport and there was concern about the state of pavements and street clutter which presents particular difficulties for those with poor eyesight and wheelchairs.

The 'Dial a Ride' and the 'Phone 'n Ride' services provide an affordable local transport service to disabled people with door to door transportation and helpful staff. However there are limitations in terms of the times that a person can travel and opportunities for spontaneous travel.

Accessing services, including health services was widely identified as problematic in the survey. 85% of respondents overall reported that they had experienced difficulties accessing health services. 90% of physical disability respondents reported difficulties compared to 80% of learning disability respondents. There was a perception that GPs are now less willing to do home visits which can present difficulties for some disabled people.

## **Recommendations**

- Ensure all public buses are modern buses designed for easy access for disabled people, including those in wheelchairs.
- One of the main problems identified by disabled people in the survey was that they needed assistance to get where they wanted to go as many were unable to travel alone. Local agencies should therefore consider the development of a buddy or befriending service which could potentially help to alleviate this problem and also break down barriers between people with disability and the wider population.
- Public transport companies should take responsibility for ensuring that disabled people feel comfortable and safe to travel on their services. As a minimum they should ensure that all public transport staff have attended appropriate disability awareness training and understand the needs of disabled people.
- Ensure the needs of disabled people are considered within street design & management and that damage to pavements is rectified promptly.
- Consider the findings of this needs assessment when preparing future transport plans.
- Take appropriate action to stop private vehicles parking in disabled parking spaces and on pavements.
- Consider extending the operating hours of the 'Dial a Ride' and 'Phone 'n Ride' services and increasing membership opportunities.

## **Information and Communications**

The use of the internet for information and communication has become much more common in recent years. However the results of this needs assessment show that this should only be used as an additional form of communication for this client group and more traditional forms of information and communication such as magazine and information leaflet are required as the norm. Overall just over a quarter of respondents used the internet. Of those who did not currently use the internet, three quarters expressed no wish to use it or were unable to do so because of their disability. Similarly, other modern forms of communication such as the 'red button' and mobile phone text messaging were not favoured by respondents.

There is a danger that the tendency for organisations to focus on modern forms of communication will significantly disadvantage those who choose not to or are unable to use these communication methods. These groups tend to be especially vulnerable and we risk increasing health inequalities if we do not ensure that people continue to receive the information they need in the form that is most suitable for them. It is also important that the use of modern communication systems does

not replace the personal touch which was identified by respondents to this survey as important. This is especially true when it comes to complex issues such as benefits and finance.

Finally we need to ensure wherever possible that the information we send out is useful to the recipient. Sending out too much information will often result in important information being missed or discarded.

## Recommendations

- When communicating with disabled people agencies need to ensure that information is sent out using appropriate methods. Whilst internet/ email/ text message/ digital communications will appeal to some disabled people, the evidence from this needs assessment strongly shows that the majority of disabled people prefer information and communication using traditional forms such as magazine/ leaflet/ letter etc. It is also important that information is kept up to date and there was a suggestion from some services that many of their leaflets are out of date.
- Many disabled people and their families/ carers value face to face contact for sharing information and this is especially the case for complex information. Agencies working with disabled people in North East Lincolnshire should ensure that inter-personal forms of communication and information sharing continue to be provided by their services.
- Agencies need to be aware of the low amount of people with disability in North East Lincolnshire who use the internet. There is growing evidence that those people unable to use the internet in modern Britain are disadvantaged in many different ways, e.g. paying more for energy bills. At a local level agencies should investigate opportunities for increasing the proportion of disabled people using the internet, e.g. focused training sessions.
- Consider the establishment of a computer equipment recycling scheme to provide low cost computers to hard to reach groups as recommended by Digital Britain.

## Conclusion and Overarching Recommendation

The needs assessment has identified many of the challenges that people with disability and their families/ carers face in trying to live a normal life in North East Lincolnshire. On the positive side there is evidence that statutory services, especially those supporting people with learning disability, are responding well with many new and innovative services developed in recent years. There also appears to be a vibrant voluntary sector which is making a major contribution to local service provision.

However there is evidence from the needs assessment that many people with physical disability are struggling both with their health and with a multitude of social factors within their daily lives.

The final recommendation of this needs assessment therefore is that the results of this study are used to **develop a new strategy and/ or commissioning plan which is focused on improving the health and wellbeing of adults and children with physical disability in North East Lincolnshire.** The strategy/ commissioning plan needs to address the considerable difficulties being faced by people with physical disabilities in North East Lincolnshire in living an ordinary life. Evidence from this needs assessment suggests that many face difficulties with their general health and mental health, they are more likely to live in inadequate housing in deprived communities within the area that they find difficult to heat adequately, they are more likely to be lonely and socially isolated but less likely to have access to day services and initiatives to support work or training.

The development of the strategy/ commissioning plan should be multiagency involving North East Lincolnshire Care Trust Plus, North East Lincolnshire Council, Grimsby hospital, voluntary and community organisations, representatives of local businesses, especially those who provide services for disabled people and significant involvement from North East Lincolnshire residents with physical disabilities.

# 1. INTRODUCTION

The scoping exercise for this needs assessment identified the need for credible information about:

- the physical health of disabled people and their care and support needs
- disabled people's level of knowledge about staying healthy and improving health
- the mental health of disabled people
- social support and networks
- dignity and respect
- employment and education opportunities
- housing
- transport
- how people with disability prefer to receive information

## 1.1 Study Aim

- To assess the health and social needs of people between the age of 16 and 64 with disabilities in North East Lincolnshire. This is the first stage in the planning process to ensure the right services are commissioned to maintain the health and social well-being of our disabled residents.

## 1.2 Study Objectives

- To identify current health and social needs of disabled people in North East Lincolnshire
- To determine disabled people's perceptions of their needs
- To explore some needs in greater depth and to provide an opportunity for disabled people to raise other issues
- To explore the needs of carers of people with disability
- To review current services for disabled people and identify opportunities to improve services.

## 1.3 Study Methods

A detailed account of research methods used in the needs assessment is contained in appendix 5. A summary is provided below.

### Ethical Approval

Ethical approval for the research was sought from the South Humber Research Ethics Committee and Research Governance approval from North East Lincolnshire Care Trust Plus sponsored by Northern Lincolnshire and Goole Hospitals NHS Foundation Trust. The Ethics Committee reported that they had no ethical concerns and research approval was granted. A project steering group was established which included representatives from the Care Trust Plus, Local Authority and service users.

### Postal Survey

A major component of the study was a postal questionnaire to collect non-routinely available information. This was sent to all people between the age of 16 and 64 registered with either the Learning Disabilities Service, the Physical Disabilities service or the Children's Disabilities Transitions service in North East Lincolnshire Council (the Children's Disabilities Service provides services to people between the age of 13 and 25).

The questionnaire sample was obtained via service provider lists. The Learning Disability, Physical Disability and Transition teams provided SWIFT ID numbers of all clients receiving services who were resident in North East Lincolnshire, these numbers were then entered onto questionnaires to

allow respondents to be logged into the system and non-responders issued with reminder letters. Everyone between the age of 16 and 64 registered with these services was invited to take part. For those who were unable to complete the survey themselves, the invitation letter asked if someone such as a family member or carer would help them to complete it.

There was concern from the steering group that one limitation of the study was that the sample could only be obtained from the lists of service users provided by the disability services in North East Lincolnshire, and that there would be a significant number of people with disabilities who would not be registered with these services. Therefore in order to try and involve people with a disability who were not registered with any of the disability services, posters and an accompanying letter explaining the nature of the study and its aims were sent to all care and nursing homes, GP surgeries, libraries and day centres in North East Lincolnshire, with a request that they should be displayed in prominent positions to advertise the study and raise awareness of it.

The survey commenced in early February 2009 and questionnaires with a covering letter signed by the Director of Public Health (Appendix 1) were sent out in mid February and March 2009, with reminder letters (Appendix 2) and a new copy of the questionnaire (Appendix 3) posted to those who had not responded three weeks after the date of the original posting.

The survey administrative databases were held in Excel. The questionnaire database was coded and entered into SPSS by analysts in the Public Health Intelligence Unit. All care home or residential home residents were coded as 'living with friends or others'.

In total, 950 potentially eligible questionnaires were dispatched. The number of returned questionnaires, number of questionnaires eligible for return (questionnaires were considered ineligible for return if the person was not known at the address provided or had since died) and the response rate for that team are shown below.

Table 1.1                      Survey Response Rates

	<b>Number returned</b>	<b>Number eligible</b>	<b>Response rate</b>
Learning Disability	297	430	69.1%
Physical Disability	234	398	58.8%
Transition	34	122	27.8%
<b>Total</b>	<b>565</b>	<b>950</b>	<b>59.5%</b>

#### Focus Groups and Interviews

Focus groups and interviews took place between May and August 2009. Focus group participants were recruited through the flyer which was sent out with the questionnaire pack. This listed the focus groups to be conducted and invited potential participants to tick those they would be interested in attending. The scheduled focus groups were transport, physical accessibility of services, finance, sexual health & relationships, transition and community. In the event the sexual health focus group was abandoned as few people expressed a willingness to participate.

Interviewees were recruited mainly through the local Carer's forum and the Community Learning Disability Team. Semi structured interviews were conducted with the parents of disabled people who were going through transition from children's services to adult services and with carers of people with disabilities.

#### Service Review

A review of services for people with disability in North East Lincolnshire was undertaken. Semi-structured interviews were undertaken with approximately 35 health and social care professionals and managers, referred to as stakeholders. Service managers also submitted documents which described their service.

#### Data Analysis



Data to support the needs assessment was obtained from a wide range of sources. For instance data estimating future trends in the incidence of various types of disability were obtained from the Projecting Adult Needs and Service Information System and data about benefit claimants were obtained from the Office for National Statistics. All data sources are referenced in the text. Analysis and/ or interpretation of this data were carried out by the Public Health Intelligence Unit.

## 1.4 POLICY CONTEXT

### National

In the 1999 White Paper, *Saving Lives: Our Healthier Nation*<sup>1</sup>, the Government signalled a new approach to tackling poor health, recognising the 'potent social, economic and environmental' determinants and that it will take individuals, communities and government working in partnership to improve the health of everyone and particularly that of the worst off. As well as a range of public health interventions to secure better health the report identified a £21 billion investment in the NHS alone.

Shortly after this in 2000, *The NHS Plan*<sup>2</sup> was introduced, setting out the agenda for transforming and improving the NHS, firmly putting people at the heart of public services. The *Choosing Health* White Paper<sup>3</sup> in 2004 introduced a range of support mechanisms to help people to make healthy lifestyle choices and in 2005 with the Green paper *Independence, Well-being and Choice*<sup>4</sup> the first step in transforming social care was taken, building on the drive to maintain the independence of individuals and providing greater choice over how needs are met.

After wide consultation, the *Our Health, Our Care, Our Say* White Paper<sup>5</sup> was published in 2006 and set out a new direction for the whole health and social care system, involving local people to drive local service improvements. The White Paper aims to achieve four main goals: better prevention services and early intervention, giving people more choice and a louder voice, tackling inequalities and improving access to community services and more support for people with long-term conditions.

The local government White Paper, *Strong and Prosperous Communities*<sup>6</sup> published in 2006 focused on local partnership working and aimed to make it easier for local authorities and local NHS organisations to work together to tackle health inequalities and provide better integration of health and social care to respond to local needs. A new statutory partnership for health and well-being was proposed, with a duty to prepare Local Area Agreements and jointly agreed targets. A move from service delivery to an emphasis on strong commissioning was seen as key to this agenda and in 2007 the *Commissioning framework for health and well-being*<sup>7</sup> was introduced for commissioners of health services, social care services and broader local government services, putting people at the centre of commissioning and involving people in shaping and improving services. *World class commissioning*<sup>8</sup>, the vision and competencies required, followed soon after as a statement of intent.

The NHS next stage review, *Our NHS, Our Future*<sup>9</sup> led by Lord Darzi in 2007 suggested that the NHS was about two thirds of the way through its review programme to date. It stressed the vision for a fair, personalised effective and safe NHS and heralded the next stage review for a world class health service with health and social care staff empowered to lead change. Lord Darzi's final report in 2008, *High Quality Care for All*<sup>10</sup>, stresses that having concentrated on increasing the amount of care provided there is a need to focus on improving the quality of care. It recognises the need to commission well-being and prevention services and reinforces the requirement for partnership working and giving patients more information and choice.

*Putting People First*<sup>11</sup>, outlined a shared vision and commitment to the transformation of adult social care in 2007 and was followed shortly after in 2008 by *Transforming Social Care*<sup>12</sup>, a Local Authority Circular that looks at the vision for the development of a personalised approach to the delivery of adult social care and support mechanisms for councils with social service

responsibilities to deliver the modernisation agenda. The cross-Government reform agenda aims, by radically reforming public services, to enable people to take control of their own lives to live as independently as possible and with dignity. Investing in preventive interventions for health, housing and social care is key. In addition, *Transforming Social Care*<sup>12</sup> recognises that a whole system reform is required. In future, those eligible for publicly funded social care will receive a personal budget (receiving some or all of it as a direct payment) to use to meet their needs (including broader health and well-being needs) with support, if required, to design their own package of care and to make informed choices. Importantly, for the first time, it details a new ring-fenced grant for three years to help councils reshape their systems.

#### Local

In North East Lincolnshire the need for closer working between the local authority and the NHS to influence the 'potent social, economic and environmental' determinants of health and well-being, and the need for closer integration of the health and social care agenda, has been recognised for some time. Local policy has resulted in the development of the 'Care Trust Plus', with children's health services and the public health Directorate staff seconded to the Local Authority and Adult Social Care staff transferred to the NHS. It is believed that this will enable a more effective delivery of the policy agenda in North East Lincolnshire, resulting in better services for residents.

The Local Strategic Partnership operates a sub-structure of four partnership boards, one of which is for healthier communities. Support for vulnerable adults is a Local Area Agreement (LAA2) priority.

## 2. POPULATION & DEMOGRAPHY

### 2.1 Population Estimates: General Population

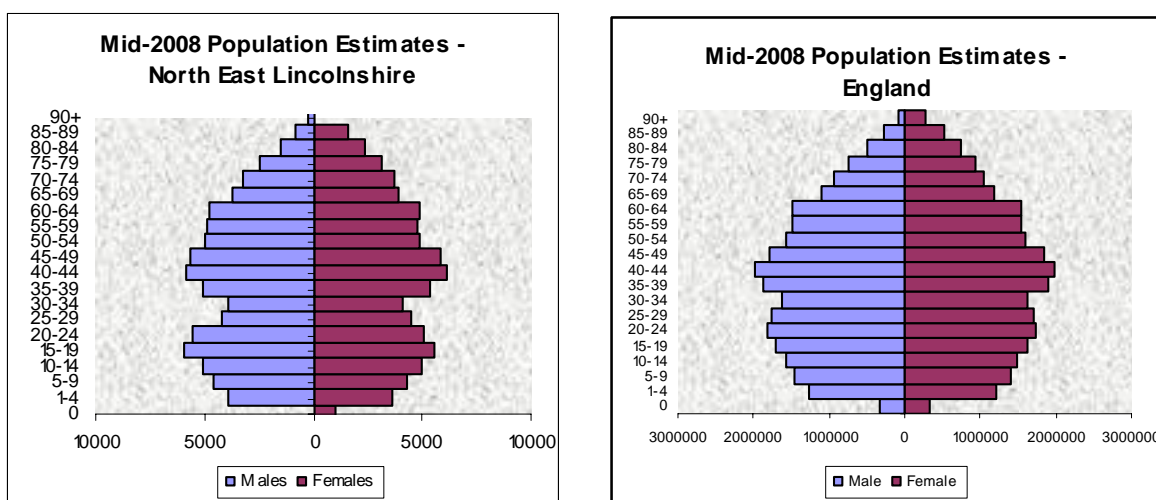
North East Lincolnshire has seen increasing life expectancy in recent years, and this trend is likely to continue. It is therefore important to have accurate population figures both current and projected with which to determine current and future need. The Office for National Statistics (ONS) provides mid-year estimates of population each year, the most recent being for 2008, based upon the 2001 census. The age breakdown for North East Lincolnshire unitary authority is in Table 2.1 below.

Table 2.1 North East Lincolnshire Unitary Authority: 2008 mid-year population estimates

Age-band	Males	Females	All People
0-4	4900	4600	9500
5-9	4600	4300	8900
10-14	5100	5000	10100
15-19	5900	5600	11500
20-24	5600	5100	10700
25-29	4200	4500	8700
30-34	3900	4100	8000
35-39	5100	5400	10500
40-44	5800	6100	12000
45-49	5700	5800	11500
50-54	5000	4900	10000
55-59	4900	4800	9700
60-64	4800	4900	9700
65-69	3700	3900	7500
70-74	3200	3700	6900
75-79	2500	3100	5600
80-84	1500	2400	3900
85+	1100	2500	3500
<b>All Ages</b>	<b>77500</b>	<b>80700</b>	<b>158200</b>

Source: ONS Crown copyright

Figure 2.1 North East Lincolnshire Unitary Authority: 2008 mid-year population estimates pyramids



Source: Mid-2007 Population Estimates, Office for National Statistics, [www.statistics.gov.uk](http://www.statistics.gov.uk), © Crown Copyright 2008

The population distribution of North East Lincolnshire illustrated in Figure 2.1 has two distinct differences compared to the mid 2008 population estimates for England. There is initially an increase in numbers with age but after the 25 to 29 age band there is a distinct drop in the population, until the 35 to 39 age band where it increases by over 2,000. Analysis by the Dr Foster organisation in support of the Joint Strategic Needs Assessment for North East Lincolnshire<sup>13</sup> shows a more marked drop in the 20-40 age group among the 20% most affluent in our population than among the 20% most deprived. This probably reflects numbers leaving the area for work or university and not returning. This may have future implications.

However, there is another data source at a more local level that is able to estimate the population of North East Lincolnshire. The data is obtained from the national Exeter Patient Registration system. The postcode of the patient can be used to calculate resident populations and for this analysis, the postcode used was coterminous with the geographical boundary of North East Lincolnshire Unitary Authority.

**Table 2.2** Estimated resident population for North East Lincolnshire Unitary Authority – Exeter Data (April 2009)

Age band	Males	Females	All People
0-4	4845	4470	9315
5-9	4514	4312	8826
10-14	5166	4845	10011
15-19	5752	5481	11233
20-24	5731	5293	11024
25-29	5128	5000	10128
30-34	4648	4266	8914
35-39	5863	5382	11245
40-44	6350	6179	12529
45-49	6333	6039	12372
50-54	5428	5110	10538
55-59	5167	4824	9991
60-64	5180	5064	10244
65-69	3872	3889	7761
70-74	3297	3656	6953
75-79	2562	3107	5669
80-84	1599	2344	3943
85+	1123	2385	3508
<b>All Ages</b>	<b>82558</b>	<b>81646</b>	<b>164204</b>

Source: Exeter Patient Registration System

Even though there is a 2 year difference, when compared to the ONS estimates, the Exeter Patient Registration system has nearly 6,000 more people living in the North East Lincolnshire Unitary Authority area. The extra numbers are found on the male side, as previously, the ONS estimated there to be more females than males in the authority but this situation is now reversed with the Exeter data. Overall, there is still a substantial drop in the early age bands but this occurs at the 30 to 34 age group rather than the 25 to 29 age band. However, there is an increase in the population for the 60 to 64 population that is not seen in the ONS data.

## 2.2 Population Estimates: Disabilities

Unfortunately, there is a dearth of substantial information surrounding population estimates for those with disabilities and therefore we need to look at data that may be used as a proxy for this cohort. Table 2.3 below shows the proportion of the population with a limiting long term illness. A limiting long-term illness is any long-term illness, health problem or disability that limits daily activities or work. There were 14.2% of the working age population of North East Lincolnshire

which had a Limiting Long Term Illness, slightly lower than for the Yorkshire and Humber region but higher than the national average, which is 13.3%<sup>14</sup>.

**Table 2.3** Limiting Long Term Illness in North East Lincolnshire

Illness	North East Lincolnshire		Yorkshire & the Humber SHA	England
	Count	%	%	%
People with a limiting long-term illness (All People)	30,019	19.0	19.5	17.9
Working-age people with a limiting long-term illness	13,154	14.2	14.6	13.3

Source: 2001 Census [KS08 Neighbourhood Statistics] ONS. [www.statistics.gov.uk](http://www.statistics.gov.uk)

There is prevalence data available for adults over the age of 18 with learning disabilities from NCHOD (National Centre for Health Outcomes Development - [www.nchod.nhs.uk/](http://www.nchod.nhs.uk/)). Within the context of this information a learning disability is defined as the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood (18 years), with lasting effect on development. The definition encompasses people with a broad range of disabilities but does not include all those people who have a “learning difficulty”<sup>15</sup>.

The numerator data is calculated as those adult patients on the learning disability register, registered with GP practices within North East Lincolnshire Care Trust Plus on the 14<sup>th</sup> February 2007 (National Prevalence Day). The data is derived from the Quality Management Analysis System (QMAS) though the use of this data should recognise that QMAS was established as a mechanism to support the calculation of Quality Outcome Framework (QOF)<sup>a</sup> payments for each GP practice and not as a person based epidemiological tool.

**Table 2.4** Prevalence of those with Learning Disabilities in North East Lincolnshire CTP (Age Adjusted 18+) 2007/08

Area	Number of Patients on LD Register	Percentage	LCI 95%	UCI 95%
North East Lincolnshire CTP	525	0.39	0.36	0.43
Yorkshire & Humber SHA	14425	0.34	0.34	0.35
England	144909	0.34	0.34	0.34

The adjusted percentage prevalence rate for North East Lincolnshire CTP is 0.34. This is significantly statistically higher than both the regional and national rates. There is no equivalent system for monitoring the prevalence of physical disability.

## 2.3 Population Projections

Population projections are particularly useful for anticipating future demands on services and data provided by the Office for National Statistics (ONS), based on mid-year estimates, allows for yearly projection up to 2031. Projections for North East Lincolnshire unitary authority based on the 2006 mid-year estimates for the year 2010, 2015 and 2025 are available within the Joint Strategic Needs Assessment 2009<sup>16</sup>.

<sup>a</sup> QOF is part of the General Medical Services (GMS) contract, with a focus on prevalence and management of common chronic diseases at general practice level. It is aimed at measuring the achievement of general practices against a set of evidence based negotiated standards and encouraging good practice.

There is some data that exists to enable projections around disabilities. This comes from PANSI (Projecting Adult Needs and Service Information – [www.pansi.org.uk/](http://www.pansi.org.uk/)) a service that allows authorities to project needs of adults in the local area for ages 18 to 64. It uses the 2006 based long term ONS sub national population projections.

### Learning Disabilities

These predictions are based on prevalence rates in a report produced by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University<sup>17</sup>. The prediction rates in the table below have been applied to ONS population projections of those aged 18 to 64 in the years 2011 and 2021 and linear trends projected to give estimated numbers predicted to have a learning disability, in the years 2010, 2015, 2020 and 2025. Table 2.5 suggests there will be little change overall in the number of adults between the age of 18 and 64 with Learning Disability in North East Lincolnshire although there will be significant fluctuations at certain ages.

**Table 2.5** Projections to 2025 of those predicted between the ages of 18 to 64 to have a Learning Disability in North East Lincolnshire

Age Band	2010	2015	2020	2025
People aged 18-24 predicted to have a learning disability	418	384	343	336
People aged 25-34 predicted to have a learning disability	451	540	563	528
People aged 35-44 predicted to have a learning disability	526	457	470	551
People aged 45-54 predicted to have a learning disability	526	556	517	454
People aged 55-64 predicted to have a learning disability	448	447	500	527
Total population aged 18-64 predicted to have a learning disability	2,370	2,384	2,394	2,396

Figures may not sum due to rounding. Crown copyright 2007

Emerson and Hatton<sup>17</sup> also estimated the prevalence of moderate or severe learning disability likely to need, and be receiving, care services. A similar pattern can be observed in Table 2.6 with little change overall in the number of adults 18-64 with moderate or severe learning disability in North East Lincolnshire.

**Table 2.6** Projections to 2025 of those predicted between the ages of 18 to 64 to have a moderate or severe Learning Disability in North East Lincolnshire

Age Band	2010	2015	2020	2025
People aged 18-24 predicted to have a moderate or severe learning disability	96	89	80	79
People aged 25-34 predicted to have a moderate or severe learning disability	97	111	120	117
People aged 35-44 predicted to have a moderate or severe learning disability	132	115	118	139
People aged 45-54 predicted to have a moderate or severe learning disability	118	125	116	102
People aged 55-64 predicted to have a moderate or severe learning disability	97	97	109	114
Total population aged 18-64 predicted to have a moderate or severe learning disability	540	536	542	551

Figures may not sum due to rounding. Crown copyright 2007

### Physical Disabilities

Projections are also available for those with physical disabilities and are based upon prevalence data for moderate and serious physical disability by age and sex. It is included in the Health Survey for England, 2001.

**Table 2.7** Projections to 2025 of those predicted between the ages of 18 to 64 to have a moderate or serious Physical Disability in North East Lincolnshire

Age Band	2010	2015	2020	2025
People aged 18-24 predicted to have a moderate physical disability	631	582	521	512
People aged 18-24 predicted to have a serious physical disability	123	114	102	100
People aged 25-34 predicted to have a moderate physical disability	760	911	949	890
People aged 25-34 predicted to have a serious physical disability	72	87	90	85
People aged 35-44 predicted to have a moderate physical disability	1,204	1,042	1,070	1,249
People aged 35-44 predicted to have a serious physical disability	366	316	325	379
People aged 45-54 predicted to have a moderate physical disability	2,202	2,309	2,134	1,862
People aged 45-54 predicted to have a serious physical disability	613	643	594	518
People aged 55-64 predicted to have a moderate physical disability	2,950	2,935	3,278	3,457
People aged 55-64 predicted to have a serious physical disability	1,148	1,143	1,276	1,346
Total population aged 18-64 predicted to have a moderate or serious physical disability	10,070	10,081	10,338	10,399

Figures may not sum due to rounding. Crown copyright 2007

The total numbers for 18 to 64 indicate a 2.9% rise in 2025 of the 2010 numbers.

Projections are also available for those with physical disabilities and permanently unable to work. It is based upon prevalence data taken from the Health Survey for England, 2001<sup>18</sup>.

This table below (Table 2.8) suggests gender differences. Total males permanently unable to work have a greater increase in numbers to the year 2025 when compared to total female numbers. There is also a difference in the age bands as most are relatively static or increase over time except for the age group 45 to 54 which decreases over time.

The information in Table 2.9 below is taken from two sources. The helped to live at home data is taken from the Social Services Performance Assessment Framework Indicators 2006-2007. The data covers people receiving any amount of care and is being used to show how much low level care is provided. Such care can prevent or postpone a person needing more intensive care packages or residential care. There is projected to be a big increase in the number of people requiring this care during the next five years with the numbers being stable from then until 2025.

The data for the supported by social care in care homes is taken from Community Care Statistics 2006-07<sup>19</sup>, which was developed to provide a coherent set of national statistics on adult community care, purchased or provided by Councils with Social Services Responsibilities (CSSRs). It is based upon prevalence data taken from the Health Survey for England, 2001. Numbers in this category are expected to be static until 2025.

**Table 2.8** Projections to 2025 of those predicted between the ages of 18 to 64 (males) and 18 to 59 (females) to have a Physical Disability and be permanently unable to work in North East Lincolnshire

Age Band	2010	2015	2020	2025
Males aged 18-34 predicted to have a physical disability and be permanently unable to work	176	194	195	186
Males aged 35-44 predicted to have a physical disability and be permanently unable to work	331	281	293	349
Males aged 45-54 predicted to have a physical disability and be permanently unable to work	807	843	778	678
Males aged 55-64 predicted to have a physical disability and be permanently unable to work	1,350	1,337	1,485	1,553
Total males 18-64 predicted to have a physical disability and be permanently unable to work	2,663	2,654	2,752	2,766
Females aged 18-34 predicted to have a physical disability and be permanently unable to work	166	176	174	165
Females aged 35-44 predicted to have a physical disability and be permanently unable to work	277	239	244	280
Females aged 45-54 predicted to have a physical disability and be permanently unable to work	670	711	647	570
Females aged 55-59 predicted to have a physical disability and be permanently unable to work	486	528	621	600
Total females 18-59 predicted to have a physical disability and be permanently unable to work	1,600	1,655	1,686	1,616

Figures may not sum due to rounding. Crown copyright 2007

**Table 2.9** Projections to 2025 of those predicted between the ages of 18 to 64 with a physical or sensory disability helped to live at home or in residential care in North East Lincolnshire

Age Band	2010	2015	2020	2025
People aged 18-64 with a physical or sensory disability helped to live at home	283	340	341	341
People aged 18-64 with a physical or sensory disability in residential and nursing care during the year, purchased or provided by the CSSR	41	41	41	41

Figures may not sum due to rounding. Crown copyright 2007

## 2.4 Ethnicity

Data sources to estimate ethnic minority groups are scarce. The Office for National Statistics produces annual population estimates by ethnic group, though they are currently classed as experimental statistics.



Table 2.10 Estimated ethnicity of North East Lincolnshire's population (Mid 2007)

Census Ethnicity Categories	North East Lincolnshire (%)	Yorkshire & Humber (%)	England (%)
White: British	95.20	88.00	83.65
White: Irish	0.38	0.62	1.12
White: Other White	1.20	1.94	3.48
Mixed: White and Black Caribbean	0.19	0.44	0.55
Mixed: White and Black African	0.13	0.15	0.22
Mixed: White and Asian	0.32	0.42	0.51
Mixed: Other Mixed	0.19	0.27	0.41
Asian or Asian British: Indian	0.63	1.48	2.58
Asian or Asian British: Pakistani	0.38	3.43	1.77
Asian or Asian British: Bangladeshi	0.13	0.37	0.69
Asian or Asian British: Other Asian	0.19	0.46	0.66
Black or Black British: Black Caribbean	0.13	0.49	1.17
Black or Black British: Black African	0.44	0.69	1.43
Black or Black British: Other Black	0.06	0.09	0.23
Chinese or Other Ethnic Group: Chinese	0.25	0.66	0.78
Chinese or Other Ethnic Group: Other	0.19	0.51	0.74

Source: Mid-2007 Population Estimates by Ethnic Group, Office for National Statistics, [www.statistics.gov.uk](http://www.statistics.gov.uk) © Crown Copyright 2009

#### KEY POINTS

- ONS estimates for the population of North East Lincolnshire in 2008 are just over 158,000 people, with more women than men.
- Exeter registration estimates for April 2009 for the population of North East Lincolnshire are just over 164,000, with more men than women.
- There is a distinct drop in the numbers between the ages of 25 and 35 in North East Lincolnshire.
- The ethnicity of the area is predominately white.
- There is projected to be little change in the number of people between the age of 18 and 64 with a learning disability in North East Lincolnshire up to 2025. There is projected to be an increase of 2.9% in the number of people with a physical disability in North East Lincolnshire in the same period.

### 3. HEALTH, HEALTH SERVICES & LIFESTYLE

#### 3.1 Health Status

Self reported status can be useful as an indicator of the general health of a population. International studies have found this measure to be predictive of future mortality<sup>20</sup> and the development of chronic conditions<sup>21</sup>.

Participants in the needs assessment survey were asked questions about their health and lifestyle. The first question on health asked how they viewed their health. The results are summarised in Table 3.1 below.

**Table 3.1 Self reported health status in North East Lincolnshire by Disability**

Disability Type	Learning Disability	Physical Disability	Learning AND Physical Disability
Excellent Health	9.1%	1.9%	2.2%
Very Good Health	36.1%	7.2%	17.0%
Good Health	38.5%	25.0%	43.7%
Fair Health	13.5%	33.2%	25.9%
Poor Health	2.9%	32.7%	11.1%

The table shows a substantial difference between how people with learning disabilities viewed their health and how those with physical disabilities viewed their health. More than 80% of learning disability respondents reported that their health was excellent, very good or good, compared with just 34.1% of those with physical disabilities. Similarly 32.7% of respondents with physical disabilities reported that their health was poor compared with under 3% of learning disabilities respondents. More learning disabilities respondents reported positive health than was the case for the general population of North East Lincolnshire surveyed in the Household Place Survey 2008, where 75.5% self reported their health to be good or above<sup>22</sup>.

For those suffering from both learning and physical disabilities, the majority of people stated their health to be good, very good or excellent. Overall for this cohort, there was approximately a ratio of 2 to 1 who felt their health was good or above when compared to fair or below.

**Table 3.2 Self reported health status in North East Lincolnshire by Gender and Disability Type**

Gender	Learning Disability		Physical Disability		Learning AND Physical Disability	
	Health Good or Better		Health Good or Better		Health Good or Better	
	Number	%	Number	%	Number	%
Females	62	81.6%	38	31.9%	46	64.8%
Males	109	85.2%	32	39.0%	39	61.9%
All Genders	174	83.7%	71	34.1%	85	63.0%

Table 3.3 breaks down the results on self reported health status by gender. The survey results suggest that gender factors do not have a major influence on health status amongst respondents to this survey with broadly similar results for males and females within the respective physical disability, learning disability and learning AND physical disability cohorts.

**Table 3.3 Self reported health status in North East Lincolnshire by Age Band and Disability Type**

Age Band	Learning Disability		Physical Disability		Learning AND Physical Disability	
	Health Good or Better		Health Good or Better		Health Good or Better	
	Number	%	Number	%	Number	%
15 to 19	21	95.5%	3	75.0%	14	66.7%
20 to 24	23	92.0%	3	100.0%	10	58.8%
25 to 29	15	75.0%	1	33.3%	8	88.9%
30 to 34	13	81.3%	5	62.5%	6	66.7%
35 to 39	13	86.7%	5	55.6%	8	80.0%
40 to 44	24	92.3%	4	28.6%	12	75.0%
45 to 49	20	71.4%	10	41.7%	11	57.9%
50 to 54	9	69.2%	9	29.0%	5	50.0%
55 to 59	18	90.0%	11	25.0%	5	45.5%
60 to 64	12	75.0%	13	25.5%	4	44.4%
65 to 69	0	0.00%	5	50.0%	0	0.0%

Generally, it is expected that as people become older they are more likely to be suffering from some form of condition affecting their health, regardless of whether they have had a disability from birth or not. Coping with one or more conditions with age is likely to influence detrimentally a person’s view on their general health over time. In general, the data from Table 3.3 seems to confirm this.

Interestingly however, the majority of those suffering with learning difficulties at whatever age self-report their health to be excellent, very good or good. Percentages for each age band are above two thirds of those surveyed, and for some age bands, percentage figures are in the nineties. The lowest dip in the figures occurs around the 45 to 49 and 50 to 54 age bands.

Those surveyed with physical difficulties generally report their health to be good or better in the younger age band brackets. For those aged 40 and over with physical disabilities, 29.9% reported their health as good or better compared with 63% for those aged 39 and under.

The trend for people with learning AND physical difficulties follows roughly the same pattern as that for physical disabilities. Within the younger age bands generally over two thirds of people self reported their health as good or better but there was a noticeable drop from the 45 to 49 age band and by the 55 to 59 age band, more people were reporting their health to be poor or fair.

**Table 3.4 Self reported health status in North East Lincolnshire by Deprivation Quintiles and Disability Type**

Quintile	Learning Disability		Physical Disability		Learning AND Physical Disability	
	Health Good or Better		Health Good or Better		Health Good or Better	
	Number	%	Number	%	Number	%
Lowest Quintile	29	78.4%	22	33.3%	14	56.0%
Top 4 Quintiles	122	84.7%	46	35.4%	64	62.7%
NELUA	151	83.4%	68	34.7%	78	61.4%

Research in to the area of socio-economic indicators is associated with raised odds of poor health outcomes<sup>23</sup>. In order to analyse the data, the postcode was taken of each respondent and assigned to a quintile based upon the Index of Multiple Deprivation (IMD) score at lower super output area level (LSOA) for 2004.

For all types of disability, those living in the top four quintiles within the North East Lincolnshire Unitary Authority boundary had self reported higher percentages for their health being good or better than those within the lowest quintile. With learning difficulties, 84.7% of the top 4 quintiles compared to 78.4% of the lowest quintile had excellent, very good or good health. The percentages and difference were lower with physical disabilities, 35.4% compared to 33.3%, whereas for people with learning AND physical disabilities it was 62.7% compared to 56%.

**Table 3.5** Self reported health status as Excellent, Very Good or Good within the 15 Wards of the North East Lincolnshire Unitary Authority by Disability Type

Ward	Learning Disability	Physical Disability	Learning AND Physical Disability
	% of Health Good or Better	% of Health Good or Better	% of Health Good or Better
Croft Baker	86.1%	27.3%	37.5%
East Marsh	73.1%	33.3%	62.5%
Freshney	50.0%	13.3%	50.0%
Haverstoe	75.0%	50.0%	80.0%
Heneage	88.9%	35.3%	66.7%
Humberston & New Waltham	100.0%	66.7%	77.8%
Immingham	75.0%	31.6%	75.0%
Park	100.0%	23.1%	55.6%
Scartho	66.7%	60.0%	16.7%
Sidney Sussex	94.4%	37.5%	50.0%
South	93.3%	38.5%	62.5%
Waltham	71.4%	0.0%	80.0%
West Marsh	50.0%	46.2%	66.7%
Wolds	100.0%	60.0%	75.0%
Yarborough	72.7%	18.2%	42.9%

Health status at ward level was also analysed, though only percentages are displayed due to confidentiality in reporting small numbers. For those with learning difficulties the majority of people in every ward reported their health as good or better with the exception of West Marsh and Freshney where there was a 50:50 split. Two of the most affluent areas within North East Lincolnshire unitary authority, Wolds and Humberston & New Waltham actually self reported at 100% but numbers were small in these wards.

A similar picture is apparent for respondents with physical disabilities in that the more affluent areas, Scartho, Humberston & New Waltham and Wolds, were the only areas where the majority of respondents reported their health as good or better.

### 3.2 Conditions and Illness

The local survey asked a number of questions on the conditions and illnesses that each respondent suffered from. Some people may only suffer from one condition, others from multiple. It was decided to treat each condition separately so if a person suffered from asthma, diabetes and epilepsy, these were three separate pieces of data rather than assigning one main condition to the respondent. These conditions were then further grouped in to their ICD 10 classification<sup>b</sup>. It must be noted that the information was subjective as the information came from the individual who stated what they believed was wrong with them rather than any medical case notes. The data were

<sup>b</sup> The ICD 10 classification stands for the International Statistical Classification of Disease and Related Health Problems 10<sup>th</sup> Revision. Every health condition can be assigned to a unique chapter and each chapter can include a set of similar diseases. There are 22 chapters in the current revision and they help to promote international comparability in the collection, processing, classification, and presentation of morbidity and mortality statistics.

then analysed by the chapter it belonged to e.g. heart disease would belong to the chapter on diseases of the circulatory system (see Appendix 7).

**Table 3.6** All Disabilities – What conditions or illnesses do you suffer from?

ICD 10 Chapter Classification	Number of Conditions	% of Total Conditions
Mental & Behavioural Disorders (F00-F99)	332	26.54%
Diseases of the Nervous System (G00-G99)	231	18.47%
Diseases of the Musculoskeletal System and Connective Tissue (M00-M999)	107	8.55%
Diseases of the Circulatory System (I00-I99)	99	7.91%
Endocrine, Nutritional & Metabolic Diseases (E00-E90)	82	6.55%
All Other Chapters	400	31.97%

There were a total of 1251 conditions associated for all respondents regardless of their type of disability. The top five ICD 10 chapters accounted for over two thirds of all conditions, with the most numerous being those classified as mental or behavioural disorders. Within this chapter, learning disabilities, autism and depression made up the majority of conditions, but Asperger's Syndrome, dyspraxia and anxiety were examples of some of the other conditions.

**Table 3.7** Learning Disabilities – What conditions or illnesses do you suffer from?

ICD 10 Chapter Classification	Number of Conditions	% of Total Conditions
Mental & Behavioural Disorders (F00-F99)	198	59.82%
Congenital Malformations, Deformations & Chromosomal Abnormalities (Q00-Q99)	27	8.16%
Diseases of the Nervous System (G00-G99)	27	8.16%
Endocrine, Nutritional & Metabolic Diseases (E00-E90)	21	6.34%
Unable to Identify Condition	12	3.63%
All Other Chapters	46	13.90%

There were a total of 331 conditions for respondents who were classified as having learning disabilities with the top five ICD 10 chapters accounting for 86.1% of all conditions. As for all disabilities, by far the most numerous belong to conditions classified as mental or behavioural disorders. The second most common condition belonged to two chapters, congenital malformation, deformations and chromosomal abnormalities of which the vast majority were for Down's Syndrome and those diseases of the nervous system, of which the majority were epilepsy.

**Table 3.8** Physical Disabilities – What conditions or illnesses do you suffer from?

ICD 10 Chapter Classification	Number of Conditions	% of Total Conditions
Diseases of the Nervous System (G00-G99)	113	19.82%
Diseases of the Musculoskeletal System and Connective Tissue (M00-M999)	86	15.09%
Diseases of the Circulatory System (I00-I99)	76	13.33%
Endocrine, Nutritional & Metabolic Diseases (E00-E90)	52	9.12%
Diseases of the Respiratory System (J00-J99)	49	8.60%
All Other Chapters	194	34.04%

There were a total of 570 conditions for respondents who were classified as having physical disabilities with the top five ICD 10 chapters accounting for approximately two thirds of all conditions. The most numerous chapter for physical disabilities belonged to conditions classified as diseases of the nervous system. Within this chapter epilepsy, multiple sclerosis and cerebral palsy were the most frequent conditions, but the chapter did include paralysis and muscular dystrophy.

It is interesting to note that for physical disabilities, there are two chapters of conditions within the top five that are associated with chronic health conditions that can be associated with lifestyle. These are diseases of the circulatory system, which contain the conditions high blood pressure, cardiovascular disease and angina, and disease of the respiratory system, containing the conditions chronic obstructive pulmonary disorder and bronchitis. These diseases can be physically debilitating and unlike some learning disability conditions, are not from birth but can be affected through external factors such as diet, smoking, alcohol and exercise.

**Table 3.9** Learning AND Physical Disabilities – What conditions or illnesses do you suffer from?

ICD 10 Chapter Classification	Number of Conditions	% of Total Conditions
Mental & Behavioural Disorders (F00-F99)	106	31.18%
Diseases of the Nervous System (G00-G99)	89	26.18%
Unspecified Physical Disability (Unable to Categorise)	21	6.18%
Unable to Identify Condition	21	6.18%
Congenital Malformations, Deformations & Chromosomal Abnormalities (Q00-Q99)	15	4.41%
All Other Chapters	88	25.88%

There were a total of 340 conditions for respondents with both learning AND physical disabilities. The top five ICD 10 chapters accounted for 74.12% of all conditions with the most numerous again for those with mental and behavioural disorders, with learning difficulties and autism the most common within the chapter. Third on the list is not a true chapter, but it is where respondents merely put down that they were suffering from a physical disability but did not elaborate any further.

There were 10 people who did not complete the part of the questionnaire which asked what type of disability they suffered from, but did go on to indicate what conditions they had. As the numbers are so small, for confidentiality reasons, it is not possible to display this data by chapter, but the conditions included diseases of the nervous system, digestive system, circulatory system and neoplasms (cancer).

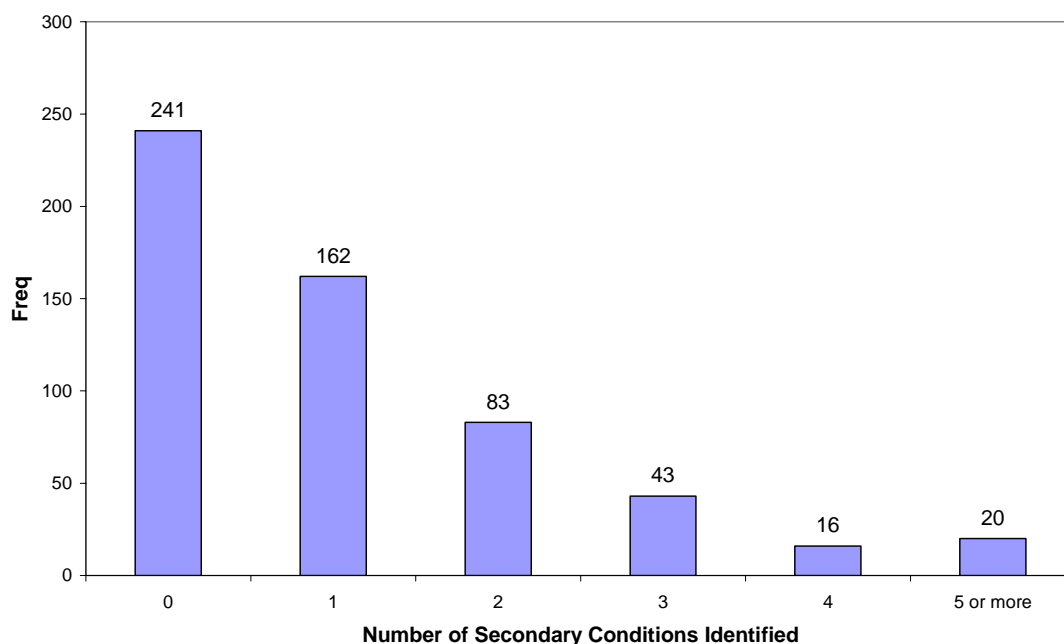
Of the 565 respondents to the local survey, 324 stated they had at least one secondary illness or disability (57.3%). Table 3.10 displays this information and also shows that secondary conditions were more common amongst those who reported a primary learning disability and those who had learning AND physical disability.

**Table 3.10** Respondents suffering from more than one illness or condition

	Learning Disability	Physical Disability	Learning AND Physical Disability	Not Indicated	Total
No. with Multiple Conditions	139	87	95	3	<b>324</b>
Total Respondents	211	210	138	6	<b>565</b>
% of Disability Type	65.9%	41.4%	68.8%	50.0%	<b>57.3%</b>

Figure 3.1 displays the number of secondary conditions reported by respondents to the survey. There were 162 respondents (28.7%) who mentioned one condition in addition to their primary disability, 83 respondents (14.7%) mentioned two additional conditions, 43 respondents mentioned three (7.6%), 16 respondents mentioned four (2.8%) and 20 respondents mentioned that they had five or more additional conditions (3.5%).

**Figure 3.1**     Number of secondary conditions identified by Needs Assessment respondents



Epilepsy was one of the most commonly mentioned conditions in the survey. It was identified by 29 respondents as their primary disability and a further 65 mentioned it as a secondary condition. In the vast majority of cases it was identified as a secondary condition associated with a primary learning disability with 27% of all learning disability respondents identifying epilepsy as a secondary condition. In particular, 12 out of 26 respondents who identified their primary disability as being associated with cerebral palsy mentioned epilepsy as a secondary condition.

The next most frequently identified secondary condition was diabetes. Overall 44 respondents identified that they had diabetes, which represents 7.8% of all respondents. Diabetes affected respondents with a wide range of conditions across all cohorts. It was mentioned by seven respondents with a physical disability associated with arthritis and eight respondents with unspecified learning disabilities.

In addition to the 26 respondents who identified arthritis as their primary disability, a further 34 respondents identified arthritis as a secondary condition. Therefore 59 people who participated in the survey reported some degree of arthritis (10.6%). In the majority of cases it was a secondary condition to another physical disability such as multiple sclerosis, blindness and spinal problems.

Overall 33 respondents reported asthma as a secondary illness or a symptom associated with their disability representing 5.8% of all respondents. Once again it appeared to affect respondents with a wide range of conditions within the various cohorts.

There were 20 respondents who mentioned anxiety and/ or depression as a secondary symptom or condition. This was most commonly associated with people who identified their primary condition as arthritis with five out of the 26 respondents mentioning that they sometimes felt depressed. A further eight respondents, all within the learning disability cohort, made reference to unspecified mental health problems associated with the condition. There were six respondents who cited Attention Deficit Hyperactivity Disorder (ADHD) as a secondary condition, four respondents made reference to challenging behaviour, one respondent referred to schizophrenia and one referred to obsessive compulsive disorder.

In addition to six respondents who identified a heart condition as their primary disability, a further 19 respondents identified an illness or condition associated with their heart as a secondary

condition. A further nine respondents mentioned angina as a secondary symptom or condition, though the majority of people reporting a heart condition or angina had a primary physical disability, arthritis being the most common.

Other conditions associated with an increased risk of cardiovascular disease were also mentioned frequently. There were 26 respondents who identified high blood pressure or hypertension as a secondary condition of their disability in addition to two who identified it as their primary disability. Once again numbers were evenly distributed across the cohorts. Five people with arthritis as their primary disability reported high blood pressure as a secondary condition and seven respondents with unspecified learning disability did so. Only eight respondents mentioned high cholesterol as a secondary condition, six of whom had also mentioned high blood pressure.

There were 13 respondents who identified COPD as a secondary condition in addition to 11 who identified it as their primary disability. All but one of those who identified COPD as a secondary condition had a physical disability as their primary condition. In six respondents the primary disability was arthritis. A further seven respondents identified unspecified breathing difficulties as a secondary condition.

In addition to the 18 respondents who identified autism as their primary disability and nine who identified Asperger's Syndrome as their primary disability, a further 10 respondents identified it as a secondary symptom or condition. In all but two cases the primary condition was a learning disability.

In addition to the 22 respondents who identified blindness or restricted vision as their main disability, a further 17 respondents identified visual impairment as a secondary symptom or condition. In the majority of cases visual impairment was a secondary condition of a primary learning disability such as cerebral palsy.

Just three respondents identified deafness or hearing impairment as their primary disability in addition to two who identified blindness and deafness as their primary condition. A further 10 identified hearing impairment as a secondary condition. These were evenly divided between those with primary physical and learning disabilities.

### 3.3 Health Services

The tables below look at access to and use of local health services by each respondent and whether they have all the support they require or if there may be a specific untapped need. Those that responded were asked if they had used any health service within the past three months on the date that they had completed the questionnaire. For all those who completed a survey, 97% had used some form of health service, including over 99% of those with physical disability.

**Table 3.11** Have you used any Health Services within the past 3 months?

	<b>Learning Disability</b>	<b>Physical Disability</b>	<b>Learning AND Physical Disability</b>	<b>Total</b>
<b>Yes</b>	93.8%	99.1%	98.6%	<b>97%</b>
<b>No</b>	6.2%	0.9%	1.4%	<b>3%</b>

Table 3.12 below expands upon this by asking which health services were used. Over three quarters (75.9%) of those who replied to the questionnaire had seen their GP within the last three months. This was double the number of the next most used health service which was for outpatients or day patient appointments (37.5%). At least a third of people who responded also indicated that they had visited the chiropodist (36.1%) or visited the practice nurse (32.7%). Conversely, only 3.4% of respondents had used a self help group and 3.5% had used a counsellor or therapist.



**Table 3.12** Which of the following Health Services have you used within the past 3 months? (Overall)

Health Service	Yes	%	No	%
GP / Doctor	429	75.9%	136	24.1%
Outpatients / Day Patient Appointment	212	37.5%	353	62.5%
Chiropody	204	36.1%	361	63.9%
Practice Nurse	185	32.7%	380	67.3%
Optician	167	29.6%	398	70.4%
Physiotherapy	84	14.9%	481	85.1%
Community / District Nurse	81	14.3%	484	85.7%
Psychiatrist / Psychologist	78	13.8%	487	86.2%
Visit to A&E / Casualty	63	11.2%	502	88.8%
Occupational Therapy	61	10.8%	504	89.2%
Been Admitted to Hospital	56	9.9%	509	90.1%
Other	51	9%	514	91%
None of these	26	4.6%	539	95.4%
Counsellor / Therapist	20	3.5%	545	96.5%
Self Help Group	19	3.4%	546	96.6%

Respondents were also invited to identify other services not included in the list within Table 3.12. The most popular other service used was the grouping of Specialist Services identified by 16 people. Of this Specialist Services subset group, examples included the Junction Service (which deals with adults with drug and/ or alcohol dependency with possible further issues), Stop Smoking Groups and Foresight (which is a registered charity that operates throughout North East Lincolnshire to meet the needs and requirements of disabled people, families and their carers). Dentists were mentioned by 13 people, nursing homes by five people, specialist nurses by four people, specialist clinics by four people, home visits by three people and dieticians by three people.

Of those people that responded to the questionnaire, 81% were happy that they were in receipt of all the Health Services they needed for their conditions compared to 13% that were not. Between disability types, those with learning disabilities were the happiest that their needs were being met with 91% responding 'Yes'. This contrasted with physical disabilities where only 72% replied they get all the services they need. These results are displayed in Table 3.13.

**Table 3.13** Do you get all the Health Services that you think you need?

	Learning Disability	Physical Disability	Learning AND Physical Disability	Total
Yes	91%	72%	81%	81%
No	6%	19%	14%	13%
Don't Know	1%	4%	3%	3%
Not Answered	2%	5%	2%	3%

The questionnaire also asked those respondents who believed they were not receiving all the health services they required to identify which health services they were not receiving. As the number of respondents was quite small, Table 3.14 below summarises the replies for each type of disability in order of popularity.

**Table 3.14** What do you need that you don't get?

Learning Disability	Physical Disability	Learning AND Physical Disability
Dentist Attendance Issues Better Service Therapist Chiropodist Other Psychologist Appointment with Specialist	Physiotherapist Better Service Appointment with a Specialist Home Help Other Optician Attendance Issues Chiropodist Information Dentist Financial Pain Management Carers	Physiotherapist Other Psychologist Dentist Information Better Service Therapist Carers Chiropodist Appointment with a Specialist

People with physical disabilities feel that they need more physiotherapy for their condition and this was also the most common reply for those with learning AND physical disabilities. This contrasts with learning disabilities, where no one requested a need for physiotherapy, and the most common reply was the dentist<sup>24</sup>. This reflects a recent report by the British Dental Association (BDA) on oral health inequalities which identified that people with disabilities were one of the groups whose oral health is not improving. The BDA argue that greater priority needs to be given to the development of services that meet the needs of disabled people<sup>25</sup>. A better service than the respondent was currently getting also featured prominently as emphasised by the following respondents.

*“Every time I go for my appointment I see different doctors, I have to explain every time. If I want to see the same doctor I have to ask. I feel I've not been listened to sometimes. I suffer in silence. The doctors don't seem to take much time. I'm complicated but that's not my fault, all I want is answers to why I'm so ill, not to suffer in silence any more.”*

*“Due to reorganisation of CAMHS no input at present.”*

Attendance issues were more of a concern for those with learning disabilities than physical, but did highlight the multitude of reasons. Examples of responses for attendance issues included transportation problems, the cancellation of appointments by the hospital/ clinic, assistance to be able to attend and agoraphobia.

### Medication

Medication is an important aspect of helping to control or to alleviate symptoms associated with conditions experienced by those with disabilities and in some cases can be life saving. To view how medication was managed and if there were any areas for greater assistance the following question was asked.

**Table 3.15** How do you take your medication?

How is Medicine Taken	Learning Disability	Physical Disability	Learning AND Physical Disability	Total
Someone helps me	56.2%	33.2%	68.8%	50.6%
I take it on my own	11.0%	54.0%	15.2%	28.3%
I don't take any	26.7%	6.6%	10.1%	15.0%
I take it but need help sometimes	2.9%	4.7%	2.2%	3.4%
I need help but don't get it	0.0%	0.9%	0.7%	0.5%
Not Answered	3.3%	0.5%	2.9%	2.1%
<b>TOTAL</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

Over 80% of respondents overall were taking medication associated with their condition(s). This varied between the cohorts with around 70% of learning disability respondents, over 90% of physical disability respondents and just under 90% of learning AND physical disability respondents reporting that they were taking medication.

More than two thirds of Learning AND Physical Disability respondents receive help to take their medication compared with 56% of learning disability respondents and around a third of physical disability respondents. There were three respondents to the survey that indicated that they need help when taking their medication but do not receive any. A further 19 respondents indicated that there are times when they need help with their medication.

*"I have contact with a guy across the road who gets my medicine or helps me in an emergency."*

Another supplementary question asked those who took medicines whether their medicines had been reviewed. Without regular reviews of medication, people can be subject to inappropriate or inadequate treatment, possibly exacerbating conditions suffered. Of the 463 respondents who stated they were taking medication, nearly two thirds (65.2%) had been reviewed within the last six months and this increased to 86.6% who had received a review within the past year. Less than half a percent had not had a review and only 0.6% had been involved in a review that was longer than 12 months ago. The remainder were not sure when their last review had taken place.

The figures for each disability cohort are similar. There were 94.4% of respondents with learning difficulties that had received a review within the year and no-one reported that they had waited longer than a year to have their medication reviewed. The figures for those with physical disabilities were a little lower; 82.1% reported that they had been reviewed within the past year. As only half a percent had waited longer than a year, the main discrepancy between the two cohorts was that nearly 14% of those with physical disabilities were unsure when they had been last reviewed.

**Table 3.16** Has a doctor or nurse reviewed the medicines you are taking?

Review Last Undertaken	Learning Disability	Physical Disability	Learning AND Physical Disability	Total
Within the last 6 months	70.3%	65.8%	61.5%	65.9%
6 to 12 months	24.1%	16.3%	28.2%	21.6%
Longer than 12 months	0.0%	0.5%	1.7%	0.6%
I don't know	2.1%	13.8%	6.8%	8.9%
No review	0.0%	1.0%	0.0%	0.4%
Not answered	3.4%	2.6%	1.7%	2.6%
<b>TOTAL</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>

Access to Health Services

The survey then asked respondents if they had difficulty accessing health services. More than 85% of the total number of those who responded said that they had experienced difficulties in accessing or using local health services. This applied to almost 90% of physical disability respondents and almost 80% of learning disability respondents.

**Table 3.17** Have you had any difficulties using local Health Services?

	Learning Disability	Physical Disability	Learning AND Physical Disability	Total
<b>Yes</b>	79.9%	89.6%	88.4%	<b>85.3%</b>
<b>No</b>	20.1%	10.4%	11.6%	<b>14.5%</b>

Those who indicated that they had at some time experienced difficulties accessing services were invited to identify the reason(s) for these difficulties. Table 3.18 summarises these results.

**Table 3.18** Do any of the following make it hard for you when you use local Health Services?

Question	Learning Disability	Physical Disability	Learning AND Physical Disability	Total
I need someone to accompany me	110	111	87	308
I don't feel safe going out	19	43	27	90
Cost / Lack of money	14	44	21	82
Other Reason	32	27	18	78
Transport problems	12	42	17	72
I can't always see the same person	14	39	14	68
I can't find an NHS dentist	17	41	8	67
Can't get an appointment when I want	6	30	13	49
I don't know where there is locally	6	21	12	39
How staff speak to me	13	15	9	38
Problems getting into the building	4	24	9	37
Bad past experience	7	19	10	36
Other	12	16	6	35
Unsuitable toilets	4	13	11	29
I don't have enough time	3	2	1	7
I can't find an NHS doctor	0	1	0	2

The need for someone to accompany them was by far the largest response to this question and was the same for all types of disabilities. The next most common issue was safety, closely followed by the cost/ lack of money. 'Other' reasons identified included home confinement parking difficulties, communication difficulties and pride.

*"My health is a big issue to me but it is the threats, especially in the areas where I go to. I don't feel safe."*

*"In my case people who can talk to me using BSL."*

### 3.4 Lifestyle

A question asked whether anything was stopping the respondent from living a healthier lifestyle. A wide range of answers were received and these have been grouped by common themes and summarised in Table 3.19 below.

**Table 3.19** Does anything stop you leading a healthier lifestyle?

Reason	Number of Respondents
Nothing Stops Me	383
Issues with Disability, Illness & General Health	109
Other Reasons	21
Lifestyle Choices	18
Money & Financial Issues	10
Support	9
Confidence	8
Issues around Weight	7

Encouragingly, almost 68% replied that there was nothing that stopped them from leading a healthier lifestyle. However 109 respondents (19.3%) identified factors related to their disability, illness or general health which prevented them from having a healthier lifestyle. The next most common category was other reasons. Examples within this group included the need for prior planning, information about healthier lifestyles, communication and motivation. Just 18

respondents cited lifestyle factors as preventing a healthier lifestyle. These included lack of exercise, excess weight, drinking and smoking.

*"I am very overweight due to medication & boredom."*

#### KEY POINTS

- Over 83% of those with learning disabilities self report their health as being good or better when compared to only just over 34% for those with physical disabilities.
- Over 59% of those with learning disabilities suffered with conditions from mental and behavioural disorder ICD 10 classification.
- 58% of respondents identified a secondary condition that affected their health in addition to the primary disability. 14% of respondents identified three or more secondary conditions.
- The four most frequently mentioned secondary conditions were epilepsy, diabetes, arthritis and asthma.
- Multiple secondary conditions were frequently reported amongst respondents who identified conditions such as arthritis, cerebral palsy, fibromyalgia and paralysis as their primary disability.
- Over a quarter of those who stated they suffered from learning disabilities and a secondary condition, had the secondary condition of epilepsy.
- Over 97% of respondents had used a local health service within the last three months.
- Over 75% of respondents had visited their GP within the last three months.
- Over 80% of those surveyed believe they received all the health services they need.
- Over half of those with learning disabilities and learning AND physical disabilities required assistance taking their medication.
- Over 85% reported difficulty accessing health services.
- Main reasons for access difficulties were the need for accompaniment, safety and lack of money.

## 4. ACTIVITIES OF DAILY LIVING

Activities of daily living (ADL) is a term used in healthcare to describe common daily self care activities and to assess the capacity of people to perform these activities on their own. There are six basic activities of daily living, which consist of the following self-care tasks<sup>26</sup>:

- Bathing
- Dressing and undressing
- Eating
- Transferring from bed to chair, and back
- Using the toilet
- Continence.

There is also another category. Instrumental Activities of Daily Living (IADL) are not necessary for fundamental functioning, but they let an individual live independently in a community. Some of these include<sup>27</sup>:

- Doing light housework
- Preparing meals
- Shopping for groceries or clothes
- Managing money.

There are a number of evaluation tools to measure someone's ADL, e.g. the Barthel Index, which health professionals can use to measure the health status of a person and whether it changes over time<sup>28</sup>. They are also used to assess what type of long term care is required, though the best outcome for anyone is to help them achieve the greatest level of independence possible.

The local survey questionnaire asked respondents about a number of their ADLs and IADLs to view whether there was a need for services or how these activities were currently being assisted. Table 4.1 below summarises the responses regarding what type of help, if any, had been needed within the past three months around activities. Over 90% of respondents had required some assistance with their ADL.

**Table 4.1** Have you needed any help with activities of daily living within the past 3 months?

Disability Type	Yes	%	No	%
Learning Disability	191	91.0%	19	9.0%
Physical Disability	187	88.6%	24	11.4%
Learning AND Physical Disability	129	93.5%	9	6.5%
Disability Not Indicated	5	83.3%	1	16.7%
<b>Total</b>	<b>512</b>	<b>90.6%</b>	<b>53</b>	<b>9.4%</b>

The question then went further and asked the respondents about a number of daily activities and how they coped. Could they do it by themselves?; Do relatives or friends help?; Do paid carers help?; Do they need help but do not get it? The respondents were asked to tick which option applied to them but in some instances multiple options were ticked.

### Personal Care

This category centred on dressing, washing and getting to the toilet. Only eight people stated they needed help but did not get it, with a near equal split between all three types of disability. The most common answer in terms of total numbers (173) was that the person could do it themselves. This was followed by help from a paid carer.

### Getting In or Out of Bed

Only a small number (6) needed help but did not get it, four had learning disabilities and two had physical disabilities. The most common response (260) was that the person could do it themselves. This was followed by help from relatives or friends (79) and then help from a paid carer (71).

### Getting Out and About

Only a small number (6) needed help but did not get it, five had physical disabilities and one had learning AND physical disabilities. The most common response (188) was that relatives or friends helped.

### Preparing Meals

Only a very small number (4) needed help but did not get it, two had physical disabilities and two had learning AND physical disabilities. The most common response (221) was that relatives or friends helped, followed by help from a paid carer (174).

### Shopping

Again only a very small number (3) needed help but did not get it, one had physical disabilities and two had learning AND physical disabilities. The most common response (230) was that relatives or friends helped. The next most frequent response was help from a paid carer (181).

### General House Cleaning

Just four people needed help but did not get it, three had physical disabilities and one had learning AND physical disabilities. The most frequent answer (203) was that relatives or friends helped.

### Doing the Laundry

Once again only a very small number (3) needed help but did not get it, two had physical disabilities and one had learning AND physical disabilities. The most typical answer (205) was that relatives or friends helped. The next most common response (155) was help from a paid carer.

### Money Matters

There were 12 people that needed help but did not get it, with eight of those having physical disabilities. The most common answer (215) was that relatives or friends helped. The next most frequent response was help from a paid carer (144).

### Gardening or Household Repairs

This activity had the most people (26) in need of help but not getting it, 21 of whom had physical disabilities. The most frequent response, after those who did not answer the question (197), was help from relatives or friends (167). The next most common answer was for help from a paid carer (136).

Respondents were also invited to identify 'other' areas where help with ADL was required. A broad range of responses were received, some of which expanded upon assistance mentioned in categories above, e.g. gardening, shopping or getting about. There were no particular common 'other' responses as each answer explained an individual's needs and examples included help with ironing, help with an oxygen ventilator and help filling out various forms.

Respondents were then asked if they had any problems doing the food or other shopping. The responses are displayed in Table 4.2 below. There were 63.8% of respondents with learning disabilities that stated they had problems shopping. This compares to 65.2% of respondents with physical disabilities and 73.2% of respondents with learning AND physical disabilities.

**Table 4.2**      Do you have any problems doing your food or other shopping?

Response	Learning Disability		Physical Disability		Learning AND Physical Disability	
	No.	%	No.	%	No.	%
Yes	104	63.8%	103	65.2%	60	73.2%
No	59	36.2%	55	34.8%	22	26.8%
<b>Total</b>	<b>163</b>	<b>100.0%</b>	<b>158</b>	<b>100.0%</b>	<b>88</b>	<b>100.0%</b>

Respondents who replied that they had problems with food or other shopping were asked a supplementary question asking why this was an issue for them.

**Table 4.3**      Why do you have problems doing your food or other shopping?

Type of Problem	Learning Disability		Physical Disability		Learning & Physical Disability	
	No.	%	No.	%	No.	%
Need Assistance	70	67.3%	35	33.7%	27	45.8%
Disability Prevents	5	4.8%	29	27.9%	10	16.9%
None Given	9	8.7%	16	15.4%	15	25.4%
Understanding of Money	12	11.5%	0	0.0%	2	3.4%
Difficulty Getting Out	3	2.9%	9	8.7%	2	3.4%
Other	2	1.9%	8	7.7%	2	3.4%
Unable to Use Equipment Safely	2	1.9%	4	3.8%	1	1.7%
Access	1	1.0%	3	2.9%	0	0.0%
<b>Grand Total</b>	<b>104</b>	<b>100.0%</b>	<b>104</b>	<b>100.0%</b>	<b>59</b>	<b>100.0%</b>

Table 4.3 shows that the main shopping difficulty for those with learning disabilities is that they need assistance (67.3%), followed by the understanding of money (11.5%).

*“Family have to help clothes shopping so I get correct size.”*

*“I need support to know what to purchase and not overspend.”*

*“Do not understand the value of money.”*

Although the same problem, needing assistance, was the most common issue for those with physical disabilities the proportion who ticked this box was only half that of those with learning disability (33.7%). Many more respondents with physical disabilities indicated that their disability prevented them from being able to do the food or other shopping (27.9%).

*“I need assistance to get to shops, if shelves too high I ask anyone for assistance. I use an electric scooter at supermarket.”*

For those with learning AND physical disabilities, the need for assistance was again the most common problem.

Respondents were also asked if they had any problems cooking or preparing food and the results from this question are displayed in Table 4.4. There were 64.6% of respondents with learning difficulties that had problems preparing or cooking any food compared with 61.5% of physical disability respondents and 73% of learning AND physical disability respondents.



**Table 4.4 Do you have any problems preparing or cooking your food?**

Response	Learning Disability		Physical Disability		Learning AND Physical Disability	
	No.	%	No.	%	No.	%
Yes	102	64.6%	91	61.5%	54	73.0%
No	56	35.4%	57	38.5%	20	27.0%
<b>Total</b>	<b>158</b>	<b>100.0%</b>	<b>148</b>	<b>100.0%</b>	<b>74</b>	<b>100.0%</b>

Respondents who replied they had problems preparing and cooking food were invited to explain what the nature of the problem was. The results were then categorised and are summarised in Table 4.5 below.

**Table 4.5 Why do you have problems preparing or cooking your food?**

Type of Problem	Learning Disability		Physical Disability		Learning & Physical	
	No.	%	No.	%	No.	%
Need Assistance	61	59.8%	7	7.7%	14	25.9%
Disability Prevents	4	3.9%	44	48.4%	9	16.7%
None Given	10	9.8%	13	14.3%	16	29.6%
Unable to use Equipment Safely	12	11.8%	5	5.5%	5	9.3%
Other	7	6.9%	9	9.9%	3	5.6%
General Difficulties	4	3.9%	9	9.9%	4	7.4%
Cannot Cook	4	3.9%	1	1.1%	3	5.6%
Adaptations Required	0	0.0%	3	3.3%	0	0.0%
<b>Grand Total</b>	<b>102</b>	<b>100.0%</b>	<b>91</b>	<b>100.0%</b>	<b>54</b>	<b>100.0%</b>

Respondents with learning disabilities again reported that their main problem was that they needed assistance (59.8%).

*"I need support when cooking or I may be distracted."*

*"Paid carers support me to cook as I cannot use the cooker on my own."*

The second most common issue was the inability to use equipment safely (11.8%).

*"Not safe around gas or electricity."*

*"Unable to use cooker for safety reasons."*

The situation was very different for those with physical disabilities. The main issue for this cohort was that their disability prevented them from preparing or cooking food (48.4%).

*"My fingers do not bend when peeling vegetables and I do not coordinate very well in preparing food."*

*"I can only stand for short times and cannot reach some kitchen cupboards which makes cooking difficult."*

### KEY POINTS

- Roughly equal percentages of those with physical and those with learning disabilities needed assistance with activities of daily living within the last three months.
- The greatest need for help that was not currently being provided was for those with physical disabilities, specifically around gardening and household repairs.
- The overwhelming majority of activities required assistance that was being provided by friends, relatives or paid carers.
- In all activities questioned, the greatest percentage receiving assistance from relatives and friends was for those with physical disabilities.
- Other than personal care and getting in and out of bed, the greatest percentage receiving assistance from paid carers was those with learning difficulties.
- The need for assistance presented the greatest problem shopping for all disability cohorts.
- The need for assistance presented the greatest problem preparing and cooking food for those with learning disabilities.
- The greatest problem for preparing and cooking food for those with physical disabilities was the disability itself preventing them from doing things.

## 5. MENTAL HEALTH

The mental health of people with disabilities is an issue that is frequently ignored and there is a suspicion that many disabled people lack the support available to the wider population during periods of depression or anxiety. In addition people caring for disabled people also face considerable challenges in their daily lives which can leave them vulnerable to poor mental health.

### 5.1 Depression

Turner and Noh<sup>29</sup> found that both men and women with physical disabilities living in the community were at much greater risk of depressive symptoms than the general population. Covic (cited by Patient Plus)<sup>30</sup> found that chronic pain and some conditions are sometimes associated with depression, particularly rheumatoid arthritis and other long standing health conditions such as coronary heart disease and diabetes<sup>31</sup>. Prevalence figures for depression among people with physical disabilities are however difficult to obtain, in part due to the difficulty in defining what constitutes physical disability.

Prevalence estimates of depression in learning disability vary, in part due to difficulties in obtaining consensus about whether or not diagnostic criteria used in non learning disabled populations can be applied to people with learning difficulties who may not be able to express their feelings in words<sup>32</sup>. Therefore, although standard criteria may pick up cases of depression among those with mild to moderate learning difficulties they may miss those with more severe problems who may exhibit less typical symptoms of depression. To assist with diagnosis, the Royal College of Psychiatrists has produced a set of guidelines on psychiatric diagnosis for use with adults with learning disabilities.

In total, 543 (96.1%) respondents answered the question regarding frequency of feeling low or depressed. 28 (5.2%) reported 'always', 86 (15.8%) 'often' and 270 (49.7%) 'sometimes' feeling low or depressed. A further 93 (17.1%) 'rarely' and 66 (12.2%) 'never' felt low or depressed. Self rated feelings of depression by disability type are shown in Table 5.1.

**Table 5.1** Self rated feelings of depression by disability type

<b>Frequency of feeling low or depressed</b>	<b>Learning Disability</b>	<b>Physical Disability</b>	<b>Learning AND Physical Disability</b>	<b>Total</b>
Always	4 (2.0%)	20 (9.5%)	3 (2.3%)	27 (5.0%)
Often	16 (8.1%)	54 (25.7%)	15 (11.5%)	85 (15.8%)
Sometimes	97 (49.2%)	99 (47.1%)	71 (54.6%)	267 (49.7%)
Rarely	45 (22.8%)	24 (11.4%)	24 (18.5%)	93 (17.3%)
Never	35 (17.8%)	13 (6.2%)	17 (13.1%)	65 (12.1%)
<b>Total</b>	<b>197 (99.9%)</b>	<b>210 (99.9%)</b>	<b>130 (100.0%)</b>	<b>537 (100%)</b>

Considerable variation existed in self reported depression ratings between respondents with different types of disabilities. Among those that answered, 82.3% of people with a physical disability 'always', 'often' or 'sometimes' felt low or depressed, compared to 59.3% of those with a learning disability and 68.4% of those with a learning AND physical disability.

*"I break down crying every day."*

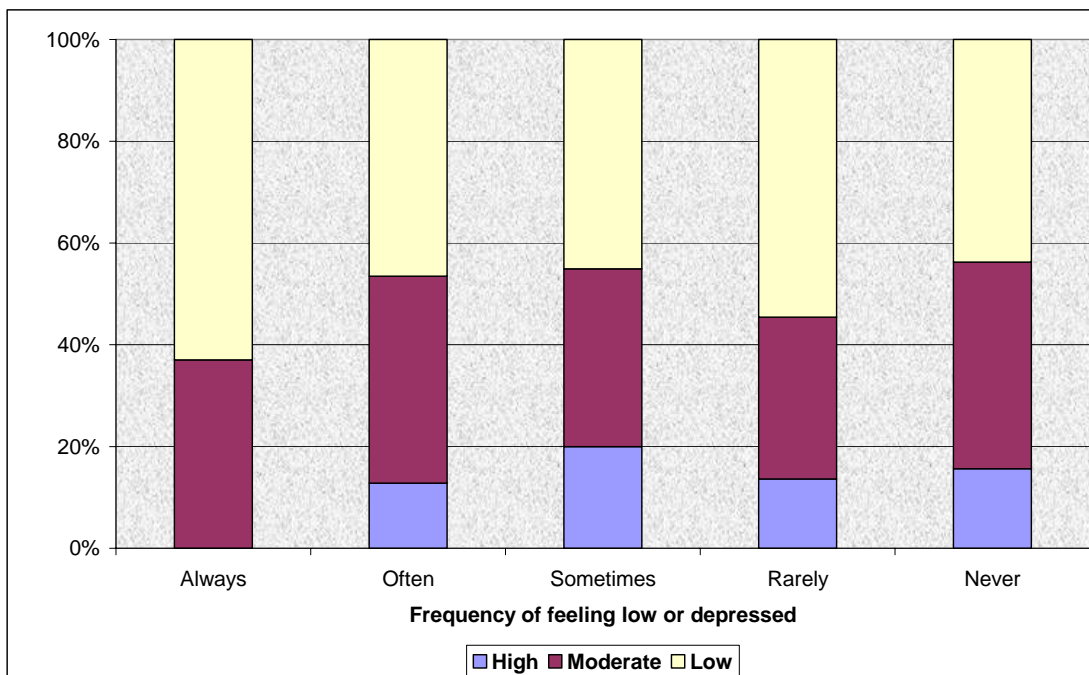
*"I can't [be involved socially] because I am mainly stressed out, I am not fit, I cry and get upset. So I don't want to go anywhere where I can't cope with the situation or upset anybody else."*

When depression ratings were crossed with social diversity network scores, it was apparent that those with the lowest diversity network scores, i.e. those with the least number of social contacts, reported feeling low or depressed more than those with a higher number of social contacts. Frequency of feeling low or depressed by social diversity network score for all survey respondents is shown in Figure 5.1.

*"I have no family in Lincolnshire and I live alone and get depressed."*

*"I cannot find places to go and I get depressed in the house thinking where I could go if I had money I could get a taxi, where can I go? I live on \*\*\*\*\*. Feel lonely and sick of watching TV, I want to be part of the community."*

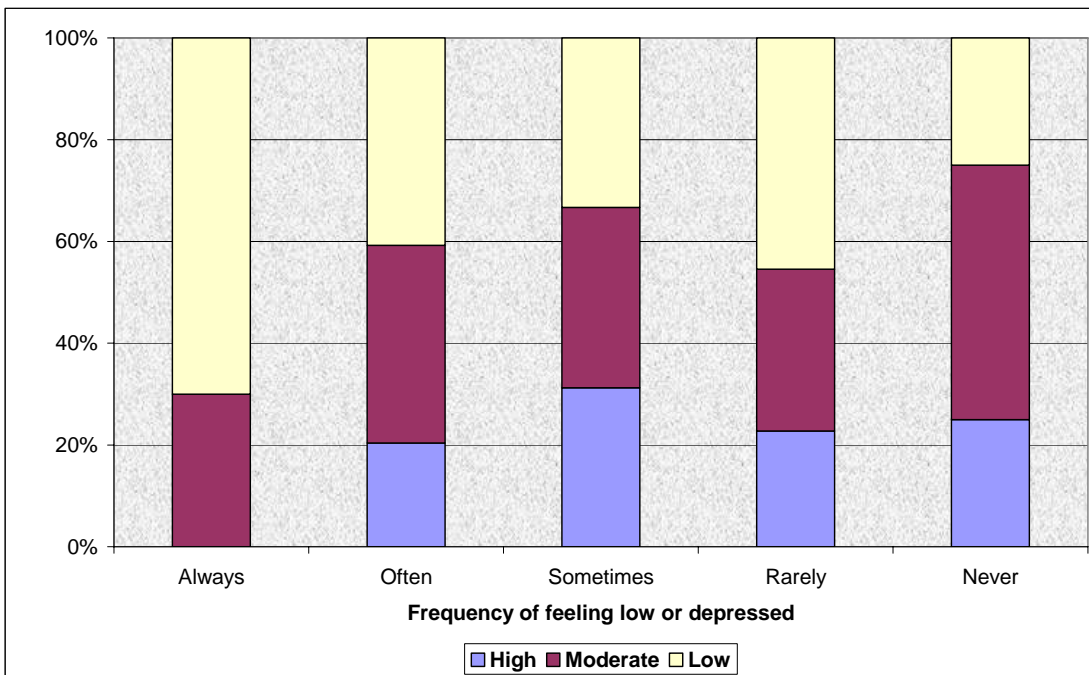
**Figure 5.1** Self reported frequency of feeling low of depressed by social diversity network score (high, moderate, low)



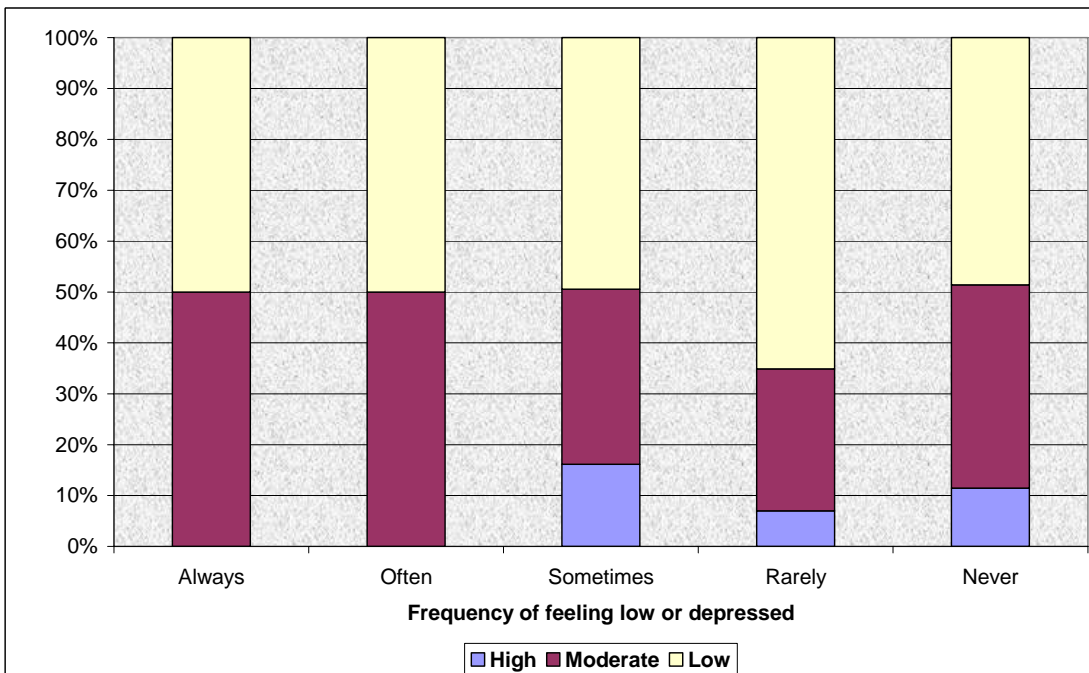
No-one with a high diversity network score reported 'always' feeling depressed, however those with a low network score did.

Depression rating and social diversity network scores were analysed by disability type. Frequency of feeling low or depressed by social diversity network score for respondents with a physical, learning and learning AND physical disability are shown in Figures 5.2, 5.3 and 5.4.

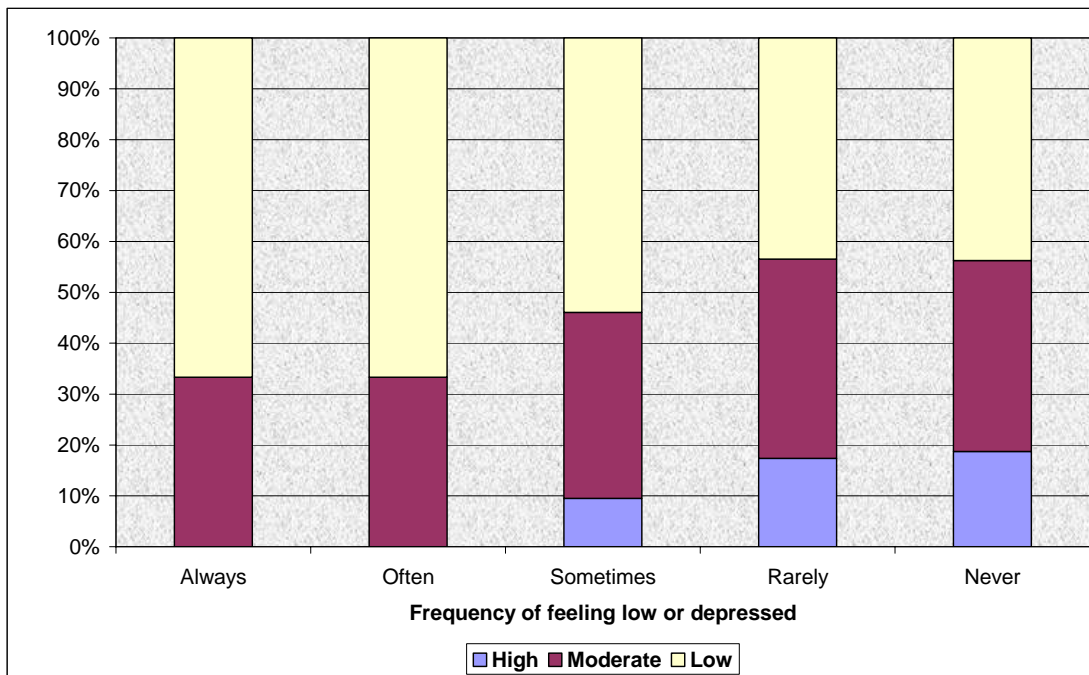
**Figure 5.2** Self reported frequency of feeling low of depressed by social diversity network score (high, moderate, low) – physical disability



**Figure 5.3** Self reported frequency of feeling low of depressed by social diversity network score (high, moderate, low) – learning disability



**Figure 5.4** Self reported frequency of feeling low or depressed by social diversity network score (high, moderate, low) – learning AND physical disability



## 5.2 Anxiety

Some studies have found links between anxiety symptoms and disability or progression of disability. deBeurs<sup>33</sup> found that anxiety was linked to increased physical disability in older adults and Brenes et al<sup>34</sup> found that women with symptoms of anxiety at baseline were at greater risk of worsening disability over three years. Sareen et al<sup>35</sup> discovered that anxiety disorders were particularly associated with people suffering from conditions such as arthritis, respiratory conditions, thyroid disease and migraine and were higher than expected in conditions such as cancer, hypertension and some other conditions. Those suffering from both a physical condition and anxiety tended to suffer from worse health than someone suffering from a physical or anxiety condition alone.

Anxiety disorders among people with learning disabilities are considered to be at least if not more prevalent than among the general population<sup>36</sup> but are underdiagnosed. As with depression, diagnosis may be difficult due to communication problems with putting symptoms into words, clinicians may also wrongly attribute symptoms of the anxiety to the person's learning disability. For people with learning disability who are diagnosed with anxiety disorders, treatment is as for the non learning disabled population – for example via medication or psychological therapies.

In total, 546 (96.6%) respondents answered the question about frequency of feeling anxious or worried. 30 (5.5%) reported 'always', 118 (21.6%) 'often' and 272 (49.8%) 'sometimes' feeling anxious or worried. A further 66 (12.1%) 'rarely' and 60 (11.0%) 'never' felt anxious or worried.

Self rated feelings of anxiety by disability type are shown in Table 5.2.

Table 5.2 Self rated feelings of anxiety by disability type

Frequency of feeling anxious or worried	Learning Disability	Physical Disability	Learning AND Physical Disability	Total
Always	10 (5.0%)	15 (7.1%)	4 (3.1%)	29 (5.4%)
Often	38 (18.8%)	56 (26.7%)	23 (17.8%)	117 (21.6%)
Sometimes	97 (48.0%)	98 (46.7%)	74 (57.4%)	269 (49.7%)
Rarely	29 (14.4%)	21 (10.0%)	16 (12.4%)	66 (12.2%)
Never	28 (13.9%)	20 (9.5%)	12 (9.3%)	60 (11.1%)
<b>Total</b>	<b>202 (100.1%)</b>	<b>210 (100.0%)</b>	<b>129 (100.0%)</b>	<b>541 (100.0%)</b>

Some variation existed in self reported anxiety ratings between respondents with different types of disabilities. Among those that answered, 80.5% of people with a physical disability ‘always’, ‘often’ or ‘sometimes’ felt anxious or worried, compared to 71.8% of those with a learning disability and 78.3% of those with a learning AND physical disability.

Being fearful of people was mentioned on several questionnaires. For some this fear was having a profound impact on their life.

*“...he doesn’t go anywhere that includes docs, hos[pital], shops, anywhere. I can’t get him out the house due to being scared of people. He lives in his bedroom.”*

*“\*\*\*\* is going backwards with mixing with people, he’s scared of everything and anything.”*

*“I don’t go out because of the fear of the public causing me problems .I can get out when my mum or my support worker takes me. I can get out when supported by my brother or friends. ”*

For some, fear of going out was linked to a fear of being a victim of crime.

*“I would not go out in the dark on my scooter...do not feel safe.”*

*“I feel like I am a million percent isolated. I cannot go outside my flat, the area, I cannot go outside anywhere without being harassed by residents who threaten eviction and threaten me and want to see my ID that I am disabled. They threaten, abuse and intimidate me and swear at me especially when I pass the pub on the corner. I get harassed and intimidated every time I go out of my door.”*

In some cases this was due to having been a victim of crime previously.

*“We don’t like the area and the kids and on a night time because he has had his car smashed 3 or 4 times and he has to pay for it... Me and my neighbour get it all. It looks quiet in the day but it’s not at night. They sit and stare into the window. They make \*\*\*\* very nervous.”*

*“I was down Freeman Street a week ago, got a bag on my back, going over crossing near Wellington Street. Two lads came up on bikes and the lights were on red, that’s why I crossed. When I got half way across the lads came up to me and tried to pull my stick off my bike but it was stuck on with Velcro, I was so frightened. One was trying to drag me [off] and the other one was calling me dozy, disabled so and so and then they went. I went into ASDAs and I broke down I was so upset, I couldn’t wait to get home.”*

### 5.3 Mental Health and Wellbeing of Carers

A survey of 1,941 carers conducted by Carers Week 2009 found that 74% had reached breaking point and that many had suffered extreme stress and depression as a result of caring for someone<sup>37</sup>. In an earlier study of 5000 carers conducted by Carers Week 2006, 79% stated that caring had made their own health worse and 71% of carers said that their health problems were

affecting their ability to care. The most common conditions were psychological impacts of caring such as depression and anxiety<sup>38</sup>.

In this study most carers reported that they were in reasonable health. Feelings of depression were however mentioned on a number of occasions by carers. The notion of having to 'fight' was mentioned by some.

*"Normally depression is about a situation, within time the situation gets better and their depression goes but with a disability it's not really going to go, it's there constantly. If I'm feeling down or depressed I still have to carry on with everything. \*\*\*\*s or other places do not take into account the health of the carer. It's depressing because I feel like I'm in a prison and I'm trapped and lonely."*

*"Depression as a carer is forever fighting battles, inability to relax, constantly on edge. It is hard for my husband working 12 hour shifts he is so tired when he comes home from work and I'm like, do that, do this. On a weekend he should be chilling out relaxing ready to go back to work on the Monday and he's not because he's having to do the garden, having to fetch the washing in etc."*

Several carers in the North East Lincolnshire survey mentioned anxiety about the future. Although they were currently meeting the needs of their children, concern existed about who would do that once they were no longer able or there to do that, or if existing facilities closed down.

*"...we love her and want her to be safe. Our worry is the future, \*\*\*'s dad will be 70 in March, I'm 67 in April. In spite of having had a triple heart bypass and having a pacemaker \*\*\*\*'s father is fit and so am I, it's the future for \*\*\*\* we are trying to ensure..."*

*"I must admit I am frightened of the future. If they shut Queen Street down, it is their lifeline, it's their friend."*

Some carers who participated in the study faced additional problems as they themselves had disabilities and yet were caring for family members with disabilities. Due to the nature and longevity of the disabilities suffered by family members, some carers had looked after their children who were now adults and still required care, leading to some older carers trying to care for their family and cope with their own disabilities.

*"Had a lot of blood on me brain from the strokes, if it got bad I just press the button. They couldn't pick me up last time I had one, my arms got stiff and my legs went so I went to bed and lay down. I don't like to worry him. I think it was the pressure of him collapsing what brought it on. I haven't been checked out by the doctor for a couple of months, just get my prescription. My speech is getting worse, I get tongue tied if strangers come to the door and it's embarrassing. I'll get through it I always do."*

*"I am a registered disabled person here looking after my mother as well as myself."*

Most considered that rather than being carers they were doing what a husband/ wife or parent should do.

*"He always says he will go in a home if he's really bad, I say you won't."*

*"I gave my life up for my son for carer's pay, that's called love."*

*"...being a parent really. He has always been here with us so I suppose we don't class ourselves as carers."*

It was mentioned that very little help was provided to people with disabilities who are parents of young children.

*"Since becoming a disabled parent I have been disgusted in the fact that there is no help given for help looking after the child as they still need looking after even when the parent is unable and not everyone has friends and family that can help them out. I think there should be help available to them."*

*"More help for disabled parents with young children."*



Carers spoke about the impact that caring had on their lives. Since most had been in a caring role for many years, often with a child who had been disabled since birth, some had found that any special requirements were a part of their normal lives.

*"It does have its restrictions without a doubt, but as we have never been free of them we can't really grumble because we adjust our lifestyle to what suits everybody in the household ... We would miss him if he was not here. We have not had the freedom of thinking that we could go out until 8pm tonight because we know he would be home around 6pm."*

*"You are tied down 24 hours a day, that's my life but I can't leave them and my son doesn't like going out on his own. The [shop] is as far as he goes, he goes to work twice a week. I don't sleep well, it is tiring."*

*"In the early years we did not go out at all as we could not leave him for a minute. I can't leave him now, I cannot leave him on his own. If we go on holiday we have to pick a holiday suitable for him not for ourselves. Our life is 'him', it does not revolve around my husband and myself our life revolves around 'him', whatever his needs are they always come first."*

Although some carers were unwilling to ask for respite care, others accessed day care respite breaks or respite facilities.

*"It has always been a family holiday. I wouldn't like him to think that mum and dad are going on holiday and have put me in somewhere. I wouldn't like that at all."*

*"He could go to Stanage Lodge but he never used to like going there but this last couple of years, what we could not have before was a day out. We have been retired for a lot of years and we could not say 'we are going to York today' because you have to wait for the bus picking him up and you have to be back by 3pm. How can you get to York, enjoy a day out, come back for 3pm? We brought this up with Tina and Nicola, (Carer's Support) they are brilliant and they arranged days out for us, about twice a year, which is good. We are always home by 6pm because we have to pick him up..."*

*"Yes I have 4 or 5 holidays a year, he goes in Stanage Lodge. When his mum passed away the position was to go into Stanage Lodge every 6 weeks to give me a weekly break but I didn't want that, I wanted the break when I wanted it to go away on holiday. I can ring up and say can I have so and so date, they might say it's fully booked but I can have the next week, I book around that. There are certain holidays you can't book around. There is flexibility."*

### Key Points

- Considerable variation existed across disability types in terms of frequency of feelings of depression, with 82% of respondents with a physical disability feeling low or depressed 'always', 'often' or 'sometimes' compared to 59% of respondents with a learning disability.
- A higher proportion of respondents with a physical disability (80.5%) reported 'always', 'often' or 'sometimes' feeling anxious or worried compared to 72% of those with a learning disability and 78% of those with a learning AND physical disability.
- Fear of people and of going out was mentioned as an issue for some people and this was having a considerable impact on their lives. In some respondents this was linked to a fear of crime. Being a victim of crime was mentioned by several who felt they were targeted because of their disability.
- For some carers, anxiety was linked to fear of the future and who would care for the person they looked after when they were no longer there to do it.
- Carers mentioned restrictions on their lives in terms of lack of freedom to come and go without planning. Some used respite facilities whereas others preferred to organise things as a family unit.

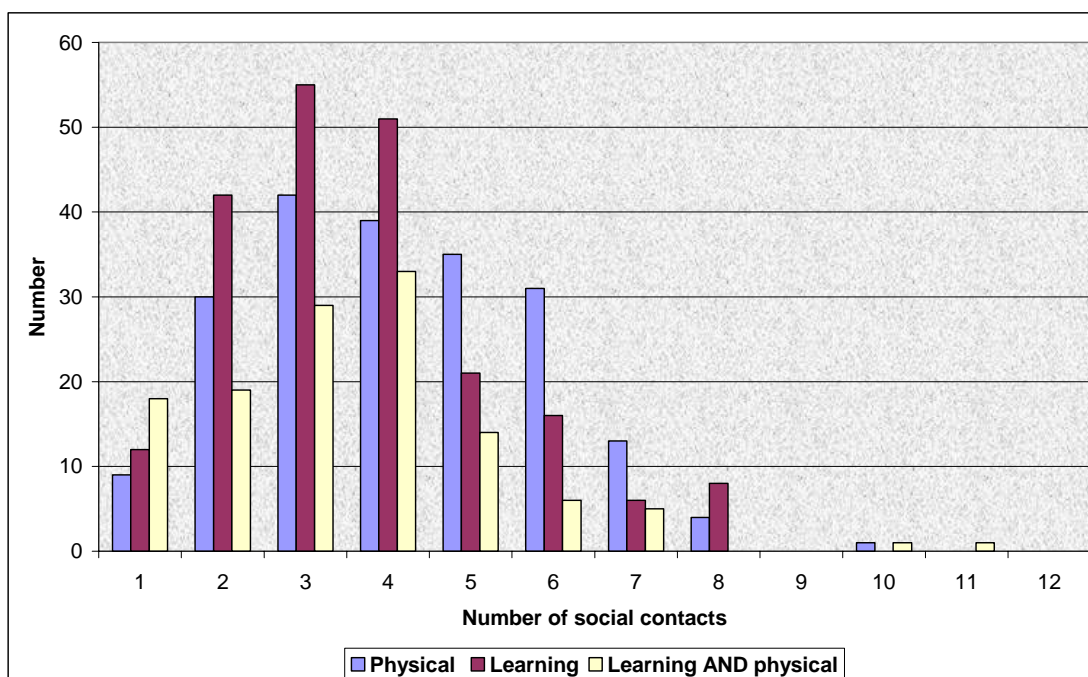
## 6. SOCIAL SUPPORT AND NETWORKS

The Government set up the Social Exclusion Task Force in 2006 to attempt to reduce social exclusion in vulnerable groups<sup>39</sup>. The personalisation agenda and individual budgets scheme (see Section 9) were intended to assist people with disabilities to reduce their isolation by being more in control of what they wanted from their care budget, enabling them to purchase services which best suited their wishes, for example through paying for carer accompaniment to social activities if required.

Respondents were asked how many types of social contact (e.g. spouse, parents, children, friends, neighbours, care-workers etc.) they spoke to in person or on the telephone at least once every two weeks. Possible scores ranged from 0 (no social contacts) to 12. 539 (95.4%) respondents answered the question. Some respondents to the survey were unable to speak and therefore probably answered on the basis that they communicated through gestures. Others may have understood the question to mean those people the person saw in the previous two weeks and answered on that basis. Any of these interpretations offer a measure of the degree of social interaction a person experiences and so all were included.

Results showed social network scores between one and 11. 29 respondents did not complete the question and this data was recorded as missing. The largest proportion of respondents had a social network score of three (127, 23.6%). Figure 6.1 shows social network score by disability type.

Figure 6.1 Social network score by disability type



Among respondents with a physical disability the number of social contacts ranged between one and 10 with an average (mean) number of 4.14. For those with a learning disability, the range was one to eight with an average number of contacts of 3.51. Among respondents with a learning AND physical disability, the range was one to 11, with an average of 3.47.

Table 6.1 shows the number of people who spoke to each type of contact in an average fortnight.

**Table 6.1**      Type of social contact

<b>Contact</b>	<b>Number (% of 539 who responded)</b>
Friend	392 (72.7%)
Other family members	337 (62.5%)
Care worker or privately paid help	333 (61.8%)
Parent(s)	283 (52.5%)
Neighbour	162 (30.1%)
Child(ren)	118 (21.9%)
Members of other groups	117 (21.7%)
Husband/wife/partner	91 (16.9%)
Current or former work colleagues	60 (11.1%)
Fellow volunteers	49 (9.1%)
Members of your church (other religious group)	40 (7.4%)
Parent(s) in law	33 (6.1%)

The number of contacts was then recoded as per Cohen et al<sup>40</sup> to give a social network diversity classification of low diversity (1-3 contacts), moderate diversity (4-5 contacts) and high diversity (6+ contacts). Of the 539 who responded, the largest proportion, 48.2% (260) had a 'low' social network diversity score. The next highest proportion, 36.0% (194) had a 'moderate' score and 15.8% (85) had a 'high' network score.

Social diversity network classification by disability type is shown in Table 6.2. It shows clear differences between the social network classifications of the different types of disability, with respondents with learning disabilities (either learning or learning AND physical disabilities) having a much lower diversity network score than those with a purely physical disability. Over half of learning disability (109, 53.4%) and learning AND physical disability respondents (66, 52.4%) had a low network classification score compared to 39.7% (81) of those with a physical disability, suggesting that those with a learning disability are at increased risk of social isolation.

**Table 6.2**      Social diversity network classification by disability type

		<b>Social diversity network classification</b>			
		<b>High</b>	<b>Moderate</b>	<b>Low</b>	<b>Total</b>
Disability type	Physical	49 (24.0%)	74 (36.3%)	81 (39.7%)	204 (100.0%)
	Learning	23 (11.3%)	72 (35.3%)	109 (53.4%)	199 (100.1%)
	Learning AND Physical	13 (10.3%)	47 (37.3%)	66 (52.4%)	126 (100.0%)
	<b>Total</b>	<b>85 (15.9%)</b>	<b>193 (36.1%)</b>	<b>256 (47.9%)</b>	<b>534 (99.1%)</b>

**Someone to confide in**

Of the 541 who answered, 84.7% (458) had someone that they could confide in about the things that were important to them. 9.1% (49) did not have someone to confide in and the remaining 6.3% (34) of those who responded were unable to talk/ communicate.

For respondents with a physical disability, 81.0% (166) had someone they could confide in, whereas 17.0% (35) did not. 2.0% (4) were unable to speak.

For learning disability, 93.1% (189) had someone they could confide in, 3.0% (6) did not and 3.9% (8) were unable to speak.

For those respondents with a learning AND physical disability, just over three quarters (99, 77.3%) had someone to confide in, however 17.2% (22) of this group were unable to speak, with only 5.5% (7) saying that they had no-one to confide in.

When analysed by social diversity network score, 4.7% (4) of the 85 people with a 'high' network score stated that they had no one to confide in, 10.8% (20 of 186 respondents) with 'moderate'

scores also had no one to confide in, as did 9.5% (24 of 252) of respondents with a 'low' social diversity network score.

### Living Alone

People who live alone are at greater risk of social exclusion. Of the 211 respondents with a physical disability, 41.9% (88) lived alone. This is a much higher proportion than respondents with a learning disability, of whom only 8.6% (18) lived alone and respondents with a learning AND physical disability, of whom only 8.1% (11) lived alone.

Of the 539 people who responded to both questions, 114 people lived alone and were able to be assigned a social diversity network score. Perhaps unsurprisingly, half of those (57, 50.0%) had a low diversity network score, 41.2% (47) had a moderate score and only 8.8% (10) had a high diversity network score. Of the 84 respondents with a physical disability who answered both questions, over half (45, 53.6%) had a low diversity network score, 39.3% (33) had a moderate score and 7.1% (6) had a high score, suggesting that people with a physical disability who live alone are at an increased risk of social isolation due to a decreased number of social contacts.

*"I have contact with a guy across the road who gets my medicine or helps me in an emergency. He once helped when a mob of 10 were harassing me and shouting, but they started picking on him. No, other than that I don't have contact with anyone."*

### Loneliness

533 (94.3%) respondents answered the question about frequency of feeling lonely. A small proportion (20, 3.8%) stated that they felt lonely 'all the time', whilst 5.4% (29) felt lonely 'most of the time'. The largest proportion of respondents (223, 41.8%) felt lonely 'sometimes', 18.9% (101) felt lonely 'almost never' and 30.0% (160) 'never' felt lonely. Self reported frequency of loneliness by disability is shown in Table 6.3.

**Table 6.3**      Frequency of feeling lonely

		Disability type			Total
		Physical	Learning	Learning AND Physical	
Frequency of loneliness	All the time	13 (6.4%)	4 (2.0%)	2 (1.6%)	19 (3.6%)
	Most of the time	19 (9.3%)	6 (3.0%)	4 (3.2%)	29 (5.5%)
	Sometimes	93 (45.6%)	76 (38.4%)	52 (41.6%)	221 (41.9%)
	Almost never	36 (17.6%)	40 (20.2%)	24 (19.2%)	100 (19.0%)
	Never	43 (21.1%)	72 (36.3%)	43 (34.4%)	158 (30.0%)
<b>Total</b>		<b>204 (100.0)</b>	<b>198 (99.9%)</b>	<b>125 (100.0%)</b>	<b>527 (100.0%)</b>

Table 6.3 shows that despite small numbers, the proportion of people suffering from regular feelings of loneliness is more than three times higher in those with physical disabilities compared to those with learning or learning AND physical disabilities.

*"[I] only see people who come to see me at home..."*

Frequency of feeling lonely was analysed by social diversity network score. Of those who reported feeling lonely most/ all of the time, 8.3% (4) had a high diversity network score, 37.5% (18) had a moderate score and more than half (26, 54.2%) had a low network score. For respondents who were sometimes lonely 17.0% (37) had a high network score, 35.8% (78) had a moderate score and 47.2% (103) had a low network score. Proportions for those who almost never or never felt lonely were similar to those who sometimes felt lonely. 17.0% (43) had a high network score, 36.8% (93) had a moderate network score and 46.2% (117) had a low network score.

Responses to the question regarding frequency of feeling lonely were analysed with another question regarding frequency of leaving the home. For those respondents that reported feeling lonely most or all of the time, a fifth (10, 20.4%) 'almost never or never' left their house and almost a further third (16, 32.7%) left their house 'at least once a week', suggesting a link between being housebound and loneliness. For those who left the house 'a few days a week' 18.4% (9) reported feeling lonely most or all of the time, as did 16.3% (8) who left the house 'most days' and 12.2% (6) who left the house 'every day'. For respondents who stated that they felt lonely 'sometimes', 'never/almost never' there was no clear association between leaving the house and frequency of feeling lonely.

### Sense of Community

Of the 494 (87.4%) who answered, 228 (46.2%) felt part of their local community however more than half (264, 53.4%), did not. These results are disappointing and suggest that work should be undertaken by community groups to promote integration within their local communities to reduce social isolation among people with disabilities in their local areas, reduce stigma about disabilities in the local community and fear of the general public among disabled residents.

*"Not any more... made the effort to get to know people but no support from others."*

Among those with a physical disability, 37.8% (73) of respondents felt part of the local community compared to 62.2% (120) who did not. For learning disability, more than half (107, 59.1%) felt part of the local community compared to 39.8% (72) who did not. Among respondents with a learning AND physical disability, 39.7% (46) felt part of the community compared to 60.3% (70) who did not.

Several respondents wanted to see more integration with able bodied groups and communities to assist with breaking down barriers and remove some of the discrimination that they perceived against disabled people.

*"Inclusion, respect, dignity. See the person not the disabilities."*

*"Integration into able-bodied groups instead of segregation."*

Many commented about the need for education, particularly among young people about the nature of disability issues. Several had experienced abusive comments or physical violence and the perception of the public as an 'enemy' to be protected from was mentioned by some.

*"With him being autistic you get these hooligans that pick on him..."*

*"I don't go out alone as I was assaulted a couple of years ago by other youths because I have a disability."*

*"Better education in schools about disabilities with hands on experience for youngsters to meet and help disabled, try shopping in a wheelchair, or with a blindfold or earplugs"*

542 (95.9%) respondents answered the question about daytime activities. Over half (287, 53.0%) did attend daytime activities such as lunch clubs, church groups, day centres or hobby groups, whereas 47.0% (255) did not.

Only 30.7% (62) of respondents with a physical disability attended daytime activities compared to 69.3% (140) who did not. For learning disability, over two thirds (136, 67.3%) attended activities compared to 32.7% (66) who did not. Among respondents with a learning AND physical disability, 64.9% (87) attended daytime activities compared to 35.1% (47) who did not.

Attendance at organised daytime activities were analysed against frequency of feeling lonely. 518 people answered both questions. 156 people reported 'never' feeling lonely, of these, 103 (66.0%) attended organised daytime activities. 99 people 'almost never' felt lonely, more than half (54, 54.5%) attended daytime activities as did 100 (46.7%) of the 214 people who 'sometimes' felt

lonely. Only nine (31.0%) of the 29 people who felt lonely 'most of the time' attended daytime activities, for those who 'always' felt lonely the figure was much lower, with only two (10.0%) attending. This is perhaps unsurprising due to the low number of people with physical disabilities attending organised daytime activities and the previous finding that people with physical disabilities reported feeling lonely more frequently than respondents with learning disabilities. Provision for organised activities for people with physical disabilities should be looked at as a priority to reduce risk of further isolation in this group, in conjunction with potential service users to establish a successful service which users will want to use.

Comments were received about gaps in availability for those who did not fit into the younger people or older people age category. Despite a perception of plenty to do for these two age categories it was felt that those in the middle were missed out. Others felt there were not enough day facilities about locally.

*"My health needs are mainly met but my social needs such as being able to meet people, join groups are not. This is where I need help. Sometimes I feel I am in a cage, trapped, scared and if I scream I won't stop... Is there anywhere I can meet people younger in my age group?"*

*"Is there any activities place where I can go, I don't know anywhere I can go because I'm not old and I'm not young? I feel totally cut off and isolated, I don't know who to ring and ask what I can do."*

*"I feel I find myself in an age group that is neglected. There seems to be plenty for the young and those over 60/65."*

*"More things for my age, everything is for older people or if there is for younger it's for [those with learning disabilities]"*

### Barriers to Social Participation

Respondents were asked if there was anything which prevented them from being more active socially and 517 (91.5%) answered this question. More than half (285, 55.1%) stated that something did prevent them from being more socially active, 44.9% (232) said that nothing did.

Two thirds (129, 66.5%) of respondents with a physical disability stated that there was something that prevented them from being more socially active compared to a third (65, 33.5%) who said there was not. Among respondents with a learning disability, 42.3% (82) felt something restricted their social participation compared to 57.7% (112) who did not. For those with a learning AND physical disability, more than half (71, 57.3%) indicated that something restricted their social participation compared to 42.7% (53) who did not.

Those who responded that there was something which prevented them from being more socially active were asked to provide details of what this was. 272 (95.4%) of the 285 who answered yes did so. These responses were categorised and the main groups of responses are displayed in Table 6.4 below.

**Table 6.4**      Barriers to social participation

<b>Reason</b>	<b>Number (% of 272 comments received)</b>
Disability/illness/pain	148 (54.4%)
Anxiety/shyness/lack of friends/fear of other people/fear of violence	36 (13.2%)
Need support/someone to accompany at all times	26 (9.6%)
Inability to communicate/mix with others	17 (6.3%)
Transport/getting around	11 (4.0%)
Physical access to buildings	7 (2.6%)
Lack of money	5 (1.8%)
<b>Total</b>	<b>250 (91.9%)</b>

For some respondents, the nature of their disability was such that they were unable to take part in social activities. Many mentioned pain caused by their condition. It was common that people wanted to take part in social activities but simply felt unable to do so.

*"My illness stops me from (taking part in) different activities, sometimes the pain I'm in is really bad. So it stops me from going out. I'd love to be more socially active. I miss out on a lot."*

*"My behaviour is inappropriate at times and I don't like to be around a lot of people."*

*"Pain makes me feel inadequate in social situations as I have trouble keeping a clear head. Also, I daren't invite anyone to my house as it embarrasses me."*

Approximately a third of people with learning disabilities say that they have no contact with friends, with one in 20 stating that they have no friends at all. For most, their friends also have learning difficulties<sup>41</sup>. Several respondents mentioned feeling worried or anxious around other people, or that they did not have many friends and this impacted on their ability to take part in social activities. Shyness and lack of confidence around strangers was also mentioned.

*"Don't feel safe being outdoors, stay at home. Doctor is getting me a counsellor to see if they could help me to go out."*

*"I've been on my own so long I don't know how."*

*"I find it difficult to mix with new people and get to know them."*

Further issues raised were the need for constant accompaniment for some people with disabilities. Some were able to pay for a carer to help them to have a social life but not all felt that this was ideal. For many, being accompanied was essential due to health needs or lack of awareness that could lead to dangerous situations.

*"Having to have someone with me when I go anywhere."*

*"I'm limited where I can go because I'm reliant on someone being with me or taking me by car."*

*"I don't know many people here and can't get to meet anyone to have a social life with. If I have a meal out it's with a carer and I pay, same with coffee out. I was very socially active before I moved here and had lots of friends. I'm scared to go to the theatre without anyone, what if I am stranded because of steps? I have lost a lot of confidence now since being here."*

Problems with communication and poor speech were raised, particularly by those with learning disabilities. For some respondents, the nature of their learning difficulty made the understanding of social interaction difficult and conversations problematic. This was also the case for respondents with hearing difficulties due to the low number of people able to communicate using British Sign Language (BSL).

*"Inability to talk well. Constantly having to apologise for not knowing what people are saying to me."*

*"No-one can use BSL so I cannot talk to anyone. I need a translator on call for visits to doctors and the like"*

Transport to venues was considered a problem for some and complaints were received from wheelchair users about difficulties in physical access to buildings.

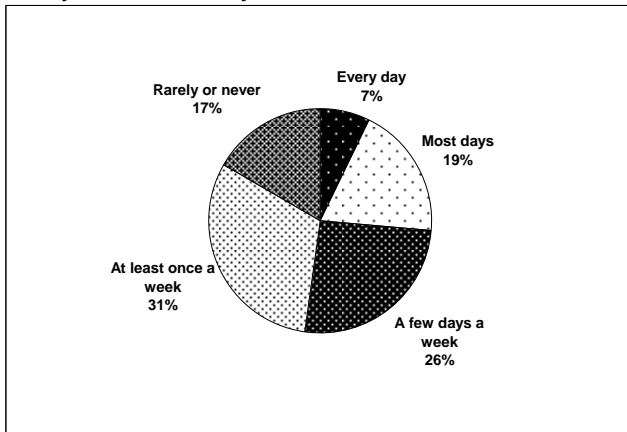
*"Lack of transport and escort, parents elderly and can't do night driving."*

*"I need to feel part of something, although I am married my emotional and social needs are more than my husband can provide. I need to be out socialising but toilets are too small for myself, my wheelchair and my hubby. So cannot go places, cannot visit friends, can't get in."*

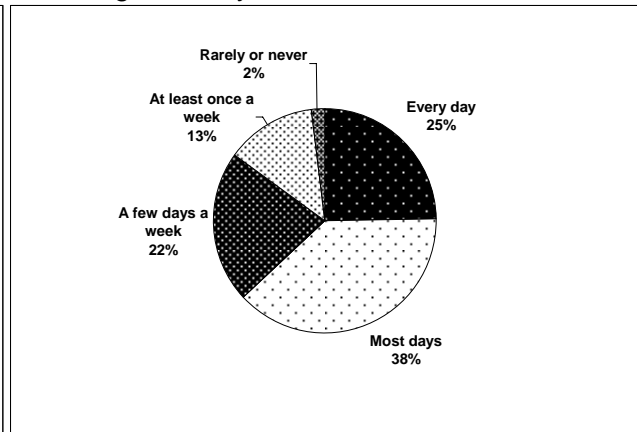
550 (97.3%) respondents stated how frequently they went out each week, such as to visit friends or go shopping. 97 (16.5%) went out 'every day', 156 (28.4%) said 'most days', a further 132 (24.0%) answered 'a few days a week', 121 (22.0%) went out 'at least once a week' and 50 (8.8%) stated that they 'rarely or never' went out. The following pie charts show the breakdown of frequency of leaving the house by disability type.

Figure 6.2 Frequency of leaving the house by disability type

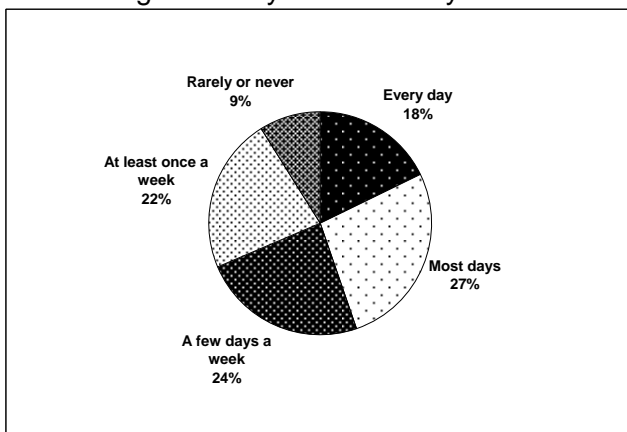
i. Physical disability



ii Learning disability



iii. Learning AND Physical disability



The above figures clearly show that leaving the house infrequently (at least once a week/ rarely or never) was much more common for respondents with a physical disability (48%) than for those with a learning disability (15%) or learning AND physical disability (31%). Clearly, those with physical disability are at increased risk of isolation if they are unable to leave their homes, this risk is exacerbated for those who live alone.

As mentioned in Section 5, caring responsibilities also impact upon the freedom to take part in social activities. Requirements of having respite care or a 'sitter', or a venue which is able to accommodate the entire family make planning social activities difficult for some.

Reducing Social Isolation

Many respondents expressed a desire for improved opportunities for social interaction. Some simply expressed a desire to have more opportunities to mix with other people with a similar disability, others wanted to give their parents/ carers a break. There were several requests for more social groups for young people with learning disabilities.



*"I would like to see more opportunities to meet people with the same disability."*

*"More activities with support to give my carers a break."*

*"Feel isolated...need more social activities, people to meet with and talk to, lunch centres or drop in groups, places to go. Need someone to socialise with while husband at work."*

*"Places for people to meet each other, maybe a friendship group."*

*"Volunteers to drop in, different ones so that we can maybe find a new friend."*

Care home residents also expressed a desire to interact more with other homes to expand their social networks and have the opportunity to make friends with other residents. More organised outings were also wanted.

*"Different homes to organise party and invite other learning disability or physical disability homes. Take into town."*

*"More money available for us to have party with other homes so we can social(ise) and make new friends".*

In addition to opportunities to mix for people with disabilities, several respondents mentioned the desire to see more support groups for carers, to enable them to have support and reduce isolation.

Holidays were an important topic for several respondents and cost and affordability were key issues. Several respondents wanted to see subsidised breaks for people with disabilities become available. Taking a holiday as a family was an important issue for some rather than using respite care facilities. Appropriateness of facilities was an important consideration and standards of disabled support varied. Spending money on holidays was mentioned by respondents in reply to the question asking how they would spend money differently if they could.

*"Provision of subsidised holiday breaks at properly adapted accommodation for myself and wife."*

*"Regularly paid holidays (not rest in home) all disabilities catered for 100%."*

*"More hobby groups and maybe cheap affordable holidays, we don't have anything to do in our area."*

*"We save up for 2 years to go on holiday to Disneyland (Florida, USA). I love it, it's the only place that allows me to go everywhere with ease in my wheelchair."*

Increased social opportunities were important for study participants. To do this, they wanted to be able to participate in a variety of activities and to be able to develop and maintain relationships with friends. Local community and voluntary groups can assist with this process and should be engaged with by disability services, with promotion of activities and clubs through various media such as leaflets and local newspapers to target as wide a potential audience as possible. Since respondents with physical disabilities were at increased risk of isolation, work should be targeted at engaging with this group.

#### **KEY POINTS**

- Over half (53%) of respondents with a learning disability and a learning AND physical disability (52%) had a low network score, compared to 40% of respondents with a physical disability.

- 42% of respondents with a physical disability lived alone compared to 9% of respondents with a learning disability and 8% with a learning AND physical disability.
- Frequency of feeling lonely appeared to be more common in those with lower social diversity network scores and who left their homes less frequently.
- More than half of respondents did not feel part of their local community.
- Over half (53%) of respondents attended organised daytime activities, however far fewer respondents with a physical disability did (31%) compared to learning disability (67%) or learning AND physical disability (65%) respondents.
- 55% of respondents stated that there was something that prevented them from being more socially active. The main barrier to social participation mentioned was disability, illness or pain. Other common barriers included anxiety, communication problems, the need for a companion and transport difficulties.
- Respondents wanted more opportunities for social interaction in order to develop friendships and engage in new activities.

## 7. DIGNITY AND RESPECT

### 7.1 Dignity and respect in health care services

People with learning disabilities and particularly those with severe disability and complex needs are some of the most vulnerable people in our society; they also have significantly worse health than others, yet have the highest levels of unmet need and receive less effective treatment despite legislation<sup>42</sup>. An independent inquiry into healthcare for people with learning disabilities found that this unmet need has led to unnecessary illness, disease and even death. The Disability Rights Commission reported that ‘diagnostic overshadowing’ was also a problem. Diagnostic overshadowing refers to negative bias affecting the accuracy of clinicians’ judgments when assessing people with learning disability or mental illness. It was found that those with communication difficulties found it difficult or impossible to get the support they needed<sup>43</sup>.

Mencap’s ‘Death by Indifference’ report follows from their ‘Treat Me Right’ report and campaign in 2004. Since the ‘Treat Me Right’ report highlighted inequalities in the NHS for people with a learning disability, many more cases of unequal treatment in the NHS have come to light. ‘Death by Indifference’ reports on an inquiry into the deaths of six people with learning disabilities. The inquiry found that all had occurred because of discrimination, indifference, a lack of training and a poor understanding of people with a learning disability<sup>44</sup>. It also reported that some people with a learning disability had to put up with pain and discomfort before getting the right treatment because they found it hard to communicate their symptoms and understand what they were being told, consequently some people do not receive the treatment they need.

Locally, a large majority of the needs assessment survey respondents (87.3%) said that they are treated with dignity and respect by health services, just 3.5% do not feel they are treated with dignity and respect by health services. Although fewer people with a learning disability said they were not treated with dignity and respect by health services, a higher proportion (12.6%) said they didn’t know as shown in Table 7.1. There was little difference in the proportion of people with physical and learning disability who responded that they were treated with dignity and respect. However a slightly greater proportion of people with physical disability (5.4%) responded that they were not treated with dignity and respect.

Table 7.1 Are you treated with dignity and respect by health services?

	Yes		No		Don't know		Total
	No.	%	No.	%	No.	%	No.
<b>Physical Disability</b>	179	87.3%	11	5.4%	15	7.3%	205
<b>Learning Disability</b>	179	86.5%	2	1.0%	26	12.6%	207
<b>Physical AND Learning Disability</b>	118	88.7%	6	4.5%	9	6.8%	133
<b>Total</b>	476	87.3%	19	3.5%	50	9.2%	545

The DRC found that nationally some healthcare staff did not speak directly to patients with a disability and made no attempt at alternative communication when there were communication difficulties. The DRC report also found that some physical health problems were not taken seriously and were simply put down to their disability. The local survey found that although the majority felt that health services treat them with dignity and respect, some said they wanted more respect and understanding from health care professionals:

*“More understanding of adults with a learning disability especially by health professionals.”*

*“[to be] treated with more respect and took notice of when you tell professionals there is something wrong.”*

*“Better understanding of adults with learning difficulties from health care professionals”*

*“...hospitals aren’t very good at it at all I think they are the main stumbling block really. Nursing staff don’t seem to understand people with learning disabilities at all.”*

## 7.2 Dignity and respect in social care services

More than 88% of respondents reported that they are treated with dignity and respect from social services, 3.2% said they are not and 8.6% said they didn’t know.

Table 7.2 Are you treated with dignity and respect by social services?\*

	Yes		No		Don't know		Total
	No.	%	No.	%	No.	%	No.
<b>Physical Disability</b>	160	87.9%	9	4.9%	13	7.1%	182
<b>Learning Disability</b>	147	85.0%	5	2.9%	21	12.1%	173
<b>Learning AND Physical Disability</b>	112	93.3%	1	0.8%	7	5.8%	120
<b>Total</b>	419	88.2%	15	3.2%	41	8.6%	475

\*Does not include those who do not use social services.

The DRC found that parents and carers had to battle for their children to get a good service. ‘Those who shout the loudest get the best out of the system’. This was also felt by some parents whose children were going through the transition process locally.

*“I have been horrified quite honestly. The lack of communication has been dreadful.”*

*“The only thing I get for \*\*\*\*\* is direct payments and the only reason I got that is because I fought hard for it.”*

*“The more you fight the more you will get things done. If you don’t fight you will not get anything”*

*“I fought for it and saw the need for it (a transitional package)... we pushed for one.”*

## 7.3 Dignity and Respect from the general public

The local needs assessment survey asked what respondents would like to see for people with disabilities if they had a magic wand. The largest proportion of responses was around respect, equality and understanding. This included respect and understanding from the general public about disability specific issues, equality and social integration for people with disabilities.

*“More understanding for people with mental health and learning difficulties. Because you can’t see the illness people don’t understand what it’s like, whereas if you have a physical illness everybody helps”*

*“Able bodied people to have my disability for a day to show them what I go through and understand it”*

*“Disability awareness in schools to make the kids aware, kids are young they don’t understand the effects it has shouting things at someone disabled. They pick on them because they seem different.”*

Others mentioned the desire to be treated and spoken to respectfully, or to be spoken to at all.

*“For all with disabilities to be seen as people not inferior to able-bodied people.”*

*“Giving respect not spoken to as idiots.”*

*“People with disabilities to be spoken to rather than the carer.”*

Some respondents wanted to see more integration with able bodied groups and communities.

*"Inclusion, respect, dignity. See the person not the disabilities."*

*"Integration into able-bodied groups instead of segregation."*

*"I want to be happy and not get picked on cos I'm different..."*

Discrimination against disabled people in employment was also mentioned. One person also mentioned negative perceptions against disabled people who are on benefits.

*"No discrimination. I can carry out a responsible job as well as the next person."*

*"...not to be considered as second class citizen i.e. not to be looked down upon because of being supported by the state."*

### KEY POINTS

- The majority of disabled people feel that they are treated with dignity and respect by health and social care services.
- However, there is a lack of understanding about learning disabilities amongst some healthcare professionals.
- It is felt that it is necessary to have to 'fight' for access to social care services, including direct payments and transitional packages.
- What disabled people wanted the most if they had a magic wand was more dignity, respect and understanding from the general public.

## 8. EMPLOYMENT AND EDUCATION

### 8.1 Employment

The Disability Discrimination Act made it illegal for employers to discriminate against disabled people in all areas of employment such as recruitment, promotion, redundancy or terms of employment. It also placed a duty on employers to make “reasonable adjustments” in the workplace to ensure that employees with a disability are not put at a significant disadvantage. Such adjustments could include things such as flexible hours, retraining if unable to carry on with the current job, providing modified equipment or making adjustments to the building to facilitate access. Job Centre Plus runs an Access to Work scheme to advise employers and in some cases provide limited financial assistance<sup>45</sup>.

For employers who have agreed to work positively with people with disabilities to help them remain in work, the Jobcentre Plus is able to award the disability symbol, represented by a green circle with two ticks and the words ‘positive about disabled people’. Employers with the disability symbol have agreed to offer all people with disabilities an interview subject to them meeting minimum requirements for the post, annually review how workers can best develop and use their skills, make every effort to help their workers with disabilities stay in work, ensure all other staff know what support people with disabilities require and review these commitments annually with a view to continuous improvement<sup>46</sup>.

*“Getting There, An Interim Strategy for People with Physical Disabilities in North East Lincolnshire (2007-2009)”*<sup>47</sup> outlines a commitment from local partner agencies such as the CTP, Local Authority and Northern Lincolnshire and Goole Hospitals Foundation Trust to be leaders in providing local opportunities for employment for people with physical disabilities. In the Local Authority a scheme is in place to help those with physical and learning disability into employment within the organisation. The Hospital Trust and the Care Trust Plus have established an Employability scheme to cater for those with disabilities as well as other groups who find it difficult to access employment.

553 (97.7%) respondents answered the question asking whether or not they were currently in paid employment. The vast majority (518, 93.7%) were not, 26 (4.7%) were employed on a part time basis, four (0.7%) were employed full time and five (0.9%) were retired. The proportion of people with disabilities in paid employment in this survey was much lower than national figures which suggest that 34% were in paid employment in 2008<sup>48</sup>. National figures also suggest that people with disabilities who are in employment are less likely to be employed in high status occupations and are employed on lower rates of pay than people without disabilities.

Respondents were also asked if their disability had affected their ability to do paid work. 523 (92.4%) answered this question and the majority (395, 75.5%) stated that their disability had meant that they were unable to do paid work. 49 (9.4%) respondents said that their disability had limited the kind of paid work that they could do, for four (0.8%) it had limited the time they could work for. For an additional 15 (2.9%) respondents, their disability had impacted on both the kind of work they could do and the length of time they could work for. 33 (6.3%) respondents stated that their ability to work had not been affected by their disability, the remaining 27 (5.2%) answered that they did not know. Table 8.1 shows the impact of disability on ability to do paid work by disability type.

For the remaining questions, those respondents who stated that their disability meant that they were unable to work were excluded from the analysis, leaving 128 respondents included in the analysis. They were asked whether their disability had made it difficult for them to obtain a job. Of the 121 respondents who answered the question, 47 (38.8%) said that they had found it difficult to get a job because of their disability. Just over a quarter (33, 27.3%) said they had not had a problem getting a job because of their disability and a third (41, 33.9%) said they did not know.

Table 8.1 Impact of disability on ability to do paid work, by disability type

		How has your disability affected your ability to do paid work?						Total
		I'm unable to work	Limited the kind of work I can do	Limited how long I can work for	Affected kind of work AND how long I can work	It hasn't affected it	Don't know	
Type of disability	Physical	173 (86.1%)	7 (3.5%)	3 (1.5%)	6 (3.0%)	8 (4.0%)	4 (2.0%)	201 (100.9)
	Learning	109 (57.7%)	37 (19.6%)	1 (0.5%)	6 (3.2%)	20 (10.6%)	16 (8.5%)	189 (100.1%)
	Learning and Physical	108 (84.4%)	5 (3.9%)	0 (0.0%)	3 (2.3%)	5 (3.9%)	7 (5.5%)	128 (100.0%)
<b>Total</b>		<b>390 (75.3%)</b>	<b>49 (9.5%)</b>	<b>4 (0.8%)</b>	<b>15 (2.9%)</b>	<b>33 (6.4%)</b>	<b>27 (5.2%)</b>	<b>518 (100.1%)</b>

For respondents with a physical disability, eight (28.6%) had found it difficult to get a job because of their disability, 11 (39.3%) had not and nine (32.1%) did not know. For those with a learning disability, 31 (41.9%) had found it difficult to get a job, 16 (21.6%) had not and 27 (36.5%) did not know. Among respondents with a learning AND physical disability eight (42.1%) had found it difficult to get a job because of their disability, six (31.6%) had not and five (26.3%) did not know.

Some mentioned reasons for difficulties that related specifically to their disability.

*“Because I am not able to stand for a length of time and do get very tired very easy.”*  
*“Because of my learning disability.”*

Others mentioned problems in communicating with other people or skills gaps.

*“Don't like facing other people because of my disabilities communicating with people.”*  
*“My autism restricts me, not comfortable without support...”*  
*“Being unable to read and write.”*

For others, discrimination against disabled people was considered to be an issue despite the legislation.

*“A lot of workplaces claim their insurances won't cover them to employ a person like me.”*  
*“People assume one has had a full frontal lobotomy when the word stroke is mentioned, and tend to be patronising.”*  
*“Nobody wants to employ people as old as me.”*

In addition, some respondents with physical disabilities mentioned problems with access, particularly for those in wheelchairs.

*“Was told my wheelchair was a health and safety hazard to children and adults.”*

There was a comment that little had changed over the years in terms of employing people with learning disabilities, with some placements being almost token gestures and some of the best opportunities being lost with firms going out of business.

*“...at the end of the day when you are in business it is all about profit. You have to make money otherwise you will go under and if you are making a vast amount of money you can afford to put one or two of these people under your wing and shout from the housetops and everybody thinks you are great, but when you are struggling to make the money they are the first ones out. There are only places for them in organisations who are making money and paying big taxes ...seems there are not many of those firms left because nearly all the Humber Bank things have took a bit of a hammering this last 4-5 years. Ross Group and Birds Eye were good ones, they can soon find jobs for the lads sweeping up or on health and social side so that they could learn all the Red Cross. All that has gone now because those firms are not here”*

One carer mentioned that his son had received good support from his employer and fellow employees.

*“His job is his life really and they have some understanding staff there and they look after him.”*

Some respondents mentioned that support had helped them to gain employment, or that jobs had been built around their needs, although it was not mentioned where this assistance came from.

*“...my new job is ideal because it suits me and my level of understanding, I had to wait a long time to get this job.”*

*“I have had staff support to gain employment.”*

*“...in supported work alongside my mother, job was tailored for me around my hobbies.”*

115 (89.8%) answered the question asking whether or not they required any help in finding suitable paid work. 45 (39.1%) of these said they did and 70 (60.9%) said they did not.

For respondents with a physical disability, only four (14.8%) stated that they needed help finding suitable work compared to 23 (85.2%) who did not. For respondents with a learning disability there was a much greater unmet need with almost half of respondents (36, 49.3%) stating that they needed help compared to 37 (50.3%) who did not. For those with a learning AND physical disability, a third (5, 33.3%) needed help to find suitable work compared to two thirds (10, 66.6%) who did not.

### Carers and paid work

The difficulty of being able to fit in caring responsibilities and paid work was mentioned during some interviews. Difficulty in finding suitable hours was mentioned although in some cases these experiences had been some years ago.

*“I did work but and it was awful because I wanted to work really, but you cannot get the hours. He goes on a bus at 9am in the morning and home at 3pm, so I could do 10-2...I did that time. I have not been able to do the jobs that I wanted to do.”*

There was also a suggestion that employers did not appreciate the needs of employees with children with disabilities.

*“I understand they are a bit understanding now but I don't think it is enough...what I can make out because you need full time and committed employment and with these children they are always going down sick, always got medical problems.”*

### Voluntary work

498 (88.0%) respondents answered the question asking whether the respondent did any voluntary work. 62 (12.4%) stated that they did voluntary work and 436 (87.6%) stated that they did not. Of



the 62 respondents who did voluntary work, over half had a learning disability (37, 59.7%). 16 (25.8%) had a physical disability and nine (14.5%) had a learning AND physical disability.

*“He goes to work twice a week, he doesn’t get paid for it but he likes it, it helps him to mix with people. He likes mixing with the women.”*

Respondents who did not currently take part in voluntary work were asked if they would like to. 29 (9.7%) responded that they would like to do voluntary work compared to 267 (89.6%) who did not want to do voluntary work. 20 people said that in order to do voluntary work they would need help to find a suitable placement.

### Education and Training

Questionnaire respondents were also asked if they were currently in education or training. 525 (92.8%) answered the question with 66 (12.6%) stating that they were in full time education, 61 (11.6%) in part time education, one (0.2%) in on the job training and 397 (75.6%) not in education or training. Unsurprisingly, almost all respondents approached via the Transition service were in either full or part time education, 81 (42.4%) respondents approached via the Learning Disability service were also in education or training. For those approached via the Physical Disability team, the number in education or training was much lower (14, 6.9%).

The differences in numbers in education or training are likely to be explained by the age demographics of each group, as respondents with a physical disability were more likely to be from the older age groups. Table 8.2 shows the number of respondents in full and part time education by age band.

**Table 8.2** Number of respondents in full, part time education and training by age band

Age Band	Education status				Total
	Full time education	Part time education	On the job training	Not in education or training	
15-19	38 (57.6%)	3 (4.9%)	0 (0.0%)	6 (1.6%)	47 (9.2%)
20-29	12 (18.2%)	12 (19.7%)	1 (100.0%)	50 (13.1%)	75 (14.7%)
30-39	6 (9.1%)	10 (16.4%)	0 (0.0%)	49 (12.9%)	65 (12.8%)
40-49	5 (7.6%)	19 (31.1%)	0 (0.0%)	94 (24.7%)	118 (23.2%)
50-59	3 (4.5%)	12 (19.7%)	0 (0.0%)	111 (29.1%)	126 (24.8%)
60-69	2 (3.0%)	5 (8.2%)	0 (0.0%)	71 (18.6%)	78 (15.3%)
<b>Total</b>	<b>66 (100.0%)</b>	<b>61 (100.0%)</b>	<b>1 (100.0%)</b>	<b>381 (100.0%)</b>	<b>509 (100.0%)</b>

82 (16.3%) of the 503 respondents who answered stated that they required help to find suitable education or training opportunities, whereas 421 (83.7%) said that they did not. The majority of those who needed help to find suitable education or training opportunities had a learning disability.

### Transition

Concern was raised that there was little choice locally for children with learning disabilities once they left school and that it was extremely difficult to get funding for preferred choices of education. There was a comment that there was a push towards a certain institution even if it was not suitable in the parent/ carer’s opinion.

*“I think it is wrong that they are not giving parents a choice. Why there is a facility like that [Linkage] in Grimsby and the only choice we have is Grimsby College. What my argument is, is when the rest of the children can choose Grimsby Tollbar, Agricultural College, Grimsby College, Sixth Form College and yet Special Needs have no choice. We have got a facility like that which is ideal and yet everybody is being pushed towards Grimsby College, which is not an ideal place at all...”*

*"More funding to allow me to go to better college, e.g. Linkage, Weelsby or Toynton College as this was my first choice and I was very dissatisfied not to go."*

*"...we were fortunate to get \*\*\* into Linkage and it has just been fantastic for her, she has loved every minute, but now I fear there is even less choice. You know when we are told choice is all important, that there isn't it, it is getting worse and I guess it is partly because of funding."*

Common to several parents going through the transition process was the experience of having to fight for what they wanted for their children.

*"We have been very fortunate (a) because we have this support group and (b) because we have pushed). It is actually awful but the louder your voice I believe the more you get, you have to show that you are not going to be dragged down I guess. Stand up for your child. We are fighting for accommodation, well we have already taken one step and that is the fact that we have gone through our MP and so when we have a meeting we are going to say we have been to our MP and he understands and will support us. Whether that will do any good I don't know but maybe just the threat to show we are not going to be drawn down. As I said earlier on a lot of parents are not quite as eloquent as we are."*

*"The more you fight the more you will get things done. If you don't fight you will not get anything."*

Others also felt that some children may miss out due to their parents also having learning difficulties and not being able to negotiate on their behalf.

*"What people don't understand is that a lot of people, especially in this area, with learning difficulties, the parents [also have learning difficulties] and I don't think they have taken that into consideration."*

The Rock Foundation, a charitable organisation based on Victor Street was established by 4 local parents and business people, who wished to provide a facility to enable children and adults with learning disabilities to improve their education and life skills, enabling them to reach their full potential and not simply be sat at home once formal education ended. The facility has a café where trainees work in the kitchen, a cleaning team and a gardening team who work with Age Concern to carry out gardening work. In addition a variety of workshops such as bricklaying, plastering, carpentry and puppetry give opportunities to develop skills and confidence. The foundation also hopes in the future to work with other agencies to offer health, sports and education classes.

*"...it is going to be for young people with learning difficulties and Special Needs education because what we are finding is that when they have finished education there is nothing else. It's not going to be like a day centre at all because they do all sorts of things i.e. gardening, cooking..."*

Although only in its early stages, the Rock Foundation was proving popular with service users.

*"In the garden at the moment we have quite a few and they are having a whale of a time. \*\*\*\*\*, here in the kitchen, he came and wanted to work Monday to Friday but he comes Saturday now as well as he was bored at home. He has forever got a smile on his face, just loves it, and this is what they need. [This was then verified to interviewers by the young man concerned]. They can stay until they are 65."*

#### KEY POINTS

- Only 5% respondents were in paid full or part time employment. Over three quarters of respondents stated that their disability had left them unable to work.
- Of those that were able to work and who responded, 39% stated that they had found it difficult to get a job because of their disability. This was particularly the case for respondents with a learning disability, 42% of whom had experienced problems compared to 29% of those with a physical disability.

- Only 12% of respondents did voluntary work, and a further 10% would like to do voluntary work.
- 13% of respondents were in full time education and 12% were in part time education.
- Concern was raised that at transition little choice was available about where children could continue in education and that they were being pushed towards one institution, regardless of whether they felt it was suitable or not.

## 9. FINANCE AND BENEFITS

There is general acknowledgement that some people may have extra costs associated with living because of a disability or long term condition. These costs could be incurred on services that need to be accessed, mobility issues, accommodation or specialist equipment. The welfare benefits system is there to support those people who are eligible for assistance and the main types of payments associated with disability are the Disability Living Allowance (DLA), Incapacity Benefit (IB), Carers Allowance (CA) and Income Support (IS).

### Disability Living Allowance (DLA)<sup>49</sup>

Disability Living Allowance is a tax free benefit for people under the age of 65 who have a long-term condition or disability, either physical or mental. It is further split into two parts, one for care, and the other for mobility based upon these needs. The care component is for assistance with personal care, the mobility component is for assistance in getting about and it is possible to qualify for one or the other or both.

The care component is payable at three rates (low, middle and high). This can range from help with eating, drinking and washing at the lowest rate to supervision through the day at the middle rate and 24 hour care at the highest rate.

The mobility component is payable at two rates (low and high). The lower rate is payable if someone is needed to provide guidance or supervision when a person is outside or on an unfamiliar route. The higher rate is for severe mobility problems e.g. extreme difficulty walking, deafness, blindness or a severe learning disability.

Table 9.1 below displays the latest data available (February 2009) for North East Lincolnshire Unitary Authority for those people claiming Disability Living Allowance.

Table 9.1      People claiming Disability Living Allowance within the North East Lincolnshire Unitary Authority

Age Band	Males	Females	Total
Aged Under 25	1,210	510	1,720
Aged 25-29	150	150	300
Aged 30-34	120	120	250
Aged 35-39	230	190	420
Aged 40-44	260	300	560
Aged 45-49	270	330	600
Aged 50-54	310	360	670
Aged 55-59	410	460	870
Aged 60-64	530	560	1,090
Aged 65-69	450	420	880
Aged 70-74	310	300	610
Aged 75-79	150	190	340
Aged 80-84	40	50	100
Aged 85-89	10	10	20
Aged 90 and Over	~	~	10
Unknown Age	~	~	~
<b>Total</b>	<b>4,470</b>	<b>3,970</b>	<b>8,440</b>

~ These figures are nil or negligible. Source: NOMIS (<https://www.nomisweb.co.uk/default.asp>)

NB. Due to rounding of figures by NOMIS, some of the subtotals do not add up to the figures shown in the table

Based on the 2007 Office of National Statistics (ONS) estimates for the population of North East Lincolnshire unitary authority, which is 158,356, approximately 5.3% of the population are claiming DLA (males 5.8%, females 4.9%). The highest numbers of claimants can be found in males aged

under 25, almost twice the figure of that for females at the same age bracket. The reasons for this are unknown. In most older age groups there are marginally more female claimants than male claimants.

### Incapacity Benefit

Incapacity benefit (IB) is for people of a working age who cannot work because of illness or disability and are not entitled to statutory sick pay or this has ran out. Entitlement is usually based upon having paid adequate National Insurance contributions and is payable at three rates, depending upon the length of time a person has been unable to work. These are short-term lower rate (first 28 weeks of being unable to work), short-term higher rate (weeks 29-52 of being unable to work) and long-term rate (after 52 weeks of being unable to work). The latter two rates are taxable. There are a number of other possible entitlements to additional money within this benefit, for instance if a person has adult dependants.

People with certain severe conditions are not expected to be capable of work. These conditions include severe learning difficulties and severe mental health problems.

**Table 9.2** People claiming Incapacity Benefit or Severe Disablement Allowance within the North East Lincolnshire Unitary Authority

Condition	Aged Under 25	Aged 25 to 44	Aged 45 to 64	Aged 65+
Certain infectious parasitic diseases (A00-B99)	~	~	20	~
Neoplasms (C00-D48)	~	10	70	~
Diseases of the blood and blood forming organs and certain diseases involving the immune mechanism (D50-D89)	~	~	~	~
Endocrine, nutritional and metabolic diseases (E00-E90)	~	10	80	~
Mental and behavioural disorders (F00-F99)	330	1170	1,090	30
Diseases of the nervous system (G00-G99)	60	210	230	10
Diseases of the eye and adnexa (H00-H59)	~	20	40	~
Diseases of the ear and mastoid process (H60-H95)	~	~	~	~
Diseases of the circulatory system (I00-I99)	~	30	310	10
Diseases of the respiratory system (J00-J99)	~	30	150	~
Diseases of the digestive system (K00-K99)	10	40	50	~
Diseases of the skin and subcutaneous system (L00-L99)	~	10	30	~
Diseases of the musculoskeletal system and connective tissue (M00-M99)	10	190	890	10
Diseases of the genitourinary system (N00-N99)	~	10	40	~
Pregnancy, childbirth and the puerperium (O00-O99)	~	~	~	~
Certain conditions originating in the perinatal period (P00-P96)	~	~	~	~
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	30	50	30	~
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	110	300	520	10
Injury, poisoning and certain other consequences of external causes (S00-U23)	20	140	190	~
Factors influencing health status and contact with health services (Z00-Z99)	~	30	40	~
Claimants without any diagnosis	~	~	~	~
<b>Column Totals</b>	<b>580</b>	<b>2290</b>	<b>3,790</b>	<b>80</b>

~ These figures are nil or negligible. Source: NOMIS (<https://www.nomisweb.co.uk/default.asp>)

NB. Due to rounding of figures by NOMIS, some of the subtotals do not add up to the figures shown in the table

Table 9.2 above is the latest data available (February 2009) for North East Lincolnshire unitary authority for those people claiming Incapacity Benefit together with claims for the Severe Disablement Allowance (SDA). This allowance was for people aged under 65 and incapable of work, but whose National Insurance contributions were not enough to claim long term Incapacity Benefit. It was abolished in 2001 for new claimants, but people may continue to receive it.

The greatest number of claimants for SDA occur within the ICD10 chapter of mental and behavioural disorders. This was the most common chapter that respondents to the local survey had conditions from for all disability types as shown in Section 3 (Table 3.6). It was also the most common chapter for conditions for those solely with learning difficulties (Table 3.7). The second greatest number of claimants for SDA occur within the ICD10 chapter for diseases of the musculoskeletal system and connective tissue, more commonly associated with those with physical disabilities. In the majority of each chapter, the age band 45 to 64 had the greatest number of claimants.

### Carers Allowance

Carers allowance (CA) may be claimed by someone who is caring for a person who is ill or disabled in their home. Not every carer is eligible because there are certain rules which apply to the carer and the person being cared for. With regards to the carer, it does not matter if they are related to the ill or disabled person, or whether they live in the same household but they must be over the age of 16, and spending at least 35 hours a week looking after the ill or disabled person. However they cannot earn over a certain amount from other work or be on a course of full-time education (21 hours a week) and it can affect other benefits.

The person being cared for must be receiving one of the welfare benefits associated with a need for care. These are the attendance allowance, care component of the DLA (paid at the middle or higher rate), constant attendance allowance, industrial injuries disablement benefit or war disablement pension.

Table 9.3 below is the latest data available (February 2009) for North East Lincolnshire Unitary Authority for those people claiming Carers Allowance. This data includes people caring for sick or disabled people of all ages.

Table 9.3      People claiming Carers Allowance within the North East Lincolnshire Unitary Authority

Age Band	Males	Females	Total
Aged Under 18	~	~	10
Aged 18-24	20	60	80
Aged 25-29	20	100	120
Aged 30-34	20	150	180
Aged 35-39	60	230	280
Aged 40-44	70	230	310
Aged 45-49	70	180	250
Aged 50-54	70	170	240
Aged 55-59	60	190	250
Aged 60-64	90	60	150
Aged 65 and Over	10	40	50
Unknown Age	~	~	~
<b>All Ages</b>	<b>500</b>	<b>1,420</b>	<b>1,920</b>

~ These figures are nil or negligible. Source: NOMIS (<https://www.nomisweb.co.uk/default.asp>)

NB. Due to rounding of figures by NOMIS, some of the subtotals do not add up to the figures shown in the table

Table 9.3 shows that there are almost 2000 people claiming Carers Allowance, just under 70% of whom are between the age of 35 and 59. Based on the 2007 ONS estimate for the population of North East Lincolnshire unitary authority, approximately 1.2% of the population are claiming Carers

Allowance. There is a gender difference with nearly three times as many females claiming the allowance. This is particularly true in younger age groups with a female to male ratio of 4.5 to one in carers under the age of 40.

### Income Support

Income Support is intended for people who cannot normally work (or who work less than 16 hours a week), and who are on a low income. In some cases this may be because the person is incapable of work due to illness or disability, or they could be caring for a sick or disabled person. It may also entitle people to other benefits e.g. housing benefit, council tax benefit, health costs. Help with health costs includes free prescriptions, free NHS dental treatment, vouchers for glasses, and help with fares to hospital for appointments.

Table 9.4 below is the latest data available (February 2009) for North East Lincolnshire Unitary Authority for those people claiming Income Support.

**Table 9.4** People claiming Income Support within the North East Lincolnshire Unitary Authority

Age Band	Males	Females	Total
Aged 16-17	~	70	100
Aged 18-24	180	1,010	1,190
Aged 25-34	440	1,270	1,700
Aged 35-44	650	1,120	1,770
Aged 45-49	300	390	690
Aged 50-54	310	340	650
Aged 55-59	330	320	650
Aged 60-64	~	~	~
Aged 65-69	~	~	~
Aged 70-79	~	~	~
Aged 80-89	~	~	~
Aged 90 and Over	~	~	~
Unknown Age	~	~	~
<b>All Ages</b>	<b>2,240</b>	<b>4,510</b>	<b>6,750</b>

~ These figures are nil or negligible. Source: NOMIS (<https://www.nomisweb.co.uk/default.asp>)

NB. Due to rounding of figures by NOMIS, some of the subtotals do not add up to the figures shown in the table

Based on the 2007 ONS estimates for the population of North East Lincolnshire unitary authority, approximately 4.3% of the population were claiming Income Support. There is a substantial gender difference with twice as many female claimants as male claimants overall, which includes five times as many female claimants in the under 25s declining to approximately even numbers in the 55-64 age group.

The data from NOMIS for Income Support and Carers allowance would suggest that women seem to be the main carers for people with disabilities. The 2001 Census revealed that 58% of carers were women.

## **9.1 Financial Advice**

The local survey asked people if they had received any advice regarding entitlements to benefits. The results are summarised in Table 9.5 below.

**Table 9.5** Have you received any advice about benefits which you may be entitled to?

Disability Type	Yes		No		Not Answered	
	No.	%	No.	%	No.	%
Learning Disability	154	73.3%	33	15.7%	23	11.0%
Physical Disability	150	71.1%	52	24.6%	9	4.3%
Learning AND Physical Disability	86	62.3%	41	29.7%	11	8.0%
Not Indicated	3	50.0%	1	16.7%	2	33.3%
<b>TOTAL</b>	<b>393</b>	<b>69.6%</b>	<b>127</b>	<b>22.5%</b>	<b>45</b>	<b>8.0%</b>

Just under 70% of the total number of people who replied to the questionnaire stated they had received advice about benefits that they may be entitled to. The percentages were slightly higher for those with learning disabilities and those with physical disabilities but lower for those with both learning AND physical disabilities. Just over one in five respondents reported that they had not received any advice about benefits.

Those who indicated that they had received advice about benefits were invited to identify all the benefits that they had received advice about. Table 9.6 below summarises the responses.

**Table 9.6** What type of benefits have you received any advice about which you may be entitled to (All Respondents)?

Type of Benefit	Yes	%	No	%
Disability Living Allowance	312	55.2%	253	44.8%
Income Support	195	34.5%	370	65.5%
Incapacity Benefit	146	25.8%	419	74.2%
Council Tax Benefits	141	25.0%	424	75.0%
Housing Benefits	114	20.2%	451	79.8%
Home Insulation Grants	45	8.0%	520	92.0%
Attendance Allowance	42	7.4%	523	92.6%
Help with Health Costs	33	5.8%	532	94.2%
Tax Credits	25	4.4%	540	95.6%
Other	14	2.5%	551	97.5%
Help with Education/Training	12	2.1%	553	97.9%
Child Benefit	12	2.1%	553	97.9%

55.2% of respondents had received advice about Disability Living Allowance, which was by far the most common benefit that information was received about for all disability types. Income Support advice was received by just over a third of people and at least a quarter of respondents had received advice about Incapacity Benefit and Council Tax Benefits.

Some of those questioned in focus groups and interviews stated that information and advice about benefits and entitlement to claims has improved over the years.

*"I think over the last few years they have been round and referred us but never anybody in the early years and no help whatsoever from anywhere. It has only been over the last five or six years where things have improved to a certain extent."*

*"I suppose it has improved over the last few years because when my son was younger there was nobody to help whatsoever."*

A further supplementary question explored where benefit information had been received from. Disappointingly, this question was not fully answered as even though 393 of the respondents had said they had received advice, only 99 people gave an indication as to where that advice had come



from. As the number of respondents was quite small, Table 9.7 below summarises the replies for each type of disability in order of popularity.

**Table 9.7**      Where have you received your advice from?

Learning Disability	Physical Disability	Learning AND Physical Disability
Carer Accommodation Manager By Post Family Social Services DWP Advice Centre School Other	Social Services Advice Centre Council Other Warm Front Benefits Agency Hospital DWP Family Pension Service Job Centre	Family DWP Social Services Council Benefits Agency Advice Centre Job Centre Other

Even though the numbers were small, there appears to be a difference in how advice was given to those with different disability types about benefits. People with learning disabilities tended to get their information from their carer or a manager at the house they were supported at. Information by post and by family came next. For those with physical difficulties, social services was the most common way of finding out information about benefits, followed by an advice centre and the council. Warm Front<sup>50</sup> was also mentioned. They are a government funded initiative designed to make homes warmer, healthier and more energy efficient by providing a home improvement or insulation package for up to the value of £3,000 (up to £6,000 for renewable technologies). Those with Disability Living Allowance or Income Support are usually eligible for a grant.

People with both learning AND physical difficulties most commonly relied on family for advice, closely followed by the Department for Works & Pensions and then Social Services.

*“We have been really blessed because we had a friend who was at the Job Centre so he took time out to explain things about Benefit Forms.”*

Within focus groups and interviews conducted during the local survey the ‘George Hardwick Foundation’<sup>51</sup> was mentioned with regards to advice on benefits. The foundation primarily provides a support network for carers with centres in Stockton (Durham), Grimsby (North East Lincolnshire) and North Tees Hospital.

They work with a number of partner organisations to provide carers with up-to-date advice, information, counselling and support. One particular service is providing benefit and financial advice to people to enable them to claim benefits that they are entitled to. One interviewee had experience of the service the foundation provided.

*“A lot of people don’t understand what they can claim for and what is available for them and they don’t claim for a lot of things they are eligible for. That’s why the George Hardwick Foundation will do well by having a place where it can explain the benefits to people in straight layman terms.”*

The local survey also asked people if they believe they had all the advice they need about benefits or if they required more. These results are displayed in Table 9.8 below.

Just over a fifth of respondents indicated a need for more advice or help with benefits. This varied between the cohorts with about 12% of learning disability respondents, 26.5% of respondents with physical disabilities and 23% of respondents with learning AND physical disabilities saying they needed further advice. This could suggest an unmet need, again mirroring Table 9.5 where 22.5% had received no advice.

**Table 9.8**      Do you need anymore advice/help about benefits?

Disability Type	Yes		No		Not Answered	
	No.	%	No.	%	No.	%
Learning Disability	26	12.4%	168	80.0%	16	7.6%
Physical Disability	56	26.5%	139	65.9%	16	7.6%
Learning AND Physical Disability	32	23.2%	99	71.7%	7	5.1%
Not Indicated	0	0.0%	3	50.0%	3	50.0%
<b>TOTAL</b>	<b>114</b>	<b>20.2%</b>	<b>409</b>	<b>72.4%</b>	<b>42</b>	<b>7.4%</b>

A supplementary question asking what sort of guidance is needed was asked to those who indicated that further advice was required. Even though 114 respondents had said they wanted further advice only 64 expanded upon exactly what assistance was required.

Many replies were focused on advice about common benefits such as Council Tax benefit, Housing Benefit, Disability Living Allowance and Income Support. In addition general financial advice and advice about home heating was identified by several respondents. However the most common requests for further help were in relation to eligibility. Of the 64 respondents, a third required assistance with eligibility, as some respondents were confused as to what they may be entitled to or whether they might in fact be eligible for more than they were currently receiving. This is illustrated by the comments below.

*"I would like to know if I'm getting the right help. As it's been 8 years since I've had anyone to give me the rundown if I'm getting the right benefits."*

*"To make sure I'm getting everything I'm entitled to."*

## **9.2 Direct Payments<sup>52,53</sup>**

Direct payments are cash payments paid by local authorities to individuals aged 16 or over who have been assessed by social services as being in need of social service provisions. This can include people with physical or sensory impairment, learning difficulties, mental health problems or a long-term illness or those who need help because of the effects of growing older. Direct payments can also be made to those with parental responsibility for disabled children and to carers aged 16 or over in respect of carer services.

The aim of a direct payment is to give service users the option of exercising choice, promoting greater independence and more flexibility than is sometimes possible with services arranged directly by local authorities. By giving individuals money in lieu of social care services, people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered and the way they live their lives.

A person must be able to consent to have a direct payment and have the capacity to manage one, although they can have assistance to manage their payment on a day-to-day basis. Direct payments are only paid if the person is willing to accept them and they cannot be forced to use this system. It is also possible to have some services still arranged by Social Services whilst the person manages part of their support package.

The payments can be tailored to meet individual needs but are not solely extra money to spend as the person may wish. The money must be used to meet the needs for which Social Services have offered payment equivalent to its estimate of the cost incurred to buy the service that has been agreed to. This would mean deciding what sort of help was needed, how the help is to be provided

and the times it is required. This can be done by employing support staff (the level of payment will include allowances to meet all statutory responsibilities as an employer), buying services from private care agencies and paying for daytime opportunities. Examples include training courses, help with housework and gardening or taxi fares.

Direct payments can also be used for one-off or intermittent services, such as buying short periods of respite care, or buying equipment to help you remain independent. However, direct payments cannot be used to buy long-term residential or nursing care or to pay a relative or partner that lives with the person to whom support is provided. This does not prevent live in carers, but the relationship with the carer must be contractual rather than personal.

**Table 9.9** Do you receive direct payments?

Disability Type	Yes		No		Don't Know		Not Answered	
	No.	%	No.	%	No.	%	No.	%
Learning Disability	69	32.9%	105	50.0%	26	12.4%	10	4.8%
Physical Disability	150	71.1%	39	18.5%	13	6.2%	9	4.3%
Learning AND Physical Disability	61	44.2%	55	39.9%	16	11.6%	6	4.3%
Not Indicated	3	50.0%	1	16.7%	1	16.7%	1	16.7%
<b>TOTAL</b>	<b>283</b>	<b>50.1%</b>	<b>200</b>	<b>35.4%</b>	<b>56</b>	<b>9.9%</b>	<b>26</b>	<b>4.6%</b>

Just over 50% of respondents overall in the local survey stated they received direct payments. Surprisingly, nearly 10% of people were unsure if they did. By disability type, those with physical disabilities were more likely to have direct payments (71.1%). This was just over twice as many as that for those with learning disabilities as only 32.9% stated they received direct payments. For those with learning AND physical disabilities, it was a more even split.

*“Post 18, she received Direct Payments of 10 hours a week which sort of covered for social life. There was someone to take her swimming on a Saturday, that sort of thing. She had 10 hours to pay someone to give her a social life. That was very smooth.”*

### 9.3 Care Package

Another question within the local survey asked respondents to state whether they were currently happy with the care package they were receiving.

**Table 9.10** Are you happy with the care package you have in place?

Disability Type	Yes		No		Not Answered	
	No.	%	No.	%	No.	%
Learning Disability	178	84.8%	10	4.8%	22	10.5%
Physical Disability	160	75.8%	20	9.5%	31	14.7%
Learning AND Physical Disability	113	81.9%	12	8.7%	13	9.4%
Not Indicated	4	66.7%	0	0.0%	2	33.3%
<b>TOTAL</b>	<b>455</b>	<b>80.5%</b>	<b>42</b>	<b>7.4%</b>	<b>68</b>	<b>12.0%</b>

Encouragingly, just over 80% of those surveyed were happy with the current care package they received and only 7.4% were unhappy. By individual disability type, almost 85% of those with a learning disability were happy with their care compared with almost 76% of those with physical

disability and almost 82% of those with Learning AND Physical disability. There were 12% of respondents that did not answer the question.

A supplementary question was then asked to those who were unhappy with the care package they were currently receiving as to why this was the case. Of the 69 respondents to the question, the number of reasons given was wide and varied. The most common response was that there was no current care package in place when the respondent felt that there should be (18 responses). The next most common concern reflected anxiety about future care. This was particularly the case for those with disabilities around the ages of transition from childhood to becoming an adult (nine responses).

*“No if you mean residential because it only goes up to 19 years of age. Where do I go next?”*

*“OK at the moment until I am 18 years.”*

Other responses included issues surrounding housing, extra services required, poor communication or additional hours within the care package.

## 9.4 Spending

Another question within the local survey asked respondents if they would like to spend their money in another way if they could.

**Table 9.11** Would you spend the money in another way if you could?

Disability Type	Yes		No		Not Answered	
	No.	%	No.	%	No.	%
Learning Disability	19	9.0%	139	66.2%	52	24.8%
Physical Disability	31	14.7%	126	59.7%	54	25.6%
Learning AND Physical Disability	22	15.9%	87	63.0%	29	21.0%
Not Indicated	0	0.0%	2	33.3%	4	66.7%
<b>TOTAL</b>	<b>72</b>	<b>12.7%</b>	<b>354</b>	<b>62.7%</b>	<b>139</b>	<b>24.6%</b>

Only 12.7% of all those with a disability stated that they would spend the money received for their care in another way if they could. Though just over 60% were happy with the way the money was spent, a quarter of those that took part in the survey did not answer this question. There was little variation between disability types.

Those who indicated that they would like to spend their money differently were invited to say what they would spend it on if they could. The most common response was a holiday (18 responses). Other responses included changes to current housing (6), shoes, books or clothing (6), social activities (5), respite care (5), DIY and gardening (4), carer services (4) and cleaning (3).

*“I want to experience travelling by air or ship”*

*“I would spend more money on having a better quality of life, maybe holidays.”*

*“A smaller home would be more suitable”*

*“Getting myself some clothes that fit me, selfish eh!”*

### KEY POINTS

- There are over 8000 adults in receipt of Disability Living Allowance in North East Lincolnshire, including over 6000 under the age of 65.
- Over 1900 people in North East Lincolnshire are in receipt of carer's allowance, around three-quarters of whom are women.
- Although just short of 70% of those with disabilities had received advice regarding benefits, almost a quarter of those with physical disabilities and almost a third of those with learning AND physical disabilities had not received any advice.
- At least 20% of the respondents overall required further help about benefits with advice on eligibility the most common request for extra information. This increased to 26.5% for those with physical disabilities.
- Just over 50% of all respondents receive direct payments, but this increased to over 70% of those with physical disabilities.
- Over 80% of respondents were happy with the current care package they received.
- Spending money on holidays was the most common alternative way to spend care money.

## 10. HOUSING AND ADAPTATIONS

### 10.1 Housing

*Valuing People Now* and *Improving Life Chances for Disabled People* underline the importance of informed choice about where disabled people live, who they live with and the support needed to allow people with disabilities to live independently. Without a settled home the most disadvantaged adults are at risk of exclusion from society<sup>54</sup>.

The *Improving Life Chances for Disabled People* report proposes that 'by 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life...'<sup>55</sup>. People with a disability should have the choice and freedom of independent living. For some this may be living independently in their own home and for others it may mean the right to choose and have access to suitable accommodation. Participants in the local needs assessment highlighted the importance of choice for people with disabilities.

*"She has written a letter to say she doesn't want to come home. It is their right, they should not have decisions made for them that they don't want."*

*"More choice about where you live - residential home, or in own home. Individual choice not government policy."*

The *Improving Life Chances* report found that for some people with a disability residential care was the only housing option available to them and therefore they were deprived of choice because there was insufficient housing or housing support available to them.

Overall, the majority of respondents from the local survey lived with friends or others (30.7%, of which half live in a residential/ care home), or with their parents (29.6%). Those with a physical disability only were most likely to live on their own (41.9%) compared to 8.6% of those with a learning disability and 8.1% with a learning AND physical disability. 29.5% of respondents with a physical disability said they lived with their partner compared to 2.4% with a learning disability and 5.2% with both a learning AND physical disability. Clearly there are differences between those with physical and those with learning disabilities (see Table 10.1 below). Of those who live with their parents, 28.2% are over the age of 40 and although there is no data on the age of their parents, it can be assumed that the majority of parents with a child aged 40 or older will have reached retirement age. This raises concerns for their future care.

*"Our worry is the future, \*\*\*\*\*'s dad will be 70... and I'm 67... it's the future for \*\*\*\*\* we are trying to ensure, without the care \*\*\*\*\* would die..."*

*"At meetings people say they are looking into a black void when it comes to a certain age group, when we have done everything we can for them, but what happens if I was killed in an accident or the wife and I die, where do we go from there? Especially if they have got no relatives."*

*I live with parents who give full support. What about the future?*

*What we would want to do, and hoping to do, something like an old people's complex with individual flatlets with a warden 24 hrs a day, like sheltered housing so that parents feel they are safe. It is a worry as to what will happen to them when their parents die and when their parents get older.*

**Table 10.1** Who do you live with?

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
On my own	88	41.9%	18	8.6%	11	8.1%	117	21.1%
With my child/children	13	6.2%	0	0.0%	1	0.7%	14	2.5%
With my husband/wife/partner	62	29.5%	5	2.4%	7	5.2%	74	13.4%
With friends or others	11	5.2%	114	54.5%	45	33.3%	170	30.7%
With my parents	25	11.9%	72	34.4%	67	49.6%	164	29.6%
With husband/wife/partner and child/children	9	4.3%	0	0.0%	2	1.5%	11	2.0%
With husband/wife/partner and parents	1	0.5%	0	0.0%	0	0.0%	1	0.2%
With my parents and children	1	0.5%	0	0.0%	1	0.7%	2	0.4%
with my parents and in care setting	0	0.0%	0	0.0%	1	0.7%	1	0.2%
<b>Total</b>	<b>210</b>	<b>100.0%</b>	<b>209</b>	<b>100.0%</b>	<b>135</b>	<b>100.0%</b>	<b>554</b>	<b>100.0%</b>

Data from the NELCTP Community Learning Disability team shows that 42.6% of people with a learning disability live in the family home, 24.2% live in residential care and 21.8% live in shared, supported accommodation. Just 4% were recorded as having their own tenancy and 0.6% owned their own home as shown in Table 10.2 below.

**Table 10.2** Accommodation arrangements for people with a learning disability registered with the Community Learning Disability Team with a postcode in the NELCTP area\* (February, 2009)

Accommodation arrangement	No.	%
Living at Home	201	42.6%
Residential Care	114	24.2%
Shared Supported Accommodation	103	21.8%
Floating Support	23	4.9%
Individual Tenancy	19	4.0%
Support Tenant	5	1.1%
Individual Ownership	3	0.6%
Lodging, Fostering and Family Placement	3	0.6%
Respite Care	1	0.2%
<b>Total</b>	<b>472</b>	<b>100.0%</b>

Data Source: NELCTP Community Learning Disability Team

\*53 postcodes outside of the NELCTP area were removed.

Most respondents live in houses (52.2%) regardless of disability type. Those with a physical disability are far more likely to live in a bungalow (19.6%) or ground floor flat (20.1% with a physical disability, 19.0% with both learning AND physical) than those with a learning disability. However those with a learning disability were the most likely to live in a care or residential home (26.3% with a learning disability, 21.9% with both a learning AND physical disability) compared to those with a physical disability (2.4%), as shown in Table 10.3 below.

**Table 10.3** What do you live in?

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
	No.	%	No.	%	No.	%	No.	%
House	105	50.2%	119	56.9%	66	48.2%	290	52.2%
Bungalow	41	19.6%	11	5.3%	26	19.0%	78	14.0%
Ground floor flat	42	20.1%	10	4.8%	9	6.6%	61	11.0%
Upstairs flat	15	7.2%	12	5.7%	6	4.4%	33	5.9%
Care home/residential school	5	2.4%	55	26.3%	30	21.9%	90	16.2%
Other	1	0.5%	2	1.0%	0	0.0%	3	0.5%
Total	209	100.0%	209	100.0%	137	100.0%	556	100.0%

Questionnaire respondents were asked to give their postcode, of the 565 survey participants 27 postcodes were missing and 21 could not be matched to a postcode in North East Lincolnshire. Those with a physical disability were the most likely to live in the 20% most deprived areas in North East Lincolnshire. A third (33.2%) of those with a physical disability had a postcode matched to the 20% most deprived areas in North East Lincolnshire compared to 20.8% of those with a learning disability and 19.4% of those with both a learning AND physical disability. This suggests that those with a physical disability are more likely to live in the most deprived areas compared to others who took part in the survey and compared to the North East Lincolnshire population in general.

**Table 10.4** 20% most deprived residents compared to 80% least deprived residents living in the NELCTP area (by disability type).

	Physical Disability		Learning Disability		Learning and Physical Disability		Total
	No.	%	No.	%	No.	%	No.
20% most deprived	66	33.2%	38	20.8%	25	19.4%	129
80% least deprived	133	66.8%	145	79.2%	104	80.6%	382
No. matched postcodes	199	100.0%	183	100.0%	129	100.0%	511

75.7% of people in North East Lincolnshire own their own homes, 13.8% live in social housing, 9.7% live in privately rented accommodation and 0.9% live in other accommodation<sup>56</sup>. The Disability Needs Assessment found that far fewer people with a disability own their own home than the general population of North East Lincolnshire. Of those with a physical disability, 45.8% said they own their own home, only 0.5% of those with a learning disability and 7.4% of those with both a learning AND physical disability said they own their home. 32% of respondents with learning disability rented their home from a landlord, a much larger proportion than the general population. Although people with learning disability have the same tenancy rights as any other tenant, national research suggests that they are more likely to get their rights overlooked or ignored. Therefore it is important that if more people with learning disabilities are encouraged to privately rent accommodation they are supported in doing so. 40% of those with both a learning AND physical disability said their family own the home they live in and only 7.4% own their own home as shown in Table 10.5.



**Table 10.5 Do you own where you live?**

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
	No.	%	No.	%	No.	%	No.	%
I've/we've bought it	93	45.8%	1	0.5%	10	7.4%	104	19.2%
I/we pay rent to a landlord	34	16.7%	65	32.0%	21	15.6%	120	22.2%
Family own it	18	8.9%	60	29.6%	54	40.0%	132	24.4%
Rent from Shoreline/ Havelock/ Northern Counties	53	26.1%	26	12.8%	19	14.1%	98	18.1%
Don't know	0	0.0%	2	1.0%	1	0.7%	3	0.6%
Care home/other residential eg school	5	2.5%	49	24.1%	30	22.2%	84	15.5%
Total	203	100.0%	203	100.0%	135	100.0%	541	100.0%

North East Lincolnshire's Housing Needs Survey found that 8.6% of respondents were living in unsuitable accommodation, of these 23.2% said it was unsuitable for someone with a disability living in their house. The Disability Needs Assessment found that the majority of respondents felt that the place they live is suitable for their needs, however those with a physical disability were the most likely to be living in unsuitable accommodation (22.1%) compared to those with a learning disability (8.7%) and those with both a learning AND physical disability (15.8%). Of those who felt their accommodation was unsuitable for their needs most lived in a flat (25.0% upstairs flat, 21.3% ground floor) or a house (16.3%). Those living in care/ residential homes (91.0%) and in a bungalow (90.8%) were the most likely to be living in suitable accommodation. Home owners were the most likely to be living in accommodation unsuitable for their needs (20.8%) as illustrated in Table 10.6.

**Table 10.6 Is the accommodation where you live suitable for you? (by housing tenure)**

Housing Tenure	Yes		No		Total
	No.	%	No.	%	No.
I've/we've bought it	84	79.2%	22	20.8%	106
I/we pay rent to a landlord	95	82.6%	20	17.4%	115
Family own it	114	87.0%	17	13.0%	131
Rent from Shoreline/Havelock/Northern Counties	83	85.6%	14	14.4%	97
Don't know	2	66.7%	1	33.3%	3
Care home/other residential e.g. school	76	91.6%	7	8.4%	83
Total	454	84.9%	81	15.1%	535

Of the 84 respondents who said their accommodation was unsuitable, 72 cited a reason. The most common reason was that their accommodation has stairs (36.1%) either to access the building or to access another level of their property such as their bedroom or bathroom. 18.1% said the bathroom was unsuitable and 12.5% felt their accommodation was too small for their needs (see Table A8.1, Appendix 8). Research by John Grooms in 2003 found a shortfall of 300,000 accessible homes for wheelchair users, 40% felt their current housing situation made them unnecessarily reliant on other people and 21% said it was difficult to move around or enter and leave their home<sup>57</sup>.

Some of the reasons why accommodation is unsuitable are stated below:

*"Awaiting Home Improvement Grant, at present sleeping on downstairs settee as I cannot get up the stairs."*

*"Have been asking for handrails for 2 years. Shoreline seem to have forgotten me. Very disappointed."*

*“There is no disabled access from outside my house to the road.”*

*“We would like post student accommodation for \*\*\*\* ...their care is fantastic, their attitude is always good and the accommodation is good too...the other houses we have seen, we were not impressed with the security side of it...”*

Most respondents (96.9%) have central heating in their home and of these, 96.8% use their central heating when it’s cold. Overall 77.2% said they can afford to have their heating on to keep warm. Worryingly, a large proportion of respondents with a physical disability said they cannot afford to heat their home (37.4%) as shown in Table 10.7 below.

**Table 10.7 Can you afford to have your heating on to keep warm?**

	Yes		No		Total
	No.	%	No.	%	No.
Physical Disability	124	62.6%	74	37.4%	198
Learning Disability	177	89.4%	21	10.6%	198
Learning AND Physical Disability	106	80.9%	25	19.1%	131
Total	407	77.2%	120	22.8%	527

When asked ‘if you had a magic wand, what would you like to see for people with disabilities?’ 4.6% said they wanted to see better accommodation for people with disabilities, most said they would like purpose built accommodation for independent living such as sheltered/ warden controlled accommodation. Many felt that there is a lack of purpose built accommodation in the area, in particular residential homes and warden controlled accommodation.

An interviewee commented on the length of time it took to get her daughter into a suitable residential home...

*“(In)1997 my husband was diagnosed with kidney failure that’s when we realised we had to find somewhere for her and it took all those years and he died 5 ½ yrs ago and I think he had been dead 2 years or more when they rang and said there was a place...”*

## 10.2 Aids and Adaptations

While it is important to have suitable residential/ care home accommodation, others prefer to live in their own home and to do this many people with disabilities require aids and adaptations. Current government policies emphasise the desirability of maintaining disabled people of all ages in their own homes and keeping them out of residential homes<sup>58</sup>. 22.8% of those who took part in North East Lincolnshire’s Housing Needs Survey defined themselves as having a limiting long-standing illness (LLSI), of those 12.3% live in an adapted or purpose built property. 22.4% (4,963 households) said their ability to move around their home was affected by an aspect of their home and over half of those thought this could be improved by specific adaptations.

Carelink offers a 24 hour monitoring system for the most vulnerable North East Lincolnshire residents who have a disability or illness, are isolated or have suffered violence. Carelink operators respond when an emergency alarm (push button, pull cord or neck pendant) is activated, the relevant services are then alerted to provide appropriate assistance to the client<sup>59</sup>. 41.2% of respondents to the needs assessment survey said they have an emergency alarm system and 13.4% said they don’t currently have one but would like one. Those with a physical disability (54.8%) were more likely to have an emergency alarm system compared to those with a learning disability (30.7%) and those with both a learning AND physical disability (35.6%), as shown in Table 10.8.

**Table 10.8** Do you have an emergency alarm system in your home (either push button, pull cord or neck pendant)?

	Yes		No but I'd like one		No I don't need one		Total
	No.	%	No.	%	No.	%	No.
Physical Disability	114	54.8%	38	18.3%	56	26.9%	208
Learning Disability	61	30.7%	14	7.0%	124	62.3%	199
Learning AND Physical Disability	47	35.6%	20	15.2%	65	49.2%	132
Total	222	41.2%	72	13.4%	245	45.5%	539

67.4% of respondents with a physical disability said their home had been adapted to make it easier to manage their disability. 3.8% of respondents with a physical disability had had adaptations but required further changes. 16.3% with a physical disability had not had any adaptations to their home but would like them. Those with a learning disability were less likely to have had or require any changes, 71% said they did not need any adaptations to their home. For those with both a learning AND physical disability most had had adaptations (53.7%) or required them (17.9%). 90 respondents from this survey need adaptations or further adaptations to their home to make it easier to manage their disability as shown in Table 10.9.

**Table 10.9** Has any part of your home been changed to make it easier for you to manage with your disability?

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
	No.	%	No.	%	No.	%	No.	%
Yes	133	63.6%	37	18.5%	69	51.5%	239	44.0%
No but I'd like changes	34	16.3%	20	10.0%	24	17.9%	78	14.4%
No I don't need changes	34	16.3%	142	71.0%	38	28.4%	214	39.4%
Yes but need other changes	8	3.8%	1	0.5%	3	2.2%	12	2.2%
Total	209	100.0%	200	100.0%	134	100.0%	543	100.0%

514 of the 565 (91.0%) respondents to the needs assessment survey said they had at least one piece of equipment listed in Table 10.10 below. The most common piece of equipment was the wheelchair (36.8%) and grab-rail (36.8%). Unsurprisingly aids or equipment were much more common in those who reported a physical disability.

**Table 10.10** Do you have any of this equipment to help you with your day to day life?

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
	No.	%	No.	%	No.	%	No.	%
Walking stick/walking frame	106	50.7%	3	1.7%	25	19.7%	134	26.1%
Ramp	61	29.2%	13	7.3%	36	28.3%	110	21.4%
Alterations for better access	47	22.5%	3	1.7%	33	26.0%	83	16.1%
Wheelchair	106	50.7%	12	6.7%	71	55.9%	189	36.8%
Parking space	23	11.0%	5	2.8%	15	11.8%	43	8.4%
Grabrail	103	49.3%	40	22.5%	46	36.2%	189	36.8%
Rooms all on one level	73	34.9%	8	4.5%	50	39.4%	131	25.5%
Hoist	27	12.9%	15	8.4%	29	22.8%	71	13.8%
Relocated bathroom/toilet	47	22.5%	16	9.0%	26	20.5%	89	17.3%
Stairlift	29	13.9%	4	2.2%	12	9.4%	45	8.8%
Aids to help with computer	10	4.8%	3	1.7%	2	1.6%	15	2.9%
Assistance dog	2	1.0%	0	0.0%	1	0.8%	3	0.6%
Other	30	14.4%	2	1.1%	10	7.9%	42	8.2%
Total respondents	209	100.0%	178	100.0%	127	100.0%	514	100.0%

*Total exceeds 100% since respondents could give more than one answer*

Other equipment used by survey participants can be seen in Table 10.11. The most common equipment used is for bathing, 177 respondents said they had specialist bathing equipment to help with day to day living and a further 21 listed other bathing equipment such as shower stools and wet room conversions as a help for everyday living. National research into the effectiveness of housing adaptations found that the most common reason for requesting housing adaptations was for bathing. By law every disabled person has a right to an accessible bath or shower. An inaccessible shower can cause embarrassment, humiliation and loss of dignity. The local Housing Needs Survey found that bathroom adaptations were the most common (50.9% of adaptations), followed by stair/ vertical lifts (38.8%) and hand/ grab rails (35.9%).

**Table 10.11** Do you have any other equipment to help you with your day to day life?

	Number
Electrical modifications	37
Entry telephone	38
Additional heating	12
Individual alarm system	61
Bathing equipment	177
Kitchen equipment	38
Other - Bathroom alterations	21
Other	15

Research into the effectiveness of housing adaptations found that bathroom adaptations restore dignity and self-respect and promote independence. They also reduce accidents in the home. Similarly a local survey respondent felt the adaptations made to the bathroom were excellent...

*"I've just had my bathroom made into a wet room which has been marvellous, I have a stool to sit on in the shower."*

## KEY POINTS

- 28.2% of those living with parents are aged 40 and over, which raises concerns for future care for some carers.
- Just 4% of those with a learning disability who responded to the survey rent their own home.
- The majority of respondents live in houses, regardless of their disability, however those living in a bungalow or ground-floor flat are most likely to be those with a physical disability. Those in residential care are most likely to have a learning disability.
- A third of respondents with a physical disability live in the 20% most deprived areas of North East Lincolnshire.
- Only 19% of people with a disability who took part in the survey own their own home compared to 76% of North East Lincolnshire residents.
- 22% of respondents with a physical disability said their home is unsuitable for their needs. Stairs, unsuitable bathroom and size were cited as the main reasons for unsuitability.
- 37% of people with a physical disability cannot afford to keep their home warm when it is cold.
- 17% of respondents require adaptations to their home.
- Although 97% of all respondents reported that they had central heating in their home, 37% of respondents with a physical disability reported that they cannot afford to heat their home.

## 11. TRANSPORT

The Disability Rights Commission (DRC) expects that disabled people should have the same rights and choices to use the whole travel system as everybody and should not be discriminated or disadvantaged on any journey. All transport systems should be designed and operated inclusively for the varying needs of all disabled people<sup>60</sup>. In recent years the Government have been committed to improving transport for disabled people and as a result policy and legislation have led to changes in the transport system<sup>61</sup>, including the introduction of regulations to ensure that buses, coaches and trains are accessible for disabled people.

Transport is a key enabler to participation in society and without the ability to travel disabled people are denied access to education, employment, social activities, healthcare and shopping. Disabled people travel a third less often than the general population and are less likely to drive or own a car. Disabled people are more likely to use public transport than the general public but despite this public transport is often difficult to access for them.

Table 11.1 shows a wide variation in how disabled people travel around North East Lincolnshire. People who are physically disabled are more likely to travel around the area by car while those with a learning disability are more likely to use public transport or walk to get around the area.

**Table 11.1**    How do you mostly get about locally?

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
	No.	%	No.	%	No.	%	No.	%
Car/ Van	123	62.1%	84	41.0%	77	57.5%	284	52.9%
Bus	49	24.7%	123	60.0%	54	40.3%	226	42.1%
Bicycle	0	0.0%	12	5.9%	4	3.0%	16	3.0%
Train	2	1.0%	12	5.9%	4	3.0%	18	3.4%
Motorbike	0	0.0%	1	0.5%	1	0.7%	2	0.4%
Walk	32	16.2%	95	46.3%	22	16.4%	149	27.7%
Taxi	73	36.9%	74	36.1%	38	28.4%	185	34.5%
Dial a Ride	2	1.0%	3	1.5%	5	3.7%	10	1.9%
Minibus	2	1.0%	4	2.0%	12	9.0%	18	3.4%
Mobility scooter/ Wheelchair	32	16.2%	2	1.0%	11	8.2%	45	8.4%
Total answered	198	100.0%	205	100.0%	134	100.0%	537	100.0%

The total exceeds 100% since some respondents gave more than one answer

Travel by car is the most common form of transport for people with a physical disability, both locally and nationally, 62.1% of respondents in the local needs assessment usually travel by car. Access to a car gives people with a physical disability independence, flexibility and comfort when travelling and for some is essential for maintaining social networks<sup>62</sup>. The local needs assessment survey found that those who usually travel by car had a higher social network score than those who don't usually travel by car as shown in Table 11.2 below. 20.4% of those who usually travel by car had a high social network score compared to 11.2% who don't.

Table 11.2 Social network score and car use

		Car is the main mode of transport					
		Yes		No		Total	
		No.	%	No.	%	No.	%
Network score	High	55	20.4%	30	11.2%	85	15.8%
	Moderate	98	36.3%	96	35.7%	194	36.0%
	Low	117	43.3%	143	53.2%	260	48.2%
	Total	270	100.0%	269	100.0%	539	100.0%

Although travel by car is the most popular mode of transport for people with a physical disability, the National Travel Survey (NTS) found that only 48% of adults (aged 17 and over) with mobility problems currently have a driving licence compared to 75% without mobility difficulties<sup>63</sup>. For physically disabled people access to a car can be as valuable as driving a car as it allows for comfortable door-to-door travel and doesn't involve as much planning as it might to use public transport.

The blue badge scheme makes door-to-door travel possible for badge holders. However for some badge holders, parking continues to be a problem and it is felt that there is a lack of enforcement.

*"...it really annoys me when able bodied people park on mother and baby and disabled parking spaces. It's disgusting. People don't realise it takes a lot more room to get out."*

*"Where are the traffic wardens? I haven't seen them for ages, parking is a problem...we have to park miles away, we display our badges but they don't get fined. I said to a chap you're not allowed to park there and then I got abuse off him.... Ignorance of people and lack of enforcement but you never see anyone there to tell them."*

*"Stricter enforcement of disabled parking spaces and there are not enough wherever I go, in particular at [Grimsby] hospital"*

The most used form of transport for those with a learning disability is travel by bus (60.0%), 40.3% with both a Learning AND Physical disability usually travel around North East Lincolnshire by bus and a quarter (24.7%) of respondents with a physical disability often travel by bus. 73 respondents said other, of these 18 said they usually travel around the area by minibus. Since the question did not differentiate between public buses, community transport buses and private minibuses it is not clear which type of bus is most used by people with a disability in North East Lincolnshire.

The need for advanced planning when travelling on public transport for people with a physical disability makes travelling by public transport less flexible. Getting to and from stations and stops can be difficult, making it difficult for some disabled people to travel alone. For those with sensory and/ or learning disabilities the street environment is equally as important, clear signs, a safe place to cross the road and accessible routes to and from stations are a key enabler for independent travel.

*"The worst problem I have is the pavement where I live, they are terrible... My wife doesn't like me to go out by myself really because of the pavement. I mean on several occasions she's nearly tipped me out."*

*"Larger signs for visually impaired, subtitles at noisy environments for hearing impaired i.e. train station tannoy."*

*"Bus signs to tell where bus is and inside bus (electronic). They have these in the South East of England"*

Not only do people have difficulty getting to the bus stop/ station but getting on or off buses, waiting at the bus stop/ station and, getting to and from the seat can also be difficult. Concessionary travel passes are important in giving people the freedom and independence to travel by public transport. For those who qualify in North East Lincolnshire, travel by bus around the area is free all day,

every day. Travel training was found to be a key enabler for people with learning disabilities in using public transport independently.

*"I have a disability bus pass which is ace really because you don't pay a penny. You don't have to pay for the bus pass either."*

*"He comes home on the bus himself, it's one of those things we have taught him to do with his bus pass... he knows the bus route, we did it with him about six times. Now if they changed the bus station we would have to start afresh and do the route with him to make sure he did it right"*

Travel by taxi was the second most common form of transport for those with a physical disability, just over a third of respondents travel around the area by taxi. 8.4% of people who had a problem getting around the area cited cost to be the reason, of these over half said that taxis are too expensive.

*"I have to go [to the supermarket] with \*\*\*\*\*, my wife...I'm not paying for a taxi to the supermarket, no chance... to pick me up [in a taxi] from where I live to the hospital was £9.20"*

A third of survey respondents overall had problems getting where they wanted to go, almost half of respondents with a physical disability said they had problems in getting where they wanted to go as shown in Table 11.3. The national transport survey found that adults with mobility difficulties make a third fewer journeys on average than those without.

**Table 11.3**    Do you have any problems getting where you want to go?

	Yes		No		Total
	No.	%	No.	%	No.
Physical Disability	94	47.7%	103	52.3%	197
Learning Disability	37	18.8%	160	81.2%	197
Learning AND Physical Disability	43	32.8%	88	67.2%	131
Total	174	33.1%	351	66.9%	525

Over a third (36.1%) of those who had problems in getting to places they wanted to go said it was because they were unable to travel alone, 15.5% said it was due to a lack of suitable transport. Over half of respondents with a physical disability said that improved/ repaired roads and pavements would make it easier to get around, free transport, general improvements to public transport and more parking spaces were all important factors in making it easier to get around the area. For those with a learning disability and for those with both Learning AND Physical disabilities, free/ cheaper transport was the most cited reason for making it easier to travel as shown in Table 11.4:



Table 11.4 What would make it easier for you to get about?

	Physical Disability		Learning Disability		Learning AND Physical Disability		Total	
	No.	%	No.	%	No.	%	No.	%
Free/cheaper transport for disabled people	84	44.0%	52	31.9%	52	45.2%	188	40.1%
Improved/repair roads/pavements	105	55.0%	33	20.2%	37	32.2%	175	37.3%
Improved public transport in general	83	43.5%	49	30.1%	34	29.6%	166	35.4%
More car parking spaces	79	41.4%	26	16.0%	45	39.1%	150	32.0%
Improved disabled access to buses/trains	72	37.7%	20	12.3%	32	27.8%	124	26.4%
Lower floor transport to meet pavement	70	36.6%	19	11.7%	31	27.0%	120	25.6%
Staff/drivers to be more helpful/understanding	62	32.5%	29	17.8%	29	25.2%	120	25.6%
Wheelchair access on buses/trains	70	36.6%	7	4.3%	27	23.5%	104	22.2%
More buses/trains	41	21.5%	31	19.0%	28	24.3%	100	21.3%
Less traffic jams	29	15.2%	16	9.8%	9	7.8%	54	11.5%
Nothing	9	4.7%	36	22.1%	8	7.0%	53	11.3%
Don't know	13	6.8%	19	11.7%	14	12.2%	46	9.8%
Other	18	9.4%	6	3.7%	4	3.5%	28	6.0%
Total answered	191	100.0%	163	100.0%	115	100.0%	469	100.0%

The total exceeds 100% since some respondents gave more than one answer

8% of respondents who took part in the National Travel Survey reported difficulty in travelling to the hospital or doctors. A much higher proportion of respondents to this survey reported difficulty getting to their GP or hospital. 17.5% of disabled people in North East Lincolnshire said they found it difficult to get to their GP and 3.4% said they couldn't get there at all. Those with a physical disability found it the most difficult to access their GP (28.8% found it difficult and 4.9% couldn't get there at all). Accessing the hospital for over a quarter of survey respondents was difficult or impossible. 34.1% with a physical disability found it difficult and 3.8% couldn't get there at all. The dentist was the most difficult service to access in the area. 30.6% of respondents found it difficult or couldn't get there at all. Half of physically disabled people found it difficult or couldn't get to their dentist. The majority (65.2% who couldn't access their doctor, 61.7% who couldn't access the hospital and 50.9% who couldn't access their dentist) of those who couldn't access health care services said it is because they needed assistance to get there.

35.3% of people with a physical disability said they found it difficult to visit their friends and family and 9% said they couldn't get their at all. 22% with a learning AND physical disability found it difficult or impossible to visit their friends and family while the majority of people with a learning disability found it easy.

Physically disabled people found it much more difficult to access a range of services in the area than people with a learning disability. The majority (87.1%-91.6%) of respondents with a learning disability found it easy to access services including the bank, post office, local shops, shopping centre and supermarket, for those with both learning AND physical disability it was more difficult; 62.7%-80.2% found it easy to access these services. For respondents with a physical disability, far fewer respondents found it easy to access the services (58.8%-66.9%).

14.2% of disabled people said they would make changes to the transport system if they had a magic wand. This included access to services and facilities, more accessible public transport, improved pavements and more disabled parking.

### KEY POINTS

- Travel by car is the most popular form of transport for disabled people, particularly for people with a physical disability.
- Respondents with a learning disability are the most likely to use public transport to get around the area, travel by bus is the most common use of public transport.
- Although over a third usually travel by taxi, fares are often too expensive.
- People with access to a car have a higher social network score than those who don't.
- Concessionary bus passes have given disabled people the freedom to travel around North East Lincolnshire independently.
- A third of disabled people (half of physically disabled people) have difficulty in getting where they want to go. Most said this was because they were unable to travel alone. Lack of suitable transport was also cited as a problem.
- Over half of physically disabled respondents said improvements to roads and pavements would make it easier to travel around the area.
- Needing assistance to get to healthcare services was cited as the main difficulty in accessing them.
- Accessing services was most difficult for people with a physical disability. More than a third have difficulty accessing hospital services and half have difficulty accessing dental services.

## 12. INFORMATION AND COMMUNICATION

The Digital Strategy (2005) first set out ways to improve access to new technology for all and make it easier to use for people with disabilities<sup>64</sup>. Following consultation on “Access and Inclusion - Digital communications for all”<sup>65</sup> OFCOM (2009)<sup>66</sup> identified services for disabled people as an immediate priority, with particular attention to support and access. They state that:

*“In order to fully participate in a Digital Britain, people should have equality of opportunity irrespective of sensory impairments, learning difficulties or dexterity/mobility problems.”*

Report of the Digital Britain Media Literacy Working Group, page 35

Suggestions to help disabled people overcome difficulties accessing digital services include introducing services to assist people with disabilities, subsidising the cost of equipment, ensuring all government services meet recognised accessibility standards, providing free local taster sessions and free/ low cost telephone helplines to signpost people to local services to help them to become digitally engaged.

### 12.1 Internet use and access

The needs assessment survey found that of the 544 people who responded, just over a quarter (144, 26.5%) used the internet. 337 (61.9%) said they did not use it and the remaining 63 (11.6%) indicated that they did not know what it was.

When broken down by disability, internet use was greatest among those with a physical disability (88, 42.3%). 112 (53.8%) respondents with a physical disability did not use the internet and the remaining eight (3.8%) did not know what it was.

OFCOM (2008) found that younger people with a learning disability were more likely to use the internet than older people with a learning disability. Use also varied by literacy level, with some able to use it relatively independently with only limited support, whilst others required constant support. Among respondents with a learning disability in the needs assessment survey, almost a fifth (40, 19.5%) used the internet whereas 63.4% (130) did not. The remaining 35 (17.1%) did not know what the internet was.

The lowest proportion of internet use was among respondents with a learning AND physical disability, where only 12.2% (16) respondents used it. Almost three quarters (95, 72.5%) did not and 15.3% (20) did not know what the internet was.

#### Future intention to use the internet

The Omnibus Survey 2006<sup>67</sup> found that 2% of UK households stated that they did not have the internet at home due to having a physical disability. By the time of the 2008 Omnibus Survey<sup>68</sup>, this reason was no longer listed, with reasons for not having it focusing on not wanting or needing it, cost, lack of skills or having access elsewhere.

In a recent study, Ofcom<sup>69</sup> found that in a sample of people without internet access at home, 43% stated that even if provided with a free computer and internet access they would still not want to use the internet, suggesting that perceived lack of need rather than cost was an important issue. The Digital Britain report (2009)<sup>70</sup> concluded however that for others, lack of affordable equipment or skills required to confidently use new technology may restrict its use and that those affected should be offered support. Initiatives such as free computer training have been put in place and some work has been done to provide personal computers to those currently without one at a lower cost in some parts of the country. Digital Britain (2009) argues that much more could be done by firms and individuals who are disposing of older but functional computer equipment which could be

saved from landfill by being provided to currently excluded individuals at an affordable cost once data had been removed from the system (Digital Britain, 2009).

Those respondents locally who had indicated that they did not use the internet were asked what would encourage them to use it in the future. Of the 344 people who responded, almost three quarters (256, 74.4%) stated that there was nothing that would encourage them to use the internet, or that the nature of their disability prevented them from being able to do so.

*“Ever since I had my stroke I have completely lost my computer skills.”*

*“I cannot read or understand computers.”*

The charity AbilityNet has links to large public, private and voluntary sector organisations and provides assessments and support for people with disabilities to find the right adaptations and equipment to enable them to meet their IT needs and promote digital inclusion in previously excluded people. In 2008, over 1,000 such assessments were carried out<sup>71</sup>. In addition to assisting organisations make their websites more accessible and compliant with the Disability Discrimination Act and providing assessments to clients with disabilities, AbilityNet offer a loan facility where people with disabilities can try out items of adaptive technology to establish the correct combination for them before being required to commit to purchase and possibly purchasing something that does not offer them much benefit.

A reply of “nothing would encourage me to learn about the internet” or that the person would be unable to use the internet was particularly likely from respondents with a learning AND physical disability (80, 83.3%) and learning disability (107, 75.4%) but less so for respondents with a physical disability (65, 65.1%).

Table 12.1 shows the most common responses given by participants on what would encourage them to use the internet in the future.

**Table 12.1 Attitudes to internet use among people with disabilities in North East Lincolnshire**

<b>Reason</b>	<b>Number (%)</b>
Nothing would encourage/I would not be able to use it	256 (74.4%)
Training on how to use a computer	27 (7.8%)
Cheaper computers/internet access	15 (4.4%)
Knowing more about what I can use it for	14 (4.1%)
Knowing more about what I can use it for, training on how to use a computer and cheaper computers/internet access	9 (2.6%)

Across all disability types ‘training on how to use a computer’ was the most frequently listed factor which would encourage people to use the internet. Although a large proportion of respondents were unwilling or unable to use the internet in the future, suggesting that this is not an appropriate medium for disseminating information to everyone, support could be offered for those who wish to do so through appropriate IT courses. When presented with a list of media related tasks in which skills could be developed, the Media Literacy Audit<sup>72</sup> (an OFCOM survey concerning people’s use, knowledge and competence in using technology) found that using the internet was the most popular activity in terms of having previously learned about and wanting to learn about in the future. It also found that reading a manual/ instructions was the most popular way people with disabilities wished to learn, followed by support from family or friends. Although this may be possible for some, appropriate classes could be provided for those that require them, or possibly family focused sessions enabling people with disabilities to learn supported by their family. The possibility of an affordable IT initiative in North East Lincolnshire for low income and disabled families should be considered in order to assist people to access online services.

## 12.2 Digital television access and use

The switchover from analogue to digital TV began in the UK in late 2007, with a programme in place to switchover the rest of the country by 2012. In the Yorkshire and Humber television region this change is scheduled to happen in 2011. An independent, not for profit organisation, Digital UK was set up and is owned by the UK public service broadcasters and two commercial operators and exists to coordinate the switchover and make the experience as simple as possible for the public and communal housing by advising on how to prepare for the changes. To assist with the cost of upgrading television equipment, the BBC has set up the 'Digital Switchover Help Scheme'. This scheme helps eligible people who claim certain benefits such as attendance allowance, mobility supplement or disability allowance as well as people aged 75 and over, those who are registered blind or partially sighted or live in a care home to make the switch on one of their television sets.

Of the 555 people who responded, the majority (445, 80.2%) had digital TV at home. 15.5% (86) stated that they did not and 4.2% (24) answered that they did not know what digital TV was. There was relatively little difference between the disability cohorts on this. Those respondents who had digital TV at home were also asked if they used the red button facility to get further information. 439 of the 445 (98.7%) provided an answer to this question. Only 22.3% (98) said that they used the red button facility on their digital television to obtain further information, whilst 77.7% (341) did not.

The reported usage of digital communications is encouraging, but since a high proportion of people (77.7%) did not use the red button facility to seek further information, greater promotion and awareness-raising may be necessary by the media organisations to ensure this potentially useful function is being fully utilised.

## 12.3 Access to a Telephone

In North East Lincolnshire, 92.1% (498) of the 541 people who responded had a landline telephone at home or close by, with 7.9% (43) stating that they did not. Among those respondents with a physical disability, 89.3% (183) had a telephone at home or close by compared to 10.7% (22) who did not.

Almost all (196, 96.6%) respondents with a learning disability had a telephone at home or close by, only 3.4% (7) did not. For those respondents with a learning AND physical disability, 89.0% (114) had a telephone at home or close by compared to 10.9% (14) who did not.

475 people answered the question about mobile phone ownership, with 61.3% (291) indicating that they owned their own mobile phone, whereas 38.7% (184) did not. This is lower than found by the Media Literacy Audit, in which 82% of people with disabilities had their own mobile phone. In the NEL survey, 84.3% (156) of respondents with a physical disability had their own mobile phone, compared to 15.7% (29) who did not.

For respondents with a learning disability, just over half (91, 52.6%) owned a mobile phone compared to 47.4% (82) who did not. The lowest proportion of mobile phone ownership was among respondents who had a learning AND physical disability, of whom only 34.0% (41) had a mobile phone compared to 64.0% (73) who did not. It was suggested by some respondents that the complicated nature of modern mobile phones make them too difficult for some people with learning difficulties to use. Similarly, since some respondents were unable to speak, mobile phones may be inappropriate.

*"We have tried him with a mobile phone but he just can't cope with it. There should be a simple phone for people who cannot do these things even if they are colour coded, i.e. red for mum and dad, blue for police..."*

This was also found by OFCOM (2008) in a study of people with learning disabilities and their use of communication services<sup>73</sup>, where the amount of text on screens was mentioned as difficult by people with poor literacy skills, the amount of non-essential features confusing and the size of handsets and keys were problematic for those with visual and dexterity problems. In the OFCOM study, people with disabilities who owned a mobile phone felt that it gave them greater independence as well as providing security to their family when they went out.

Having access to a telephone in the event of an emergency is crucial to be able to contact help if an emergency alarm is not available. Most people in our survey had access to either a mobile or landline telephone. The majority of those who did not have access to a phone were unable to use one due to their disability. Only two people reported living alone and having no telephone access, one of these reported having an emergency alarm, the other person stated that they would like one.

## 12.4 Preferred forms of Communication

Participants were also asked about how they wished to receive information about a range of topics in the future. In total, 440 (77.9%) answered this question, at least in part.

### How to stay healthy

The largest proportion of respondents did not want any further information on how to stay healthy (187, 43.7%). Of those that did, the overwhelming preference was for this information to be presented in a leaflet or magazine format (184, 43.0%). Some respondents mentioned special requirements such as large print or Braille. Some mentioned methods such as the internet (15, 3.5%) or digital TV (5, 1.2%) but these methods were not popular. Similarly, home (5, 1.2%) and mobile (5, 1.2%) telephone calls/ texts were not a frequently mentioned preferred communication method.

For a further five (1.2%), personal contact was important, with some respondents with learning disabilities stating that they liked their support worker to explain new things to them.

### Health care services

The largest proportion of respondents to this part of the question stated that they would prefer future information to be presented in a leaflet or magazine format (182, 43.4%). Again, some mentioned special requirements such as Braille or large print. The next highest proportion of people did not want any further information (170, 40.6%). The internet or email was the preferred method of 19 (4.5%), with only two (0.5%) citing digital TV as their preferred method. Home (11, 2.6%) and mobile (6, 1.4%) telephone call were mentioned by some and others again preferred one to one contact.

*"I like my support worker to explain new services so I can understand."*

### Social care services

Again for social care services, leaflets or magazines were the most popular way for information to be received in the future (179, 42.9%), with Braille and large print mentioned as important by some respondents. 162 (38.8%) respondents did not want any further information. Home phone calls were the preferred method of 17 (4.1%) people and mobile calls/ texts for eight (1.9%). The internet was preferred by 20 (4.8%) however the popularity of digital television remained low (2, 0.5%). Face to face contact was the preference of seven respondents (1.7%).

### Benefits

Almost half (204, 47.2%) of those that responded requested information about benefits in a leaflet or magazine format. Less than a third (135, 31.3%) stated that they did not want any further information. For some respondents (11, 2.5%), the complexity of the benefits system and confusion over entitlements led them to request one-to-one specialist advisor support to make

people aware of what they are entitled to and how certain benefits can be affected by other income such as pensions. This was also mentioned by interviewees and focus group members.

*“A lot of people don’t understand what they can claim for and what is available for them and they don’t claim for a lot of things they are eligible for. That’s why the George Hardwick Foundation will do well by having a place where it can explain the benefits to people in straight, layman terms... A lot of people don’t give the answer if the question is not asked.”*

*“The biggest problem is not enough information telling people what they are entitled to; you just hear it from word of mouth.”*

The internet was the preferred method of communication about benefits for 21 (4.9%), 27 (6.3%) preferred a home phone call and four (0.9%) preferred a mobile phone call or text.

### Leisure/ Social Activities

Leaflets or magazines were preferred by more than half of respondents (233, 53.6%) and less than a third (138, 31.7%) did not want any further information about leisure or social activities. Not knowing where to obtain information about social activities, particularly those for middle aged people were mentioned by several as a problem.

*“I don’t know where to go for social needs.”*

The internet was mentioned by 14 (3.2%), home phone calls by 10 (2.3%) and mobile phone call/text by four (0.9%) as the preferred method of communication. Again, some people wanted face to face contact, such as a support worker explaining things to them.

### Learning Opportunities

The largest proportion of respondents did not want any further information about learning opportunities (175, 43.9%). Of those that did, leaflets or magazines (with Braille, large print or pictures for some) were the preferred method of receiving information for most (170, 42.6%). The internet was the method of choice for 11 (2.8%), home phone call for 14 (3.5%), mobile phone call/text for three (0.8%). One to one discussion was again mentioned by some.

Although some people mentioned being willing to use new technology to receive information it is clear from responses to this question that people with disabilities generally prefer to receive information via traditional media such as leaflets and magazines. With the current trend towards information being presented electronically it is increasingly important that information continues to be produced in a variety of media to reduce the risk of vulnerable groups becoming further marginalised.

### **KEY POINTS**

- In North East Lincolnshire, internet was used by 42% of respondents with physical disability, 19.5% of respondents with a learning disability and 12% of respondents with a learning AND physical disability.
- 74% of respondents currently not using the internet said they did not want to use it in the future, or that the nature of their disability prevented them from doing so.
- Digital TV at home was common, with 80% of respondents having it.
- Red button use was low with only 22% stating that they used the facility to obtain further information.

- 92% of people had access to a landline telephone and 61% owned a mobile phone. Mobile phone ownership was most common among respondents with a physical disability (84%), and lowest in those with a learning AND physical disability (34%).
- When asked about preferred methods of communication, the preference was for magazines or leaflets for almost all types of information presented. Although other methods were mentioned, they were mentioned infrequently.



## 13. SERVICE REVIEW

The final stage of the needs assessment involved an informal review of current services for people with disability in North East Lincolnshire by consulting with those managers and practitioners who are currently delivering these services. The Disability Needs Assessment Steering Group identified a number of professionals across the partnership to be invited to contribute to this review covering a wide range of services including the following:

- Learning Disability (including day services)
- Physical Disability & Sensory Impairment
- Transition
- Carers
- Housing
- Community Safety
- Employment
- Transport
- Voluntary / Community Sector
- Leisure and Recreation

Informal interviews were conducted in person or over the telephone with senior representatives from all the above services. The interviews explored the structure of the service and how it was delivered to clients, the extent to which the service meets the needs of clients, the strengths and weaknesses of the service, any gaps in current service provision, future plans for the service and views on other services in addition to the participants own.

Interviews were carried out between January and April 2009, therefore team structures, activities, and comments were as identified during this period<sup>c</sup>. In addition to information obtained during the interview, many professionals also provided supporting documentation about the services provided. Due to this research including subjective information, it should be remembered that this review will include perceptions of service provision and need, which may vary between teams and across the partnership. It should also be remembered that this report is not an audit that is comprehensively listing all services that are available, but instead aims to give a summary of the major services which are available, examples of current activity and to flag up identified need.

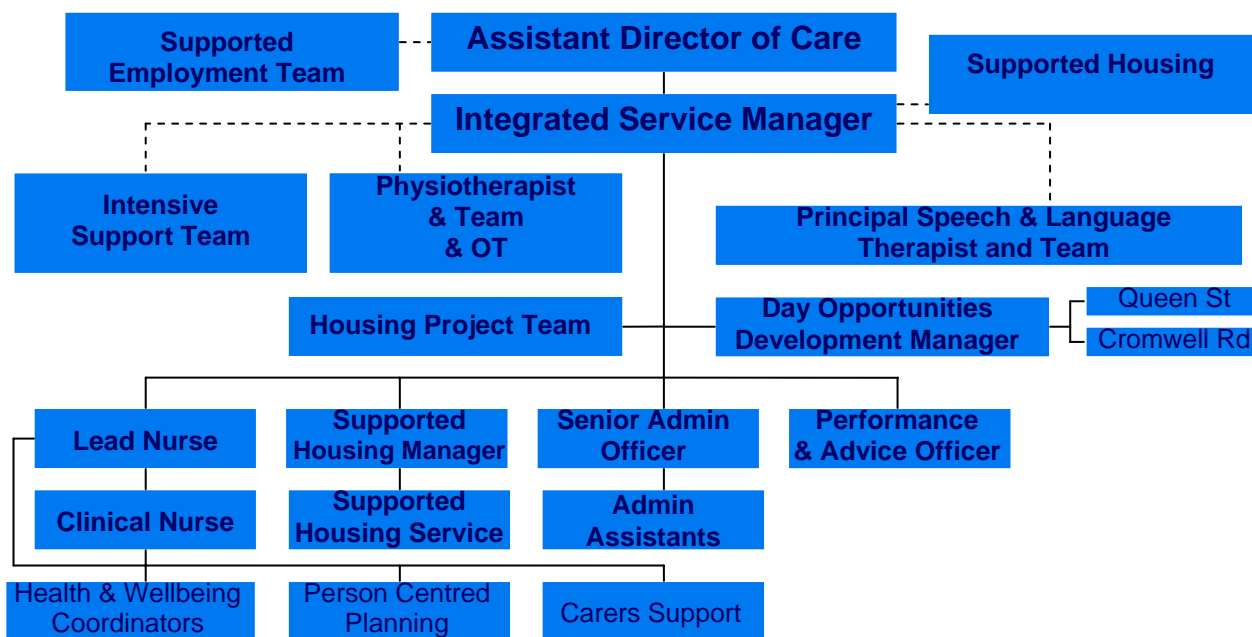
### 13.1 Learning Disability Service

Learning disability includes a wide range of conditions, many leading to substantial functional impairment and the lifelong need for support. Due to advances in medical treatment over recent years, people with learning disability particularly those with profound needs are living longer. The Learning Disability Service works with all adults aged 18-64 eligible for care across North East Lincolnshire providing an holistic service covering health and social care. Those over 65 are referred to the Older People Service if their need is predominantly related to being an older person and a joint review will take place to consider the transfer of the client. There are 517 people on the Learning Disability internal service register, of whom 402 are receiving a service (detailed on SWIFT) and a further 36 are older people who are supported. The structure of the learning disability team is shown in Figure 14.1.

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<sup>c</sup> There may be a slight discrepancy between some of the figures provided by teams e.g. numbers on registers or numbers of service users, as these numbers are not constant and the interviews were carried out on different dates.

Figure 13.1 Structure of Learning Disability Service



Source: NELCTP Learning Disability Service

Care Management includes a person centred assessment to identify specific health & social care needs. Care Management has moved from the provider arm to the commissioning arm of the organisation. However the final structure has not yet been decided. Care Plans are developed with outcomes focused on promoting good health, wellbeing and independence. Services are commissioned that focus on the individual's needs and opportunities for additional funding are explored. There are opportunities to refer onto a range of other service providers including Clinical Learning Disability Nurse, Intensive Support Team, Psychology, Physiotherapy, Speech & Language Therapy and Carer Support. Reviews take place on a regular basis to establish whether current provision is meeting the needs of the client. A carer's needs assessment can also be carried out.

### Health & Wellbeing Coordinators

As part of the 'Changing Lives in Partnership' initiative, to improve the health and wellbeing of adults with learning disability, NELCPT has introduced four posts of 'Health & Wellbeing Coordinator' (HWC). The HWCs each take a lead for one of the four Primary Care Commissioning Groups, in addition to having their own special interest areas. They work closely with the clinical support nurse and are able to offer a wide range of support to people with learning disability including:

- Support to access mainstream health services and appropriate screening
- Help to bridge gaps between health and social care
- Support service users when attending hospital
- Raise awareness of services
- Assist service users to understand about healthier lifestyles and support them to access activities for good health
- Refer on to other services e.g. speech and language therapy, physiotherapy, occupational therapy, intensive support team, health trainers etc.
- Act as an advocate to sort out problems if a service user is experiencing difficulty with a particular service
- Liaise between health professionals and support networks
- Help with capacity and consent issues.

Anyone registered with their GP as having learning disability can be referred to the HWCs. Most referrals originate from social services as the service is offered during the social care review.

Referrals will be prioritised depending on the health needs of the individual. The service is free of charge. HWCs are cross referencing the GP register with the Learning Disability Service register to identify those who may be missing out on services. Currently 617 people are identified on primary care registers as having learning disability. It is intended that all service users registered with GPs as having learning disability will be offered a Health Action Plan, which will be reviewed annually.

HWCs also attend transition meetings to capture service users moving over to adult social care. HWCs are potentially useful to this client group as when the service users are children many services are provided in school and health needs are managed by the paediatrician. Therefore parents are not always aware of the pathways of care and adult services available.

### Local Enhanced Service (LES)

It is recognised that people with learning disability have increased health needs compared to the general population. In September 2008, NHS employers and the BMA published guidance on a number of new 'Direct Enhanced Services' for GP practices for 2008/09 and 2009/10, which included annual health checks for adults with learning disability. PCTs are required to offer GP practices in their area the opportunity to provide these enhanced services. The number of eligible people receiving annual checks is one of the NHS Vital Signs indicators<sup>74</sup>.

25 GPs are signed up for the Local Enhanced Service in North East Lincolnshire. GPs may need to spend a longer time with a service user with learning disability than for many other appointments. The coordinator can prepare the service user beforehand and attend the appointment with the service user. GPs signing up to the LES are expected to attend a multi-profession education session.

### Physiotherapy

A Learning Disability Physiotherapy team operates in North East Lincolnshire and includes a Superintendent Physiotherapist, a Senior Physiotherapist, a rotational Physiotherapist, and two Physiotherapy Assistants. The service is run by NLaG and there is a Service Level Agreement with the CTP for the service which is based at the William Molson Centre. The team work with all adults aged over 19. Children with learning disability are usually under the care of paediatric physiotherapy. Referrals usually come from the Learning Disability Advice Officer but may originate from GPs, carers, health professionals, self referrals, friends etc. Physiotherapy referrals tend to be around mobility, respiratory, and pain issues. The overarching aims of the team are to:

- Enable clients of all abilities to keep as mobile as possible thus promoting independence
- Maintain access to activities of daily living
- Maintain a good quality of life and sense of community inclusion
- Support carers to look after their dependents and help them to enjoy a good quality of life.

A wide range of activities are facilitated by the physiotherapy team including hydrotherapy<sup>d</sup>, swimming, rebound therapy<sup>e</sup>, postural care management and general health promotion activities such as walking, cycling and ice skating (in partnership with other agencies).

### Occupational Therapy

Occupational Therapy (OT) is a health and rehabilitation profession designed to help people regain and build skills that are important for their health and wellbeing. OTs work with people of all ages, who require help learning skills to enable them to live as independently as possible. The Community OT Service is a joint service with NLaG and covers both health and social care issues, and focuses on rehabilitation and assessment of daily living activities with the aim of improving ability to carry out everyday tasks. The team offers rehabilitation and assessments for assistive technology and home adaptations. People are mostly seen in their own homes or in intermediate

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<sup>d</sup> Hydrotherapy involves exercise in remedial swimming pools for the rehabilitation of patients

<sup>e</sup> Therapy using trampoline

care. The Learning Disability Service has recently recruited a dedicated learning disability occupational therapy post.

### Medical Rehabilitation Unit

This team of medical consultants, therapists, and liaison officers cover both North and North East Lincolnshire and is based in Brigg. It specialises in helping disabled people who have multiple needs and whose condition is serious and ongoing. Following an assessment, the team works with the individual and their carers to facilitate rehabilitation.

### Intensive Support Team

The Intensive Support Team (IST) provides a service for adults with a learning disability and severe challenging behaviour. This is in addition to the generic Psychology Service for adults with learning disability and mental health problems. The team includes a consultant psychologist, clinical psychologist, nurse specialist, senior behaviour support workers and behaviour support workers. They operate in a variety of settings including family homes, residential homes and in special schools.

### Person Centred Planning

The Person Centred Planning (PCP) Team are fully integrated in the Learning Disability Service. The concept of PCP was launched in the 2001 'Valuing People' Strategy. PCP involves working with the service user to establish their goals and ambitions, and allocating a key worker to support the individual to move forward in the areas that have been identified.

### Autistic Spectrum Disorder (ASD) Nurse

A specialist autism nurse has been recruited to develop a local service for people with ASD. This service will operate from Open Door which is an open access service that provides support from a range of health professionals to meet health and social care needs. The IST and Mental Health Service will work closely to support this new development. The national adult autism strategy is due to be published early in 2010. The Learning Disability Service is in contact with the National Autistic Society around producing a local strategy to take this forward. There has been a growth in the number of children with ADHD (Attention-Deficit Hyperactivity Disorder) and Autism, and many of these are likely to be receiving a service as children.

### Day Services

Day opportunities are activities that support people to remain active and independent in their community. The CTP currently provide day opportunities for just under 200 people with learning disability<sup>f</sup>. Therefore nearly 50% of people receiving a service for learning disability in North East Lincolnshire attend a day centre. Two centres cater for people with learning disability (Cromwell Road and Queen Street).

Queen Street Resource Centre (QSRC) caters for people with a learning disability which is often moderate in complexity. Cromwell Road Resource Centre (CRRC) caters mainly for clients with more complex needs. The only route for referral into the QSRC and CRRC is through the Learning Disability Team who carry out an assessment. Day sessions are included in the overall package of care.

QSRC run a wide range of vocational activities for clients in partnership with other organisations and professionals such as Sports Development, health trainers, Mencap, Artlandish, Foresight, Linkage and GIFE. The following activities are available:

- 'Jobs 4 All' recycling scheme
- Creative writing
- Dream catcher
- Creative art group

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<sup>f</sup> as at February 2009

- EDAS art group
- Family history group
- Nature group
- Fitness/ exercise group
- Health & fitness lifestyle group
- Table tennis
- Chair based exercises
- Pre-retirement group

A number of service users are in paid employment at QSRC including two administration workers, two kitchen assistants, and one seasonal gardener.

Most activities provided at CRRC are therapy based to reflect the complex nature of the disability. Activities include physiotherapy, hydrotherapy, music, drama, art therapy, cookery, rebound therapy and communication skills development. A new build extension to the current day centre opened at CRRC in October 2009. This has provided a joint health and social care resource that has increased the capacity and facilities available to the service. The new facility required substantial investments including £770,000 from North East Lincolnshire Council for the new building and £81,000 from the CTP for additional staffing. The new building provides the following facilities which will improve the services and therapies available:

- Physiotherapy gym including floor level trampoline
- Speech & language therapy communication suite
- Specialist clinical room for use by clinical services e.g. psychology
- Training rooms for internal and external use
- Café open to the public and to employ people with learning disability.

To facilitate these activities there are close partnerships with many other services including psychology, speech & language therapy, psychiatry, physiotherapy, dental health, chiropody, and Foresight.

#### **Learning Disability Service – Summary of Identified Needs**

- Too many service users are currently placed in out of area residential care. A review has been commissioned regarding the development of local services to enable service users to return to the area and be supported locally.
- Learning disability is classed as a permanent lifelong condition. As acquired brain injuries are not classed as learning disability, people with these injuries are covered by the physical disability service.
- Many community facilities do not meet the needs of those with complex needs. There are particular issues ensuring compliance with the Disability Discrimination Act, e.g. disabled parking, sliding doors etc. Some leisure centres are insufficiently equipped for people with disability at the current time, for instance access to swimming sessions at Grimsby Leisure Centre and Immingham Swimming Pool for people with complex disability is difficult due to a lack of suitable changing facilities and hoists. Moving these issues forward can be complex as NELC own the buildings whereas a private company hold the contract to operate them. It is acknowledged however that partnership work is ongoing to move this agenda forward.
- Some LA public conveniences have disabled toilet facilities, however none have changing facilities. This lack of changing facilities suitable for people with profound need means that families who are out for the day may not have access to facilities to support their basic needs. The physiotherapy team are working with NELC on the 'Changing Places' agenda. Nationally the Changing Places Consortium is a group of organisations working to support the rights of people with profound and multiple learning disabilities to access their community. The Changing Places Consortium is campaigning for Changing Places toilets to be installed in large public places.

- Information is not always provided in accessible formats. For example feedback from the Learning Disability Advocacy Group about the health action plans raised a query around the possibility of producing a Braille version in instances where this would be appropriate.
- Few GP practices appear to have carried out surgery building audits around signage etc. GPs often provide information in other languages but not in Braille. Signs are often in too small a font and do not include pictures.
- A sexual health and relations group for adults with learning disability is to develop staff guidelines as there is currently some uncertainty about how to manage this issue. However a new sexual health policy was agreed during November 2009.
- It is recognised that a number of young people with profound and complex needs including medical needs will be entering the adult service in the next few years and the new Cromwell Road build is designed to cater for these complex needs. However with continual advances in medicine, especially the increased survival of premature babies, the trend of growing numbers of clients with complex needs is forecast to continue. These service users require more intensive work which is likely to require increased numbers of staff.

## 13.2 Physical Disability and Sensory Impairment

Approximately 1500 people with physical disability are known to the CTP. As at February 2009 there were 397 people receiving a service in addition to those in residential care. There was no waiting list for the service at that time. Since the review a significant restructure has taken place and people with physical disability are now assessed and case managed within the Care Management Locality Teams, and as such the specialist workers who formed the Physical Disability Team have now been relocated within these teams. This restructure was to support the development of a complex case management approach that is being adopted in North East Lincolnshire. Case Management is an approach that has been developed to manage the care needs and the disproportionate use of resources of those with complex needs – specifically multiple long term conditions. The rationale is that if this group is supported in a more focused way, the dual benefits of improving the quality and experience of care, and reducing the disproportionate use of resources by this group, can both be delivered.

The Care Management Locality Teams provide a comprehensive assessment service for people with physical disability. The teams develop care plans, and provide a range of services for adults with disability and their carers. Support aims to promote an individual's ability to remain as independent as possible.

The Care Management Locality Teams work with a range of other services in the statutory and voluntary sector. For instance clients seeking work may be referred onto services such as the Disability Employment Advisor. The service also works closely with a wide range of third sector partners including:

- Foresight which offers a befriending service and runs weekly lip reading classes
- Deaf Blind UK is a local charity which operates a monthly drop in at the Freeman Street Resource Centre
- Guide Dogs for the Blind organises a monthly meeting
- Lindsey Blind Society based in Louth employs a team of community support workers, one of whom covers North East Lincolnshire. This worker offers support to people with visual impairment who are in need.

A Rehabilitation Officer and a Technical Officer provide services for adaptations and assistive technology. This service covers all North East Lincolnshire and referrals are received from a variety of sources including GPs, district nurses, home care, NLaG audiology department, self referrals, and partner organisations. Referrals are channelled through the Advice Officer to the Rehabilitation Officer who carries out an assessment. If equipment is required, this is issued and a review date is set.

The type of service provided will depend on the disability. Services provided for people with a visual impairment include a wide range of equipment and minor home adaptations, e.g. magnifiers, removal of trip hazards, removal of sharp edges on cupboards, new flag stones etc. A variety of equipment is provided for people with a hearing impairment e.g. hearing aids and smoke alarms.

There is a monthly Occupational Therapy Clinic based at Freeman Street. The Occupational Therapy Department carry out the assessments for the Disabled Facilities Grant process. Work may include installing ramps, widening doorways etc. These home adaptations are means tested (see section 13.5).

### Day Services

The CTP currently provide day opportunities for just under 40 people with physical disability or sensory impairment<sup>9</sup>. This service is provided at the William Molson Day Centre (WMDC) and is managed by the CTP's Learning Disability service.

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<sup>9</sup> as at February 2009

The WMDC is the only day centre in North East Lincolnshire for clients with a predominant physical disability. It operates Monday to Thursday and the theoretical capacity is for 25 people per day, however capacity depends on the nature of the disability, as some younger clients have profound and complex needs whilst others have more moderate disability. Some clients also have a learning disability. A stroke rehabilitation service is operated on Fridays in the WMDC and caters for people of any age who have had a stroke.

Since the formation of the CTP in September 2007 the WMDC has been managed by the CTP's Learning Disability Service. It had previously been operated by NELC (2006-07), the Rowan Organisation (2003 – 2006), and Leonard Cheshire (1999 – 2003). The centre is staffed by a manager, four support workers, two part-time support workers, a part-time cook, and a part-time administration officer. The only route for referrals into the WMDC is via the Care Management Locality Teams.

As at February 2009, there were 37 clients receiving a service. The majority of clients are in the 45 – 65 age group and clients may attend between one and four days per week. Clients participate in a number of activities at the day centre based around education, rehabilitation, and social interaction. A tutor from adult education attends the WMDC on a Tuesday afternoon. Other activities include crafts, IT, a beautician clinic, and gymnasium work to promote a healthy lifestyle.

Approximately 75% of attendees at the WMDC require transport and buses are provided for this (see Section 13.6). However due to the need to reach people throughout North East Lincolnshire journeys can be long which can considerably impact on the time available for activities.

The WMDC is well equipped to meet the needs of people with physical disability, for example the provision of toilets with hoists and adaptive showers. It also has a specialised rehabilitation kitchen which can be used to provide cooking/ kitchen skills. This facility is used by the Community OT Team, and the Medical Rehabilitation Team.



### **Physical Disability and Sensory Impairment – Summary of Identified Needs**

- There are many people with physical disability unknown to the services (more than learning disability) as many people with physical disability live independently.
- There has not been the investment in physical disability services that learning disability services have had so services are fewer in number and less flexible. There is also less national legislation about physical disability services than there is for learning disability and older people services.
- Locally there is a lack of quality respite care especially for people with physical disability. Respite may be included in a care package but this may not meet the needs of the client and their carers, if for example provision is predominantly an old people's home, or is out of area. Lack of suitable respite care for people with disability has a negative impact on the needs of carers.
- People with visual or hearing impairment face problems locally e.g. places advertising hearing loop systems but not having them switched on. There is a lack of consultation with people around new developments e.g. the layout of GP surgeries.
- People with physical disability have less of a collective voice than people with learning disability. The voice for people with learning disability may be for example their parents, whereas the physical disability voice is more individualised. There is a need for more physical disability advocacy.
- People with acquired physical disability need access to psychology services as coming to terms with their disability and change in life may lead to associated mental health issues. There needs to be closer working with the Rehabilitation Medicine Service.
- There is need for more appropriate accommodation for people with physical disability as there are difficulties securing appropriate housing. Currently there are a small number of people in residential short stay accommodation who are awaiting the availability of appropriate accommodation. There is little supported housing for people with physical disability in the area. Suitable housing for people with physical disability has a much lower turnover rate than housing for older people.
- There is no apparent interface with Supporting People around how support can be provided for people with physical disability.
- Young people with physical disability may lose their independence after finishing college as they may have to move back in with their parents.
- The WMDC building is owned by NELC, however the service is operated by the CTP. This raises issues around the future of the building. Parts of the building are in poor condition and there have been several instances of significant flooding. The WMDC has been highlighted as a priority for re-provision.
- The WMDC does not cater for all people with physical disability. Similarly client numbers at the centre are limited by transport capacity. An outreach service would be useful to provide general support rather than day care.
- Currently there are approximately three clients aged over 65 attending the WMDC, however this will become more of an issue in 5 – 10 years time as current clients age. Decisions need to be taken on an individual basis about what will be the best provision for clients coming up to 65. It needs to be remembered that some clients may have been attending for 20 years, and any change or move may have a significant personal impact.

### 13.3 Services for Young People in Transition

The transition from school to adulthood is a time of change for all young people. Decisions need to be made about careers, where they will live; their social life and continuing education. For young people with a disability and their families transition can bring challenges that they may need support to address.

#### Aiming High

'Aiming High for Young People: A ten year strategy for positive activities'<sup>75</sup>, published in July 2007, sets out the Government's plans to help all young people, particularly those from disadvantaged backgrounds, to take part in enjoyable and purposeful activities in their free time. It was developed in response to new evidence that participation can help the development of social and emotional skills, and to address a clear demand from young people for greater access to activities. The strategy makes 55 commitments focused on increasing young people's participation in positive leisure-time activities. Designed to develop new skills and raise aspirations, the strategy will ensure that young people:

- Are empowered to have a say in the creation of services and in local funding decisions
- Can easily find out about local things to do and places to go, and are motivated to use the new and improved activities and facilities on offer
- Have access to services of an excellent quality, delivered by a diverse and professional workforce who are valued and supported to develop the skills to make a difference for young people.

Delivery of this strategy, as well as the wider programme of reforms to services and support for young people, requires the ongoing commitment of local partners, including the third and private sectors, parents and young people themselves. As part of the Aiming High agenda North East Lincolnshire successfully gained £1.2 million to spend on improving services and facilities for children with disabilities and their families. A major component of this work to date has been a consultation with parents, carers and young people about their views and desires for the development of services. This consultation took place between October 2008 and January 2009 and a summary of needs identified that are relevant to this needs assessment are detailed in Table 13.1:

**Table 13.1 Summary of Needs Identified in NE Lincolnshire Aiming High Public Consultation**

<b>Individual budgets/ Direct Payments</b>	<ul style="list-style-type: none"> <li>• Many parents did not fully understand the nature of these two schemes</li> <li>• Lack of support to implement the schemes</li> <li>• Parental concern about how the schemes would impact upon the finances of the household</li> <li>• The schemes may encourage choice but there is a lack of quality services in North East Lincolnshire in the first place. Families have to accept what is on offer rather than what they need</li> </ul>
<b>Short breaks</b>	<ul style="list-style-type: none"> <li>• Parents and carers repeatedly expressed the view that they did not know how to access services</li> <li>• Complicated assessment process leading to difficulties in obtaining a service.</li> <li>• There is a lack of choice regarding the service</li> </ul>
<b>After school activities</b>	<ul style="list-style-type: none"> <li>• Lack of activities</li> <li>• Lack of suitable toilet facilities both in the community and at leisure venues</li> </ul>
<b>Transport</b>	<ul style="list-style-type: none"> <li>• Parents stated that when they tried to use public transport they were often turned away due to the bus only being able to carry one pushchair at a time, and that if the bus did have disabled spaces these were often taken up by pushchairs</li> <li>• Parents describe transport and parking schemes as inadequate, and inflexible</li> <li>• Parents stated that there are only two taxi firms in North East Lincolnshire which accommodate power chairs and that Dial a Ride was expensive and that the service ceased at 6.00 p.m. limiting the ability to lead an ordinary life</li> </ul>

**Transition**

Parents and young people involved in the ‘Aiming High’ consultation felt there was a lack of information about transition arrangements. They also believed there were insufficient services for the 15 – 25 year old age group, and that young adults should not be using services which have been developed for the older generation just because they have a disability.

The Positive Transition Framework is a framework for multi agency working which has been adopted to improve transition arrangements by ensuring that roles and responsibilities are established which ensure that young people with disabilities and Statements of Special Educational Needs (SEN) receive the help, advice and guidance they need to make a successful transition to adulthood. It is designed for the following groups of young people:

- Vulnerable young people including those with a disability and SEN, aged 13-25, who are moving from school to college, entering training, work based learning, or planning to attend an alternative post school placement
- Young adults as they move on from college or university, into supported employment or to an alternative provider
- Young people that are ‘Looked After’ or placed at out of county schools and colleges.<sup>76</sup>

The aim of transition planning is to help the young person prepare for a successful transition to adult life. During Year nine when the child is 14 a review takes place between the school and Connexions service to plan transferring the service. This begins a long-term decision making process that should develop over the following years. A Transition Plan must be prepared for all

young people with SSEN following the Year nine review, and is an essential starting point when planning a young person's future. The Transition Plan should draw together information from a range of individuals and professionals involved in the process within and beyond the school in order to plan coherently with the young person to address their curriculum, learning needs and progression from school to adult life.

The Transition Service within NELC aims that all young people have a well managed transition from children's services to adult services. It currently provides services to approximately 140 children and young people in North East Lincolnshire between the age of 13 and 25 who are within the following groups:

- Vulnerable children
- looked after children
- children with complex health needs
- children placed out of county
- children with a statement of special educational need
- children with mental health issues
- children with learning disability
- children with physical disability or sensory impairment.

The Transition Team consists of one full-time coordinator and two transition workers. There are also three jointly funded transition worker posts within the adult learning disability service who gather intelligence on young people who will be moving between the services and become involved with joint assessments of young people who will be transferring with complex needs. The Transition Service also has good partnership arrangements with a range of other services including the adult learning disability service, Connexions, NELC Sports Development, community wardens, occupational therapy, physiotherapy, health & wellbeing coordinators, Shoreline Housing Partnership, the carers' coordinator, and Foresight. If the clients do not qualify for adult services they can receive support from the transition workers until aged 25.

Three partnership groups oversee and direct the work of the transition service and meet on a quarterly basis.

- Transition Steering Group – includes health, education and social care professionals, parents and school representative working at a strategic level.
- Transition Practice Group – includes health, education and social care professionals, parents and school representative working at an operational level.
- Transition Tracking Group – professionals only as the main remit of the group is around specific case discussions.

Further education (FE) can play an important role in transition from childhood to adulthood for young people with disabilities. The main FE providers for young people with disabilities in North East Lincolnshire are Linkage, Franklin College, and Grimsby Institute of Further Education. FE providers need to provide support for people with ASD, complex health and disability needs, and behavioural needs. Education needs to include independence and life skills e.g. managing money, shopping, house work etc.

#### **Transition – Summary of Identified Needs**

- Some young people with SSEN and with mild / moderate needs do not meet the adult Fair Access to Care eligibility criteria and funding arrangements. To address this, a team structure has been proposed to provide continuing support if a client is not picked up by adult services at 18. This involves merging the transition workers and Connexions personal advisors. There is a danger that these young people may fall into crisis.
- The Transition Service need to know from adult services at age 16 if their clients will be eligible for adult services and if so what these will be. Learning disability adult services are good at providing this information, however physical disability adult services do not appear to have the capacity to

provide this information until the client is aged approximately 17.5 years. If clients will not receive services at 18 planning needs to take place with other partners e.g. Youth Service, to establish what support will be available.

- There has been a considerable rise in young people with complex health needs over recent years. Some require long term residential care. It is proposed that all social care teams should have a transition lead.
- There are reported to be increasing numbers of boys aged 13+ with Autistic Spectrum Disorder. There needs to be a more focused service to meet the needs of these young people to prevent issues progressing to crisis.
- Lack of choice offered to the service user regarding their preferred FE provider.
- There is a need to increase the participation levels of youth service initiatives.
- There is a lack of suitable supported housing. There is a proposal for a local hostel to provide transition respite care. This facility would be short stay and based on assessed need.

## 13.4 Carer Services

The term 'carer' refers to someone who provides help or support to a partner, family member, friend or neighbour who is ill, frail, or disabled. When health and social care professionals are making decisions about a person's needs, certain carers are entitled to additional assistance. These carers are defined as those who give 'a substantial and regular amount of time and effort to care for another person and therefore make a significant contribution to the care and support of their relative or friend to enable them to remain at home. The care can be practical, emotional or supervisory. The caring role will have considerable impact on their life and that of their immediate family'<sup>77</sup>.

Research into the impact of caring on carers' health has shown that whilst many find it a rewarding experience, carers are more likely to suffer from ill health such as back injury, high blood pressure, heart problems, inability to recover quickly from routine ailments, depression, stress or nervous tension, headaches, panic attacks, and tiredness. For some people caring involves giving up education, training or employment. Caring can lead to reduced incomes and financial difficulties and also to the loss of leisure and recreational activities.

In law carers have varying rights depending upon the type of caring:

- Adults caring for adults – adults caring for other adults over the age of 18 may be entitled to their own individual assessment of need (a carer assessment). Carers should be routinely made aware of this right.
- Parent carers – people with parental responsibility for children with disability may be entitled to an assessment of their needs and to services to support them under the Children Act 1989. This is completed within an assessment framework where the needs of the child with a disability are also assessed.
- Young carers – young people under the age of 18 may help to support parents, siblings or other relatives who need care and support as a result of disability. Such children are sometimes called 'young carers'. They should not be expected to carry out inappropriate levels of caring which have an adverse affect on their development and life chances. An assessment of family circumstances should include the needs of the young carer being recognised. Locally in North East Lincolnshire a Young Carers Strategy has been developed.

Information from the 2001 census suggests there are 15,334 people with a caring role in North East Lincolnshire. At the time of this review approximately 500 carers were registered with social

services, 2000 carers registered with GPs, and 419 registered with the Carers Support Unit. Therefore many carers are unknown to agencies. Of the 500 carers registered with social services, 93 are for people with learning disability, and 48 with physical disability. It is estimated that there are around 1045 primary young carers in North East Lincolnshire. As at December 2008 there were 155 registered young carers.

The National Carers Strategy<sup>78</sup> was updated in June 2008, and the local Meeting Carers' Needs in North East Lincolnshire, Strategy 2007-2009 has been refreshed, with the new version (Caring Today & Tomorrow – A Strategy for Carers across NE Lincolnshire, 2009-2012)<sup>79</sup> launched in September 2009. Nationally there has been recognition of the importance of short breaks to carers. Locally the range of breaks offered through direct payments has improved, such as enabling day trips and sitting services but is still limited for the carers of people with physical or learning disability.

The Learning Disability Service has two carer support workers, one is funded direct from the Learning Disability Service and the other via the carers' service. These workers send out a quarterly mailing to carers, telephone carers at least every six months, facilitate training sessions, and arrange carer days out.

A pathway has been introduced for carers of people with learning disability which sets out the following provision:

- Carers assessments offered
- Follow up contact home visit or telephone call
- Professional support and advice
  - Carers over 65, four times yearly
  - Carers under 65, twice yearly or more often if required
- Record carer contact

The newly built North East Lincolnshire Carers Centre opened in Victoria Street, South in Grimsby in June 2009. The centre is run by the George Hardwick Foundation in partnership with organisations such as the Citizens Advice Bureau and is open six days a week. It offers a wide range of services to carers including information about health and social care services and benefits and finance advice. It also offers a range of relaxation therapies such as reiki, reflexology, and massage, and opportunities to make friends with others in similar situations. In addition a range of educational opportunities are being developed and will be available shortly. The centre is working closely with the Young Carers' Project within the Council. All of the services are free of charge to carers.

The performance of the service provided to carers is measured in part by NI135 'Carers receiving needs assessment or review and a specific carer's service, or advice and information'. NI135 measures the number of carers whose needs were assessed or reviewed in a year who received a specific carer's service, or advice and information in the same year, as a percentage of people receiving a community based service in the year.

#### **Carers – Summary of Identified Needs**

- There is little respite care for carers of people with physical or learning disability. Feedback from carers suggests that respite is inflexible and can only be accessed when there is capacity in the service; therefore carers are unable to plan their respite to fit their own circumstances.
- There are too many registers which do not give a true picture of the number of carers in North East Lincolnshire. There is a need for one comprehensive register which is maintained with information sharing protocols agreed.
- Work needs to continue regarding awareness raising and promotion to identify hidden carers.

## 13.5 Housing and Community Safety

### Housing

The Housing Project Team is part of the Learning Disability Service, based at the William Molson Centre. The team act as an interface with housing services. At the time of the review a housing database was being developed and this is now operational. Primary aims for developing this database were to provide up to date information of individuals entering the service and to identify those service users with a housing need.

The Council's Strategic Housing Partnership has established a planning group with the specific responsibility of identifying and meeting local need for housing and support. This Partnership Learning Disability Housing Planning sub-group meets quarterly to address the housing needs of people with learning disability. This group consists of independent housing providers, parents/carers, the housing project team, service users, and is chaired by the Chief Executive of Shoreline Housing Partnership.

Supporting People (SP) is a national Department for Communities and Local Government programme which can be accessed by a range of people including those with learning disability, physical disability, sensory impairment or mental health problems. A grant is available within the programme for housing support services which are available to develop the service user's capacity to live independently or sustaining their capacity to do so. It is expected that the SP programme will contribute to the achievement of Local Area Agreement targets – specifically the requirement to increase the number of people with learning disability 'in settled accommodation'.

The Council has recently published its Supported Housing Strategy for 2008 – 2013. This strategy identifies a number of gaps in services for people with learning disabilities. These include:

- Transitions to independent living
- Resettlement
- Challenging behaviour
- Dispersed volunteer support scheme
- Supported tenancies
- People with both learning disability AND physical disability
- Individual budgets.

In order to make good these gaps the strategy proposes that schemes need to be made more flexible so that people with low level needs can access tenancy support and that joint commissioning should be undertaken with the CTP to develop a range of housing related support and care options<sup>80</sup>.

Housing for people with disabilities is provided by a range of providers in the private and voluntary sectors in North East Lincolnshire. For instance Stanage Lodge is a home run by Humberside Independent Care Association for people with learning disability. This facility includes 11 long stay beds, along with a respite contract for 44 people. There are plans to redevelop the building to offer respite care only.

Shoreline Housing Partnership is a non-profit organisation and registered provider of housing. It manages approximately 8,200 homes in North East Lincolnshire, which were formerly run by North East Lincolnshire Council before the transfer of the housing stock during March 2005. Shoreline has developed a Disability Equality Scheme (DES)<sup>81</sup> to demonstrate how obligations will be delivered, and covers both the services that are provided to the community and the support that is given to staff. At the time the DES was introduced approximately 7.4% of tenants and 2.5% of staff had declared themselves as having a disability. All new build housing on the new Yarborough Freshney Green estate will be Disability Discrimination Act compliant. It is recognised that much of the housing stock was built many decades ago and is unsuitable for people with disability.

Havelok Homes is a Registered Social Landlord with approximately 1800 units overall. 12-1300 of these are in North East Lincolnshire and include general housing, sheltered housing for older people, and two older people care homes. Currently Havelok Homes provide approximately 200 units of supported housing which are for adults aged 18+ with mental health, learning disability or physical disability. Havelok are carrying out a full stock review, an outcome of which will be a register of which stock are adapted/ equipped for people with disability.

“Havelok at Home” is a service contracted by the CTP which is designed to enable older people or people with a physical/ sensory disability to live as independently as possible in their own homes. 14 Havelok support workers provide a range of services to help clients maintain independence including cooking, cleaning, shopping, bill paying, advice and advocacy. The emphasis for supporting people with physical disability is on enablement, i.e. doing tasks with the client rather than for them. People wishing to receive the service apply through the CTP who will carry out an assessment of need prior to passing on the Care Plan to Havelok.

There are two teams within the Havelok supported housing section. One team deals with short term housing issues and provides immediate accommodation for up to 16 weeks. Clients include those with mental health issues, mild learning disability, and mild physical disability. The other team offers ongoing support. Support may involve helping clients to keep appointments, taking medication, tackling worklessness issues through signposting to training and education, and accessing support from the wider partnership to address issues.

Many disabled people simply require adaptations to their existing home to enable them to live an independent life. All requests for disabled adaptations are considered by the North East Lincolnshire Council Home Improvement Agency through the Disabled Facilities Grant process. To be eligible for this grant the individual must be registered as disabled and applications will be subject to means testing unless the application for an adaptation is for the benefit of children aged under 19. The adaptations carried out will depend upon what the agency class as necessary and appropriate to meet the individual's specific needs as well as what is reasonable and practical. An assessment of this need will be carried out by an Occupational Therapist. Some of the adaptations the agency may consider include:

- Making it easier to get in and out of the home by widening doors, providing steps or installing a ramp
- Providing or improving access to the bedroom, kitchen, toilet, washbasin and bath and/ or shower facilities by installing a stair lift
- Providing a downstairs bedroom or bath/ shower room
- Improving or providing a heating system which is suitable to the needs of the individual
- Adapting heating or lighting controls to make them easier to use.

Occupational Therapy and Physiotherapy teams will assess clients and produce an accommodation specification which gives a minimum specification of the requirements to meet the client's needs. These specifications are passed to the housing providers.

### Community Safety

Disabled people are at greater risk of experiencing violence or hostility than the wider population. This includes violence or hostility which might be perceived as a 'hate crime'. North East Lincolnshire has some high crime hot spots and a number of partnership crime reduction initiatives have been put in place across the area. Whilst many of these are not specifically for people with disability, many of the initiatives are prioritised on the vulnerability of the client, therefore people with disability would be classed as a priority for services.

The True Vision hate crime reporting scheme was introduced in North East Lincolnshire in 2006 and provides a confidential system of reporting for minority communities. Reporting can be done at reporting centres which include NELC customer access points, and several voluntary organisations, or via self-reporting forms. True Vision allows Humberside Police and partner agencies to get a 'true vision' of hate incidents within the area, providing better intelligence of the



incidence of hate crimes and where the hot spots are. This should assist in the tackling of these crimes. Disability hate incidents include any incident which is perceived by the victim or any other person, to be motivated by the victim's disability. Hate incidents manifest themselves in a variety of ways including criminal damage, vandalism, assault, verbal abuse, harassment, intimidation and name calling.

A range of initiatives operate to try and increase community safety and reduce the fear of crime, especially in vulnerable groups. 'Target Hardening' is a free service operating in North East Lincolnshire to reduce the fear of crime, and increase household security. This involves the householder making an appointment with the team to visit their home to offer crime reduction advice. Free security measures, e.g. door chains and window locks, may be fitted if required. Priority for these checks is given to people who are vulnerable. NELC Neighbourhood Wardens provide a visible community presence and carry out a wide range of community safety duties across the area. One of these initiatives involves visiting vulnerable people in the community and individuals are able to sign up to this scheme. The aim of the scheme is to build up a friendship with the service user increasing their confidence and providing reassurance. Trading Standards work to reduce doorstep crime such as rogue traders and distraction burglaries. A priority for this scheme is to support vulnerable or housebound people.

Carelink provide a telephone based system linking the service user to a 24 hour control centre and is available to anyone who feels vulnerable through illness, disability, isolation, violence or abuse. Carelink can be called in an emergency and the operators will comfort, reassure, and arrange emergency help. The service provides the service user with independence and security, whilst providing family and friends with peace of mind.

Humberside Fire & Rescue Service offers a free home fire safety check. This involves the householder making an appointment with the team to visit their home to offer advice on how to make their home safer from the risk of fire. Free smoke detectors may be fitted if required. Priority for these checks is given to people who are vulnerable such as people with disabilities.

#### **Housing and Community Safety– Summary of Identified Needs**

- Many people with very profound learning disability needs currently live out of the area as there are no local facilities. Approximately £2.5m per year is required to fund around 20 people with learning disability for out of county services. If a local solution were provided for less cost this may allow for the remodelling of service budgets.
- There is a lack of suitable respite/ short break provision in North East Lincolnshire. Current provision is limited to residential care. There is a general lack of suitable housing stock for people with disability.
- The demand for supported housing for people with physical disability is higher than the supply. Due to adults with physical disability being younger than older people the turnover of housing is lower. There is a lack of appropriate available stock in the areas where people want to live.

## 13.6 Transport

Accessible transport is vital for people to participate and be included in their community and to enable them to access services. Problems accessing suitable transport for disabled people can cause or exacerbate health inequalities. Many disabled people use either their own private transport or public transport and the difficulties faced by people with disabilities are highlighted in Section 11. Others would be able to use public transport with support or if the public transport system was of a higher quality. However the absence of an accessible and fully integrated transport system means that many disabled people require additional specialised transport or taxis to enable them to get around.

A range of services are available in North East Lincolnshire to enable people with disability to travel around the area more easily.

'Dial A Ride'<sup>82</sup> provides accessible transport on a non-profit basis for people who find it difficult to use public transport due to illness or disability. Seven buses are available for this service, all of which have been modified to carry wheelchairs. Customers phone the office preferably a few days before they want to travel to book their ride. Drivers are all volunteers and will have taken part in training and have had their driving assessed. The scheme is open to anyone who cannot use public transport due to an illness or has a physical/ sensory impairment, for example anyone who would be eligible for a "blue badge" or receiving a Community Care package of care from Social Services. There is a £5 registration fee, which is paid annually in addition to the cost of the individual fares.

'Phone 'n' Ride'<sup>83</sup> is North East Lincolnshire Council's demand responsive bus service which operates between 7am and 7pm Monday to Saturday. The service is operated by TransLinc Ltd using three buses locally which have been converted to carry normal sized wheelchairs but cannot carry scooters. Unlike traditional bus services 'Phone 'n' Ride' has no fixed route or timetable, the customers tell the service where they want to go. To register with the service people can either complete an online registration form or alternatively contact the 'Phone 'n' Ride' team. Registration is free and the service can only be used by people who are registered, although unregistered friends may accompany them. The only eligibility criteria is that passengers must be able to board and alight from the bus with minimum assistance. Whilst it is aimed to keep journey times to a minimum, the exact route of the vehicle is wholly determined by the bookings made that day and therefore customers may not necessarily go straight to their destination. All journeys on 'Phone 'n' Ride' are based on a single fare, and these are based on geographic zones. The service can be more expensive than public transport.

The CTP, together with North Lincolnshire PCT and Northern Lincolnshire and Goole NHS Foundation Trust, are currently carrying out a review of transport provision across Northern Lincolnshire, looking at the Patient Transport Service, Social Care Transport, and The Amvale Pilot (primary care provision which aims to reduce A&E admissions). A number of focus groups have been held and a workshop for all stakeholders was held during April 2009. The review is anticipated to identify that more work is required in terms of social care transport and associated transport areas. The Patient Transfer Service contract expires in March 2010.

### **Transport– Summary of Identified Needs**

- Private transport is an issue as there is a lack of suitable transport locally. Private taxis can be expensive and there is a shortage of suitable vehicles e.g. for wheelchairs.
- Few clients appear to use the public bus services. There may also be issues with other bus users around acceptance. Not all buses have low access flooring.
- Accessing transport in the evening is particularly difficult. There is a need for more flexible transport.
- The demand responsive bus services need to be booked well in advance, therefore service users are unable to make last minute decisions, e.g. depending on the weather.
- The demand responsive bus services are membership only – due to capacity these services may not always be taking on new members.
- Throughout the review, transport for people with disability has consistently been raised as a key issue that needs to be addressed. Many professionals report poor feedback from service users. It is felt that poor transport is hampering modernisation, and inflexible transport options do not deliver person centred planning. More individual transport provision raises issues of economies of scale and the resultant need for more adapted vehicles along with drivers and escorts.

## **13.7 Employment**

The Supported Employment Team based at St Aidan's Church and Community Centre aim to help support service users into employment. Although managed by the Learning Disability Service its brief has widened to include people with physical disability, older people, and carers. The team are actively working with the HR departments of NELC and the CTP to enhance the numbers of people with learning disability supported into employment. A new post of Supported Employment Manager has been created with the responsibility for developing a range of initiatives to progress this agenda. The work of the Supported Employment Team contributes to the delivery of NI 146 (adults with learning disabilities in employment) which is an indicator chosen by the LSP as a priority for North East Lincolnshire as part of LAA2.

The team facilitate a number of voluntary and paid work opportunities. For instance the 'Jobs 4 All' recycling programme is a social enterprise supported by a range of organisations including the CTP. Other social enterprises include the 'Hair Clips' hairdressing salon based at Queen Street Resource Centre, and 'Sparkly Marques' which gives young people the opportunity to gain paid work experience in car valeting. St Hugh's Community Centre has opened a social enterprise café staffed by people with mild and moderate learning disability, which will offer training to people with learning disability within the catering environment, to enable them to find work which is suitable for them. The café will provide an opportunity for the public to see people with disability playing an active part in the success of a catering project within the community. Another café has recently been opened at the new Freshney Green Primary Care Centre.

Tukes (Training, Understanding, Knowledge, Employment, Skills) was established in 2003 and is based on Brighowgate, Grimsby. It is a service that enables people with mental health problems to gain new skills, increase their confidence, self-esteem, motivation, and quality of life. Tukes is an open service and whilst service users need to have some mental health issues the service works with many people who also have learning disability. Tukes provide training and employment opportunities to people who have little or no previous training, qualifications, or work experience, thus addressing exclusion issues within the workplace. Tukes provides a public café, a conference facility, outside catering, horticulture/ grounds maintenance (joint scheme with the Learning Disability Service) and cleaning/ laundry services. Tukes aim is to give service users meaningful

activities and is driven by a social inclusion agenda to ensure there is contact with the wider community, which in turn raises the profile of mental health locally. As a result of these projects, Tukes has been able to skill people in catering, cleaning, administration, and customer service.

Workstep is a Job Centre Plus programme which provides support to people with disability facing barriers to getting and keeping a job. Currently there are people on the Workstep programme who work in both the public and the private sector. Workstep enables people with disability to train and develop their skills, gain qualifications, and progress where possible into open employment.

Benefits to service users include:

- Enriched quality of life
- Increased choice and the chance to contribute
- Confidence and self esteem
- Finance
- Social and Community inclusion
- Development of knowledge and skills
- Independence and improved well-being.

#### **Employment– Summary of Identified Needs**

- Whilst there are a significant number of employment initiatives available for people with learning disability or mental health problems, there are far fewer which are available to people with physical disability.

## **13.8 Voluntary, Community Sector and Advocacy Services**

### *Voluntary and Community Sector*

Voluntary Action North East Lincolnshire (VANEL) is the umbrella group for all voluntary organisations in the area. VANEL has a coordinating role, ensuring that the voluntary sector has a voice in local planning and policy development and it publishes a directory of voluntary organisations in the area. There are many organisations working to improve the quality of life of people with disability some of which are detailed below.

North East Lincolnshire Disability Access (NELDA) acts as a local forum for people with disability. NELDA formed from the amalgamation of the North East Lincolnshire Disability Coalition and the North East Lincolnshire Access Group, and can be used a first point of reference for anyone with disability issues.

Foresight<sup>84</sup> (North East Lincolnshire) Limited operates throughout the area to meet the needs and requirements of disabled people, their families and carers. Their Grimsby site offers a wide range of activity and support for people with disability including social activities, courses, and befriending. They also run a Tenants Advisory Group which represents people who live in supported housing. A summer scheme is run for young people, and a 'Youth Hub' based at Foresight's premises which will be overseen by a youth worker has been proposed. The organisation is also active in influencing policy through partnership and networking and is represented on various steering groups and committees including local government, CTP and the voluntary sector forum.

Artlandish is a community arts group and is frequently commissioned to work with specific groups on art and craft projects. Art and craft is used as a medium to build self esteem and confidence and a number of projects have involved people with learning disability. Artlandish has links with local artists who can be called upon to lead particular projects.

Community Chest is a social enterprise and furniture recycling charity which aims to relieve the effects of financial hardship; increase reuse and recycling and create training and work experience

opportunities. The volunteering and training placements offer an opportunity for individuals to improve their confidence and enhance their skills<sup>85</sup>.

Rock Foundation<sup>86</sup> is a new charity organisation committed to provide daily, purposeful, constructive activities, vocational training and employment, for adults and young people with learning difficulties or other disadvantages. This will be achieved by establishing sheltered workshops that produce goods made from natural materials for sale in the community, undertaking community projects that will enhance the lives of the participants and the community, and providing training in basic skills and opportunities for work experience that may lead to paid employment. The Rock Foundation's base in Grimsby includes the Rock Café which is open to the public and staffed partly by people with learning disability.

'Adults Supporting Adults' (ASA) is a not for profit charity which operates an adult placement scheme. ASA works with clients from all disability groups including learning disability, mental health, dementia, and older people, offering extended stay and respite placements in the community with provider families. ASA also provides support with daytime activities to promote independence and social inclusion.

Disability Active is a social enterprise based in Cleethorpes and established to provide sporting activities to children and adults with disability.

North East Lincolnshire Disabled Access Partners is based at Freeman Street Resource Centre, and works to enable people with disability to campaign for equal opportunities and raise awareness of issues facing disabled people.

Voluntary groups working for children with disability include 'Face2Face' (Parents supporting Parents of Disabled Children), and 'PU.FIN' (Parents United, For Individual Needs).

Linkage Community Trust (Linkage) is a registered charity which provides education, care and employment services, to enable people with learning disabilities ranging from moderate to severe and other disabilities to realise their full potential. Linkage College provides residential further education and day courses for over two hundred students, and offers a range of vocational and work experience opportunities and programmes aimed at developing social and independent living skills. The college comprises of two campuses in Lincolnshire; Weelsby Campus in Grimsby and Toynton Campus near Spilsby, and accommodation is available. Linkage students and other service users include people with varying degrees of learning difficulty, from moderate to severe. Linkage College has been assessed as an Ofsted Grade One 'Outstanding College'<sup>87</sup>.

### Advocacy

Advocacy is important to enable service users to contribute to the shape of current services and provide a steer regarding future direction. Advocacy services are however somewhat limited in North East Lincolnshire and mainly provided within the voluntary sector. Some of the advocacy based services currently available include:

- Rethink provides predominantly mental health advocacy but will also help other groups including people with learning or physical disability.
- Day Opportunities Advocacy Group represents those participating in day opportunities.
- Headway advise and offer support to people (and their carers) with acquired brain injury.
- The North East Lincolnshire Mental Health Service User & Carer Independent Forum help to plan, develop, and monitor local mental health services.
- North East Lincolnshire Carers' Forum is a voluntary group that maintains an overview of carers' issues and services.
- The Citizens Advice Bureau offers free independent and confidential, advice and advocacy.

### **Voluntary, Community Sector and Advocacy – Summary of Identified Needs**

- More use of the Linkage facility may meet the needs identified by a number of services around the care of young people with ASD including Autism and Aspergers Syndrome, and also provide an additional choice to service users regarding FE provision.
- Advocacy services are patchy and individual groups may not have much contact with each other.
- There appear to be only small pockets of advocacy for people with physical disability, which is unlikely to be truly representative of this group.

## **13.9 Leisure and Recreation**

### Sports Development

The 'Active Lincs – Sport and Physical Activity Strategy 2008-2012'<sup>88</sup>, includes eight strategic actions specifically for people with disability:

- Increase participation levels amongst people with a disability through activities delivered by Foresight
- Increase participation levels through activities delivered by the Community Sports Coach
- Increase participation amongst 5-16 year olds with a disability in mainstream and special schools
- Increase participation in exercise amongst people with a disability through 'Inclusive Fitness Initiative' facilities at Grimsby Institute
- Increase the number of people with a disability attending activities at Council owned leisure facilities
- Increase participation levels through activities delivered by the Programme Co-ordinator for Sport and Physical Activity
- Increase participation in physical activity amongst people with learning disabilities through activities delivered by the physiotherapy team learning disability service
- Increase participation in sport and exercise activities through day opportunities for people with learning disabilities.

North East Lincolnshire Council's Sports Development Unit works in partnership with Local and National Organisations in order to improve the quality and quantity of sporting opportunities across the area. The Sports Development Unit aims to increase opportunities to participate in sport and physical activity by enhancing the skills of sports coaches, teachers and volunteers who deliver, coach, or instruct, sports and physical activity. Sports Development is configured to meet the needs of people with disability in a number of ways including:

- Providing regular sporting activities within the community
- Providing events for both children and adults including holiday activities
- Increasing social skills
- Increasing ability and awareness
- Providing safe and convenient facilities for activities to take place in.

Sports Development has two dedicated sports coaches for disability who are responsible for increasing participation in disability sports across North East Lincolnshire. The coaches are funded by Sports England and work in partnership with partner organisations such as the Learning Disability Physiotherapy Team, Linkage and Foresight, to develop and promote physical activity. Many activities are provided including ball games, swimming and sledge hockey, and there are plans to introduce wheelchair football in partnership with Grimsby Town Football Club. Sports Development also run 'Taster Days' in partnership with the Transition team, to enable disabled people to try a range of different sporting activities to find one that works for them. A scheme has

been introduced with the School Sports Partnership offering disability awareness training to all schools in North East Lincolnshire.

The Disability Sports Forum is a sport and social group for anyone with disability. The group meet on a regular basis to participate in sport.

### Public Libraries and Museums

Public Libraries operate to provide access to books, knowledge and information and provide a resource for lifelong learning and study. Libraries in North East Lincolnshire aim to enable people with disability to realise their full potential by:

- Providing access to talking books and large print titles for those who have visual impairments
- Providing a collection of audio-described and closed captioned videos for loan
- Providing magnifying sheets for people with visual impairments
- Providing a Home Library Service to people who are either housebound or have restricted mobility
- Subscribing to on-line information resources to enable people who have difficulties getting to a library to access reference information from home via the internet, e.g. Britannica Online and Oxford English Dictionary
- Making Reading Groups accessible to people with visual impairment. An example is a group that uses only talking books - the Listening Book Group held at Foresight
- Providing information about services in a variety of formats accessible to disabled people. All information leaflets are written in plain English and set out in a large font where possible
- Removing physical barriers which may prevent disabled people from gaining access to services. Building improvements have been built into Service Plans to enable the buildings to achieve compliance with the Disability Discrimination Act
- Installing hearing loops at all library counters and in all meeting rooms
- Ensuring high quality staff training on disability awareness
- Working with disability organisations to encourage group visits to the library for both leisure and informal learning
- Providing assistive technology in computer suites – large keyboards for people with visual impairments, track ball mice for people with hand/ arm mobility issues, high level desks or adjustable desks for people using wheelchairs.

The Fishing Heritage Centre is the Authority's accredited museum. The museum encourages disability access and around 17% of visitors have a disability or long term limiting illness. A number of measures are in place to ensure the museum is accessible to people with disability:

- There is an audio guide to address reading difficulties for the visually impaired
- A concessionary rate is available to people with disability, and there is free entry to carers to help address the challenges some visitors with disability may face
- Hearing induction loops are installed in areas of the museum
- A wheelchair is available free of charge to users with mobility problems.

#### **Leisure and Recreation – Summary of Identified Needs**

- There is no core funding for providing sporting activities. Sport England funding has been secured for one more year. Currently activities can be provided for free due to external funding. Charging for activities may be the consequence if funding cannot be secured.
- Transport is an issue as many members of the public find it difficult to access activities and events due to transport difficulties, especially if the activities take place in the evening.
- Work is ongoing with partners to identify the needs and possible installations required at the leisure facilities to meet the needs of people with disability. Specific requirements include suitable changing areas, specialist equipment (e.g. sprint chairs, basketball chairs), and more specialist coaches.

- The Central Library poses problems in terms of access to the upper floors. This is not easy for those with disability, however low level controls and Braille buttons are in place in the lift.
- The local and family history reference stock is often not easily accessible because of its historic nature – e.g. many of the old directories are printed in small typefaces. However, the library does have magnifying sheets available to help people with visual impairments, and a programme of digitising photo images is ongoing with a view to improving access to this collection via the website.



## Appendix 1

February 2009

Dear Sir/Madam

I write to ask for your help.

The Care Trust Plus in North East Lincolnshire is carrying out a survey about the health and social needs of adults with physical or learning disabilities living in this area.

The results of the survey will help to improve health and social services for the population of North East Lincolnshire who have a physical or learning disability.

You have been identified through local physical or learning disability registers as having a physical or learning disability and we would like to invite you to take part in this survey. I would be very grateful for your help by filling in the enclosed questionnaire. It shouldn't take many minutes of your time. If you cannot complete it yourself, please get a relative, friend or carer to fill it in for you. *Whoever completes it, it is very important that the information you send back is about **you** and not your husband or wife, relative or friend.*

**The answers you provide will be treated as strictly confidential. No information identifying individuals will be given to any person or organisation.**

If you have any queries or concerns about the survey please ring the helpline number below.

Please return the completed form in the enclosed reply paid envelope.

By completing and returning the questionnaire you will play a valuable part in making sure the services we provide meet the needs of people with disability in North East Lincolnshire.

Thank you very much for your help.

Yours faithfully

**Dr Tony Hill MB ChB MPH FFPHM**  
**Director of Public Health**

## Appendix 2

February 2009

Dear Sir/Madam

You may recall I wrote to you recently to ask for your help with a survey about the health and social needs of people with disabilities living in your area.

The survey is being carried out by the Care Trust Plus in North East Lincolnshire. The results will provide information to help improve local health and social services for people with physical or learning disabilities.

As we have not heard from you, I wonder if our first letter has gone astray. Another copy of the questionnaire is enclosed which I hope you will be able to fill in and return in the next few days in the pre-paid envelope. It won't take many minutes of your time to complete.

To better inform services for people with physical and learning disabilities, it is important that we get as many completed forms back as possible. If you cannot complete it yourself, could you please get a relative, friend or carer to fill it in for you? *Whoever completes it, it is very important that the information you send back is about **you** and not your husband or wife, relative or friend.*

**The answers you provide will be treated as strictly confidential. No information identifying individuals will be given to any person or organisation.**

If you have any queries or concerns about the survey please ring the helpline number below.

By completing and returning the questionnaire you will play a valuable part in making sure the services we provide meet the needs of our residents with physical or learning disabilities.

If your reply is already in the post, thank you very much for your help, and I apologise for writing to you again.

Yours faithfully

**Dr Tony Hill MB ChB MPH FFPHM**  
**Director of Public Health**

**PLANNING TO IMPROVE THE HEALTH AND WELLBEING OF PEOPLE WITH  
DISABILITIES IN NORTH EAST LINCOLNSHIRE**

**Confidential Questionnaire**

*Please complete as many questions as you can by ticking ✓ the boxes or writing in the spaces provided.*

**Can you please tell us about yourself and where you live:**

**Do you have a disability?**

I have a physical disability

I have a learning disability

I have both a physical and a learning disability

I do **NOT** have a physical or learning disability\*

✓

**\* If you do not have a disability, you do not need to complete this questionnaire.**

1 **Age:**  years

**Are you a:** Man  Woman

2 **Who do you live with?** (please tick ✓ as many as you need to)

On my own

With my husband, wife or partner

With my parents

With my child/children

With friends or others

- 3 What do you live in?** ✓
- |                   |                          |               |                          |
|-------------------|--------------------------|---------------|--------------------------|
| Bungalow          | <input type="checkbox"/> | Upstairs flat | <input type="checkbox"/> |
| House             | <input type="checkbox"/> | Care home     | <input type="checkbox"/> |
| Ground floor flat | <input type="checkbox"/> | Other         | <input type="checkbox"/> |

**3a What is your postcode?**

- 3b Do you own where you live?** ✓
- |  |                          |                             |                          |
|--|--------------------------|-----------------------------|--------------------------|
| Yes I've/we've bought it                   | <input type="checkbox"/> | I/we pay rent to a landlord | <input type="checkbox"/> |
| My family own it                           | <input type="checkbox"/> | I don't know                | <input type="checkbox"/> |
| I/we pay rent to the Shoreline or Havelock |                          |                             | <input type="checkbox"/> |

**4 Is where you live suitable for your needs?** Yes  No

*If no, please tell us why.....*

.....

**5 Do you have *central heating* in your home?**  
*(central heating means 2 or more rooms/landings/hallways heated from a central source)*

Yes  No

**5a If yes, do you have it on when it's cold?** Yes  No

**6 Can you afford to have your heating on to keep warm?** Yes  No

**7 Do you have an emergency alarm system in your home** (either push button, pull cord or neck pendant)?

Yes  No, but I'd like one  No, I don't need one

**8 Has any part of your home been changed to make it easier for you to manage with your disability?**

Yes  No, but I'd like changes  No, I don't need changes

**9 Do you have any of this equipment to help you with your day to day life?**

*(Please tick ✓ all that you have)*

Walking stick or walking frame	<input type="checkbox"/>	Ramp	<input type="checkbox"/>
Alterations for better access (e.g. wider door frames)	<input type="checkbox"/>	Wheelchair	<input type="checkbox"/>
Disabled/allocated parking space	<input type="checkbox"/>	Grab rail (s)	<input type="checkbox"/>
All rooms you need on one level/no steps /step free access	<input type="checkbox"/>	Hoist	<input type="checkbox"/>
Relocated bathroom or toilet	<input type="checkbox"/>	Stair lift	<input type="checkbox"/>
Aids to help you use a computer	<input type="checkbox"/>	Assistance dog	<input type="checkbox"/>
Other: <i>(please tell us)</i> .....			

**9a If you have a hearing problem do you have:** *(Please tick ✓ all that you have)*

I <b>don't</b> have a hearing problem	<input type="checkbox"/>	Hearing dog	<input type="checkbox"/>
Adaptations to fire alarm	<input type="checkbox"/>	Typetalk/text phone	<input type="checkbox"/>
Adaptation to doorbell or telephone (e.g. hearing loop systems)			<input type="checkbox"/>
Other: <i>(please tell us)</i> .....			

**9b If you have a visual problem do you have:** *(Please tick ✓ all that you have)*

I <b>don't</b> have a visual problem	<input type="checkbox"/>	Guide dog	<input type="checkbox"/>
White stick	<input type="checkbox"/>	Magnifier	<input type="checkbox"/>
Screen reader	<input type="checkbox"/>	Braille reader for computer	<input type="checkbox"/>
Other: <i>(please tell us)</i> .....			

**9c Other equipment** *(Please tick ✓ all that you have)*

Electrical modifications (e.g. moved light switches, plugs)	<input type="checkbox"/>	Entry telephone	<input type="checkbox"/>
Additional heating	<input type="checkbox"/>	Individual alarm system	<input type="checkbox"/>
Bathing equipment	<input type="checkbox"/>	Kitchen equipment	<input type="checkbox"/>
Other: <i>(please tell us)</i> .....			

**10 In the last 3 months, have you *needed any help* with any of the following?**

**For each one please tick ✓ the box which best applies to you.**

	Can do it myself	Relative /friends help	Paid carers help	I need help but don't get it
Personal care (dressing/ washing/toilet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting in or out of bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting out and about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preparing meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General house cleaning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing the laundry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with other money matters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gardening or household repairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please tell us).....				

**11 Do you have any problems doing your food or other shopping?**

**Yes**  **No**

*If Yes, please tell us what* .....

**12 Do you have any problems with preparing and cooking your food?**

**Yes**  **No**

*If Yes, please tell us what* .....

**Your health and lifestyle**

**13 Would you say your health is:** ✓  
 Excellent  Very good  Good  Fair  Poor

**14 What is your main disability?**.....

Yes  No

15 Do you have any other illness or disabilities?    
(If Yes, please give brief details).....  
.....  
.....

16 Which of these health services have you used in the past 3 months?

(Please tick ✓ all that apply)

GP/Doctor	<input type="checkbox"/>	Practice nurse	<input type="checkbox"/>
Outpatients/day patient appointment	<input type="checkbox"/>	Been admitted to hospital	<input type="checkbox"/>
Visit to A&E/Casualty	<input type="checkbox"/>	Community/district nurse	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	Occupational therapy	<input type="checkbox"/>
Optician	<input type="checkbox"/>	Chiropody	<input type="checkbox"/>
Psychiatrist/psychologist	<input type="checkbox"/>	Counsellor/therapist	<input type="checkbox"/>
Self help group	<input type="checkbox"/>	None of these	<input type="checkbox"/>
Other (please tell us).....			

17 Do you get all the health services that you think you need?

Yes  No

If no, please tell us what you need that you need that you don't get.....  
.....

18 How do you take your medication?

I don't take any	<input type="checkbox"/>	Someone helps me	<input checked="" type="checkbox"/>
I take it on my own	<input type="checkbox"/>	I need help but don't get it	<input type="checkbox"/>

19 Has a doctor or nurse reviewed the medicines you are taking?

Within the last 6 months	<input type="checkbox"/>	6-12 months ago	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	I don't take any	<input type="checkbox"/>

**20 Do any of the following make it hard for you when you use local health services? (Tick ✓ all that apply)**

- |  |                          |                             |                          |
|--|--------------------------|-----------------------------|--------------------------|
| Cost/lack of money                                       | <input type="checkbox"/> | I don't have enough time    | <input type="checkbox"/> |
| Problems getting into the building                       | <input type="checkbox"/> | Unsuitable toilets          | <input type="checkbox"/> |
| Can't get an appointment when I want                     | <input type="checkbox"/> | How staff speak to me       | <input type="checkbox"/> |
| I need someone to accompany me                           | <input type="checkbox"/> | Bad past experience         | <input type="checkbox"/> |
| I can't always see the same person                       | <input type="checkbox"/> | I don't feel safe going out | <input type="checkbox"/> |
| I don't know what there is locally                       | <input type="checkbox"/> | I can't find an NHS doctor  | <input type="checkbox"/> |
| I can't find an NHS dentist                              | <input type="checkbox"/> | None of these               | <input type="checkbox"/> |
| Transport problems ( <i>please tell us about these</i> ) | <input type="checkbox"/> | .....                       | <input type="checkbox"/> |
| .....  |                          |                             |                          |
| Other ( <i>please tell us</i> ).....                     |                          |                             |                          |

**21 Does anything stop you leading a healthier lifestyle?**      **Yes**      **No**  
        
*If Yes, please tell us*.....  
.....

**22 Do you feel low or depressed?**      ✓  
Always       Often       Sometimes       Rarely       Never

**23 Do you feel anxious or worried?**      ✓  
Always       Often       Sometimes       Rarely       Never

**These questions look at how you are treated by health and social care services**

**24 Are you treated with dignity and respect by health services?**  
Yes       No       Don't know



25 Are you treated with dignity and respect by social services?  
Yes  No  Don't know  I don't use them

**These questions ask about your work**

26 Are you currently in paid work?   
Yes - part-time  Yes - full-time  No

27 Has your disability affected your ability to do paid work?  
No it hasn't   
Yes, I'm unable to work   
Yes, it has limited the kind of paid work I can do   
Yes, it has limited how long I can work for   
Don't know

28 Have you found it difficult to get a job because of your disability?  
Yes  No  Don't know   
*If yes, please tell us why.....*

29 Do you need help to find suitable paid work? Yes  No   
*If yes, please tell us what sort of help you would like:.....*

	<b>Yes</b>	<input checked="" type="checkbox"/>	<b>No</b>
30 Do you do voluntary work?	<input type="checkbox"/>	(Please go to 31)	<input type="checkbox"/>
If NO, would you like to do voluntary work?	<input type="checkbox"/>		<input type="checkbox"/>
Do you need help to find voluntary work?	<input type="checkbox"/>		<input type="checkbox"/>

31 Are you currently in education or training?   
Yes, full time education  Yes, part time education  No

32 Do you need help to find suitable education/training opportunities?  
Yes  No

**33 Have you received any advice about benefits which you may be entitled to? Yes  No**   
*(If yes, please tick ✓ which ones)*

Income support	<input type="checkbox"/>	Attendance allowance	<input type="checkbox"/>
Tax credits	<input type="checkbox"/>	Child benefit	<input type="checkbox"/>
Disability Living Allowance	<input type="checkbox"/>	Incapacity benefit	<input type="checkbox"/>
Council tax benefits	<input type="checkbox"/>	Help with health costs	<input type="checkbox"/>
Housing benefit	<input type="checkbox"/>	Home insulation grants	<input type="checkbox"/>
Help with education/training costs	<input type="checkbox"/>	Other (please tell us).....	

*If yes, where have you received the advice from?.....*

**34 Do you need any more advice/help about benefits? Yes  No**   
*If yes, please tell us what sort of advice you would like.....*

**35 Do you receive direct payments? Yes  No  Don't know**

**36 Are you happy with the care package you have in place? Yes  No**   
*If no, please tell us why.....*

**37 Would you spend the money in another way if you could? Yes  No**   
*If yes, please tell us what you would like to spend it on.....*  
 .....  
 .....

**These questions ask about how you want to receive information**

**38 Do you use the internet (world wide web)?** Yes  No  No, I don't know what it is   
*(please go to 40) (please go to 39) (please go to 39)*

**39 What, if anything would help you to learn about or use the internet (world wide web) in the future** *(Please tick ✓ all that apply to you)*

Nothing/ I do not want to use it  Cheaper computers/internet access   
 Knowing more about it/what I can use it for  Training on how to use a computer   
 Other *(please tell us)*.....

**40 Do you have digital TV at home (a satellite dish, cable or a set-top box such as Freeview)?** ✓

Yes  (please go to 41) No  (please go to 42) No, I don't know what digital TV is  (please go to 42)

**41 Do you use the red button on your digital TV to get information?**

Yes  No

**42 Do you have:** a telephone at home or close by? Yes  No   
 your own mobile phone? Yes  No

**43 Please tell us how you would like to receive the information listed in the box below by ticking ✓ the relevant box**

Information about:	I don't want any	Leaflet/magazine	Home phone call	Mobile phone text/call	Digital TV	Internet website/electronic mail	Other <i>(please tell us)</i>
How to stay healthy							
Health care services							
Social care services							
Benefits							
Leisure/social activities							
Learning opportunities							

**These questions ask about your social contacts**

**44 Which of the following people do you speak to at least once a fortnight? This can be either in person or on the phone (Please tick ✓ as many boxes as apply to you)**

- |                           |                          |  |                          |
|---------------------------|--------------------------|--|--------------------------|
| Your husband/wife/partner | <input type="checkbox"/> | Friend   | <input type="checkbox"/> |
| Your parent(s)            | <input type="checkbox"/> | Current or former work colleagues                  | <input type="checkbox"/> |
| Your parent(s)-in-law     | <input type="checkbox"/> | Fellow volunteers (e.g.charity/<br>community work) | <input type="checkbox"/> |
| Your children             | <input type="checkbox"/> | Members of your church (other<br>religious group)  | <input type="checkbox"/> |
| Other family members      | <input type="checkbox"/> | Members of other groups                            | <input type="checkbox"/> |
| Neighbour                 | <input type="checkbox"/> | Your care worker or privately paid help            | <input type="checkbox"/> |

**45 Do you feel lonely?** ✓  
 Never  Almost never  Sometimes  Most of the time  All the time

**46 Do you feel you are part of you local neighbourhood/community?**  
 Yes  No

**47 Is there anything which stops you being more socially active?** Yes  No   
 (If Yes, please tell us what).....  
 .....

**48 Do you have someone you can talk to and confide in about things that are important to you?** Yes  No

**49 How often do you go out each week (e.g. visiting friends, going shopping)?** ✓  
 Every day  At least once a week   
 Most days  Rarely or never   
 A few days a week

**50 Do you go to any daytime activities?** Yes  No   
*(For example: lunch clubs, church groups, day centres, drop-in centres, hobby groups)*

**51 If you had a magic wand, what would you like to see for people with disabilities?**.....  
 .....  
 .....

**These questions ask about your transport needs**

**52 How do you mostly get about locally?** ✓  
 Car  Bus  Bicycle  Train   
 Motorbike  Walk  Taxi   
 Other *(please specify)*.....

**53 Do you have problems getting where you want to go?**  
 Yes  No   
*If Yes, what problems do you have*.....  
 .....

**54 What would make it easier for you to get about?** *(Please tick ✓ as many as you think)*

Improved disabled access to buses/trains	<input type="checkbox"/>	More buses/trains	<input type="checkbox"/>
Free/cheaper transport for disabled people	<input type="checkbox"/>	Improve/repair roads/pavements	<input type="checkbox"/>
Lower floor transport to meet pavement	<input type="checkbox"/>	Improved public transport in general	<input type="checkbox"/>
Staff/drivers to be more helpful/understanding	<input type="checkbox"/>	Less traffic jams	<input type="checkbox"/>
Wheelchair access on buses and trains	<input type="checkbox"/>	More car parking spaces	<input type="checkbox"/>
Improved public transport in general	<input type="checkbox"/>	Nothing	<input type="checkbox"/>
Don't know	<input type="checkbox"/>		

Other *(please tell us what)*.....  
 .....

**55 How easy/difficult is it for you to get to each of the following places?**  
 (Please tick ✓ *N/A* for any that you **do not use/visit**)

	<b>Don't use</b>	<b>Easy</b>	<b>Difficult</b>	<b>Can't get there at all</b> <i>(please tell us why)</i>
Bank/cash point	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Post Office	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
General Practitioner (GP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Chiropodist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Optician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Local shops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Shopping centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Supermarket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Visit friends/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> .....
Other <i>(please state)</i> .....				

**56 Who filled in this questionnaire?**

I did	<input type="checkbox"/>	A care worker did it for me	<input type="checkbox"/>
A relative did it for me	<input type="checkbox"/>	A friend did it for me	<input type="checkbox"/>
Other <i>(please specify)</i> .....			<input checked="" type="checkbox"/>

***Please use the space below for anything you would like to tell us about your health and social needs.***

*Please use more paper if you need to*

**Thank you very much for your help. What you have told us will help us plan future services. Please check that you have answered all the questions you can and send the questionnaire back to us in the envelope provided.**

**THERE IS NO NEED FOR A STAMP**

# Do you have a physical or learning disability?

## We need your help.

We are gathering up-to-date information about the health and social needs of adults with physical or learning disabilities between the age of 16 and 64 in North East Lincolnshire. Therefore, we would like your views about your needs.

*Do you have adequate aids and equipment to help you with day to day tasks?*

*Is there adequate and accessible public transport to get you to where you want to go?*

During the next few weeks, we will be sending some of you a questionnaire. By filling this in, you will be helping us to make sure that we have the right services in place.

If you receive a copy of our questionnaire through the post, please take a little time to complete and return it. All responses will be entirely confidential. If you do not receive a copy of the questionnaire by February 16<sup>th</sup> and would like to participate in the needs assessment please contact Andrea in the Care Trust Plus on 01472 625559.

*Are you able to access health services without difficulties?*

*Are you treated with dignity and respect?*

*Do you have difficulties preparing meals?*

*How socially active are you?*

THANK YOU

## Appendix 5

### STUDY METHODS

#### Ethics and consent

An outline of the study was submitted to the South Humber Research Ethics Committee who responded that they had no ethical concerns and granted approval. Research governance approval was obtained from North East Lincolnshire Care Trust Plus sponsored by Northern Lincolnshire and Goole Hospitals NHS Foundation Trust. Consent from individuals to participate in the postal survey was assumed to be given by return of the completed questionnaire. Similarly, blank questionnaires returned were assumed to be a refusal and that participant was then flagged on the database as a non-participant so that a reminder was not sent. For focus group members and interviewees, an information sheet was provided explaining the aims of the study and written informed consent was received (please see Appendix 6 a, b, and c for information sheets and consent forms). For both focus groups and interviews, the session was tape recorded for ease of transcription with the participant's consent. Focus group members were informed that if even one person objected then the discussion would not be recorded.

#### Sampling Frame and Sampling Method

The questionnaire sample was obtained via service provider lists. The Learning Disability, Physical Disability and Transition teams provided SWIFT ID numbers of all clients receiving services who were resident in North East Lincolnshire, these numbers were then entered onto questionnaires to allow respondents to be logged into the system and non-responders issued with reminder letters. Everyone between the age of 16 and 64 registered with these services was invited to take part. For those who were unable to complete the survey themselves, the invitation letter asked if someone such as a family member or carer would help them to complete it.

The Public Health Intelligence Unit assembled questionnaire packs containing a questionnaire, invitation to participate letter, focus group flyer and 2 pre-paid envelopes (for these documents, please see Appendices 1, 3, and 4). The participant's SWIFT ID number was written on the questionnaire and front of the pack, these were then passed back to the relevant team for address labels to be attached and dispatched. A helpline was also set up within the Public Health Intelligence Unit to deal with any queries; this was referred to in the invitation letter with the telephone number listed.

Once questionnaires were returned, the date of return for the SWIFT ID number was logged into a spreadsheet tracking respondents. Three weeks after the initial mailing date, those SWIFT IDs still with no response received were emailed to the relevant team, new packs were assembled including a reminder letter, questionnaire and pre-paid envelope and these were sent to the relevant team for addressing and dispatching as before. Due to the nature of the vulnerable groups being considered, only one reminder letter was sent in order to avoid causing undue stress or pressure to recipients who did not wish to respond.

Focus group participants were recruited through the flyer which was sent out with the questionnaire pack. This listed the focus groups to be conducted and invited potential participants to tick those they would be interested in attending. A space for name and address was included at the bottom of the flyer to identify the person and for this reason two pre-paid envelopes were provided, enabling participants to keep their questionnaires separate from their returned flyer to maintain confidentiality. Once sufficient potential numbers had been obtained for each focus group, Public Health administration arranged times, dates and venues, offering free transport and lunch to all attendees. Upon contacting those who had initially expressed interest in attending, some changed their minds leading to the cancellation of the 'sexual health and relationships' focus group after no willing



participants could be found. Low numbers for the transition group meant that this focus group was carried out as one to one interview with two parents instead. Despite good initial enthusiasm for the finance and transport focus groups, only one person attended each. The local area focus group was carried out successfully.

Interviewees were recruited through the local Carer's forum and the Community Learning Disability Team. Another was recruited via the telephone helpline. In total five carers of people with disabilities were interviewed.

### **Helpline**

A helpline number at the Public Health Department was manned by researchers during office hours to respond to enquiries. A log of all calls was kept, detailing the time, date and nature of the enquiry. If the caller stated that they did not wish to take part, this was logged and that participant was then flagged on the database as not participating so that further communication was not sent.

### **Maximising response**

There was concern from the steering group that one limitation of the study was that the sample could only be obtained from the lists of service users provided by the disability services in North East Lincolnshire, and that there would be a significant number of people with disabilities who would not be registered with these services. Therefore in order to try and involve people with a disability who were not registered with any of the disability services, posters and an accompanying letter explaining the nature of the study and its aims were sent to all care and nursing homes, GP surgeries, libraries and day centres in North East Lincolnshire, with a request that they should be displayed in prominent positions likely to be seen by service users to advertise the study and raise awareness of it. Anyone between the age of 16 and 64 with a disability who wanted to participate in the survey or the focus groups was invited to contact the helpline number to obtain a copy of the questionnaire or register their interest in the focus groups. However no calls were received from people requesting to participate

### **Duration**

The survey commenced in early February 2009 and questionnaires with a covering letter signed by the Director of Public Health (see Appendices 1 and 3) were sent out in mid February and March 2009, with reminder letters (see Appendix 2) and a new copy of the questionnaire posted to those who had not responded three weeks after the date of the original posting. As questionnaires were received they were logged into the tracking database by their SWIFT ID number. Unanswered questions were recorded as a missing entry. Defaced questionnaires were excluded and no further communication sent.

### **Data entry**

The survey administrative databases were held in Excel. The questionnaire database was coded and entered into SPSS by analysts in the Public Health Intelligence Unit. All care home or residential residents were coded as 'living with friends or others'.

### **Respondents and non-respondents**

In total, 950 potentially eligible questionnaires were dispatched. The number of returned questionnaires, number of questionnaires eligible for return (questionnaires were considered ineligible for return if the person was not known at the address provided or had since died) and the response rate for that team are shown below.

Table A5.1Survey Response Rates

	<b>Number returned</b>	<b>Number eligible</b>	<b>Response rate</b>
Learning Disability	297	430	69.1%
Physical Disability	234	398	58.8%
Transition	34	122	27.8%
<b>Total</b>	<b>565</b>	<b>950</b>	<b>59.5%</b>

**Survey Demographics**

Of the 565 questionnaire respondents, 553 (97.9%) listed their gender. 280 (50.6%) were male and 273 (49.4%) were female. 547 respondents provided their age and ages ranged from 15 to 67, with a mean age of 43. Although the survey aimed to include those up to the age of 64, a few respondents were over this age and these people were included in the analysis. The age band of respondents and the proportion of the survey sample each age band represents are shown in Table A5.2

Table A5.2 Age band of survey respondents

<b>Age band</b>	<b>Number of respondents</b>	<b>Proportion (%) of total</b>
15-19	47	8.6%
20-24	47	8.6%
25-29	32	5.9%
30-34	35	6.4%
35-39	34	6.2%
40-44	56	10.2%
45-49	73	13.3%
50-54	56	10.2%
55-59	80	14.6%
60-64	76	13.9%
65-69	11	2.0%
<b>Total</b>	<b>547</b>	<b>100.0%</b>

559 respondents specified the type of disability they considered themselves to have. It was decided to analyse results by type of disability as indicated on the questionnaire rather than by the referring service due to the large number of people with both a learning and physical disability (138, 24.7%). 211 (37.7%) specified only a physical disability and 210 (37.6%) specified only a learning disability. For further analysis, these 3 categories will be used. To ensure that the disabilities people had reflected the service they were referred from this data was analysed and it was found that two physical disability service clients indicated that they had a learning disability. On closer examination, both suffered from an organic brain illness which could cause learning disability. 10 learning disability clients indicated that they had a physical disability. Five of these had listed their main disability as learning disability and so were included in with the learning disability group, the remaining five listed physical problems which to them appeared more important than their learning disability. Overall these numbers were very small (7, 1.2%) and so it was felt that the respondent's indications of their disability types matched with the services they were referred by.

### ***Demography by disability type***

The gender breakdown by disability type is shown in Table A5.3 and as can be seen, the largest proportion of males (129, 46.2%) had a learning disability, whereas for females the largest proportion (119, 44.4%) had a physical disability.

Table A5.3     Disability by gender

Disability	Gender		
	Male	Female	Total
Physical	85 (30.5%)	119 (44.4%)	204
Learning	129 (46.2%)	77 (28.7%)	206
Learning AND physical	65 (23.3%)	72 (26.9%)	137
<b>Total</b>	<b>279 (100.0%)</b>	<b>268 (100.0%)</b>	<b>547</b>

Table A5.4 shows the age band of respondents by disability type, and this shows that the age profile varies widely for the different disability types. For example, for physical disability, over half of respondents (104, 52.4%) are aged 55 and over compared to only 17.2% (35) of the learning disability respondents in the same age group. For learning disability respondents, over a third (69, 34.0%) were aged between 15 and 29, compared to only 5.0 (10) respondents with a physical disability in the same age group. For those with a learning AND physical disability over a third (47, 35.1%) were in the 15-29 year age group.

Table A5.4     Age band by disability type

Age band	Disability – Number (%)			
	Physical	Learning	Learning AND Physical	Total
15-19	4 (2.0%)	22 (10.8%)	21 (15.7%)	47
20-24	3 (1.5%)	27 (13.3%)	17 (12.7%)	47
25-29	3 (1.5%)	20 (9.9%)	9 (6.7%)	32
30-34	8 (3.9%)	16 (7.9%)	11 (8.2%)	35
35-39	9 (4.4%)	15 (7.4%)	10 (7.5%)	34
40-44	14 (6.9%)	26 (12.8%)	16 (11.9%)	56
45-49	25 (12.3%)	28 (13.8%)	19 (14.2%)	72
50-54	31 (15.2%)	13 (6.4%)	10 (7.5%)	54
55-59	46 (22.5%)	20 (9.9%)	11 (8.2%)	77
60-64	51 (25.0%)	15 (7.4%)	9 (6.7%)	76
65-69	10 (4.9%)	0 (0.0%)	1 (0.7%)	11
<b>Total</b>	<b>204 (100.1%)</b>	<b>203 (99.6%)</b>	<b>134 (100.0%)</b>	<b>541</b>

# Planning to improve the health and well-being of people with physical or learning disabilities in North East Lincolnshire

## Information sheet for interviewees

*You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.*

*Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.*

### **What is the purpose of the study?**

One of the roles of the Care Trust Plus (CTP) is to improve the health of local people and to reduce inequalities in people's health. To do this the CTP provides and commissions services and works in partnership to influence services provided by others. To do this we need to know about people's needs.

The purpose of this study is to examine the health and social needs of adults up to the age of 65 with physical or learning disabilities in North East Lincolnshire. This is the first stage in the planning process to ensure the right resources are in place to maintain the health and social well-being of people with disabilities in the area. The study will also examine health and social inequalities among people with disabilities locally.

The project will be made up of different parts to give us a full picture in relation to the health and social needs of people with disabilities. You are being invited to take part in a one to one interview with a researcher that involves discussing your needs as a carer of someone with either a physical or learning disability, and the needs of the person you care for.

Focus groups will also be carried out with people with physical and learning disabilities to discuss their needs and views on a range of topics associated with day to day life. In addition, a questionnaire will be sent out to those identified on local physical and learning disability registers who are resident in North East Lincolnshire.

### **Why have you been invited?**

You have been invited because you care for a person who has a physical or learning disability requiring the assistance of a carer.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. You will be free to withdraw at any time if you change your mind, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care or levels of services you receive.

### **What will happen to me if I take part?**

If you decide to take part we will arrange a meeting at a time and in a location that is convenient for you. The interview will last for approximately one hour and will cover areas such as the information you were provided with and the needs and support that you and the person you care for have. During the meeting the interviewer will tape record the conversation if you give permission to do so. This allows the conversation to be captured accurately. All material obtained during interviews is strictly confidential.

**What are the possible disadvantages and risks of taking part?**

We do not expect that there would be any hazards or distress from taking part in this study. The interviewer will be happy to answer any questions that you may have.

**What are the possible benefits of taking part?**

We hope that the interviews will help to determine the needs people with physical and learning disabilities and their carers have and that the results might help us to make changes and improve services or create new services. However, this cannot be guaranteed. The information we get from this study will be passed on to the people who provide or commission services and should help to improve physical and learning disability services in the future.

**What will happen to the results of the research study?**

The information will be added together from all those who have taken part to draw out common problems and needs and these will be written up into a report which will be published next year. No names will be used and anything that you say that is used in any report or publication will be completely anonymous. Results from the report will be communicated to those who took part via the local press and electronic copies of the full report will be placed on the Care Trust Plus internet site at [www.nelctp.nhs.uk](http://www.nelctp.nhs.uk).

**What if something goes wrong?**

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you.

**Will my taking part in this study be kept confidential?**

All personal information which is collected about you during the course of the research will be kept strictly confidential. It will not have your name on it and as explained above, the combined data used for the final report will be totally anonymous.

**Who is organising and funding the research?**

The Public Health Department of North East Lincolnshire Care Trust Plus is organising and funding the research, also on behalf of the Local Authority and other local partners. There is no external funding for the study.

**Who has reviewed the study?**

Approval has been obtained from the local South Humber Research Ethics Committee for this research to be undertaken.

**Thank you for taking the time to read this information sheet. If you require further information please contact:**

Principal researcher: Mr Geoffrey Barnes, Public Health Department, North East Lincolnshire CTP, 1 Prince Albert Gardens, Grimsby, North East Lincolnshire, DN31 3HT (Tel: 01472 625531).

## **Appendix 6b**

### **Improving the Health and Social Well-being of People with Disabilities** **Living in North East Lincolnshire**

#### **Discussion Group Information sheet**

**Please read this sheet and talk about it with others to help you decide if you want to take part in our discussion group. Ask us if you would like to find out more.**

#### **Why are we doing this study?**

One of our jobs is to improve the health of local people. To do this we need to know about people's needs. The discussion groups form one part of a larger study exploring the health and social needs of people with disability who live in North East Lincolnshire.

You have been invited to talk to us about living with a disability so we can understand more about your needs. We hope to find out how we can make our services better for people in this area. We also want to make sure that people who have a disability are treated fairly.

#### **Do I have to take part?**

No, you only have to take part if you want to. Even if you say yes, you can change your mind at any time. If you don't take part it will **not** make any difference to the care you receive from health and disability services.

#### **What will happen if I decide to take part?**

The discussion groups will be organised by us and take place in a suitable location in North East Lincolnshire. You will get to meet a small group of people who also have a disability. We will talk about the topic you have chosen for about 1 hour. We will ask some questions and you can tell us what you think.

We would like to record the discussions on a tape recorder to assist us with analysis, but we will check this is OK with everyone in the group first.

#### **What will happen to the results of the research study?**

We will add all of the information together and write a report. No names will be used and anything that you say that is used in the report is confidential. The full report will be put on the Care Trust Plus internet site at [www.nelctp.nhs.uk](http://www.nelctp.nhs.uk) later in the year.

#### **Will my taking part in this study be kept confidential?**

All personal information which is collected about you and everything you tell us will be kept private. It will not have your name on it and the final report will be totally anonymous.

#### **Who has checked it is OK to do this study?**

The Hull and East Riding Research Ethics Committee has given permission for this study to be done.

**Thank you for taking the time to read this information sheet. If you would like any more information please contact:**

Mr Geoffrey Barnes, Consultant in Public Health, North East Lincolnshire CTP, 1 Prince Albert Gardens, Grimsby, North East Lincolnshire, DN31 3HT (Tel: 01472 625531).

## Appendix 6c

### IMPROVING THE HEALTH AND SOCIAL WELL-BEING OF PEOPLE WITH DISABILITY IN NORTH EAST LINCOLNSHIRE

#### DECLARATION OF CONSENT – DISCUSSION GROUP

##### **Part 1 – To be completed by you:**

By signing below I agree to the following terms of the Discussion Group:

- I have been given a copy of the **Discussion Group Information Sheet**, I have read it and I understand it.
- I understand why I am taking part in this study.
- There has been time to ask questions about this study.
- I have received answers to any questions I may have asked.
- I understand the need to treat everyone in the group with dignity and respect their views.
- I understand that I am free to leave this study at any time.
- I agree to this group discussion being audio-taped.

I agree to take part in this study:

Name (Block Capitals) \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

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##### **Part 2 – To be completed by the Researcher:**

Venue: \_\_\_\_\_

Name (Block Capitals) \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**IMPROVING THE HEALTH AND SOCIAL WELL-BEING  
OF PEOPLE WITH DISABILITY  
IN NORTH EAST LINCOLNSHIRE**

**DECLARATION OF CONSENT – INTERVIEW**

**Part 1 – To be completed by the Participant:**

By signing below I agree to the following terms of the Interview:

- I have been given a copy of the **Participant Information Sheet** which I have read and understood.
- I understand the purpose of the study and why I am taking part.
- There has been sufficient time to ask questions regarding any aspect of the study.
- I have received satisfactory answers to any questions I may have asked.
- I understand that I am free to withdraw from the study at any time without having to give a reason.
- I agree to the interview being audio-taped to enable the conversation to be accurately captured.

I agree to take part in this study:

Name (Block Capitals) \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

---

**Part 2 – To be completed by the Researcher:**

Venue: \_\_\_\_\_

Name (Block Capitals) \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_



# Appendix 7

## Certain Infectious and Parasitic Diseases (A00-B99)

Encephalitis  
Polio

## Neoplasms (C00-D48)

Bowen Disease  
Brain Tumour  
Cancer  
Cancer (Testicular)  
Cancer (Breast)  
Laryngectomy  
Myeloid Dysplasia Sideroblast Anaemia  
Myeloma  
Pituitary Tumour

## Diseases of the Blood and Blood Forming Organs and Certain Disorders involving the Immune Mechanism (D50-D89)

Blood Disorder  
Pernicious Anaemia

## Endocrine, Nutritional and Metabolic Diseases (E00-E90)

Calcium Deficiency  
Cholesterol  
Diabetes  
Fibrosis  
High Cholesterol  
Hypoadrenalism  
Hypopituitarism  
Obesity  
Pineal Gland  
PKU  
PMLD  
Thyroid

## Mental and Behavioural Disorders (F00-F99)

ADD  
ADHD  
Agoraphobia  
Anxiety  
ASD  
Asperger's syndrome  
Autism  
Behavioural Issues  
Bipolar Disorder  
Dementia  
Depression  
Dyspraxia  
Learning Difficulty  
Learning Disability  
Memory Loss  
Mental Health  
Mute  
Neurological Illness  
OCD  
Pandas Syndrome  
Psychotic Illness  
PTSD  
Rett's Syndrome  
Schizophrenia  
Speech  
Verbal Dyspraxia

### **Diseases of the Nervous System (G00-G99)**

Carpal Tunnel  
Cerebellar Ataxia Scar 7  
Cerebral Palsy  
Complex Regional Pain Syndrome  
Compressed Spinal Cord  
Critical illness neuropathy  
Epilepsy  
Fits  
Hallvorden Vorden Spatz  
Hemiparesis  
Hemiplegia  
Huntingdons  
Hydrocephalus  
Insomnia  
ME  
Migraines  
Motor Neurone Disease  
MS  
Muscle Wastage  
Muscula Fistula  
Muscular Dystrophy  
Myalgic Encephalomyelitis  
Myoclonus  
Myotonic Dystrophy  
Myotonica Dystrophia  
Neuropathy  
Paralysis  
Paraplegic  
Parkinsons  
Peripheral Nerve Disease  
Quadraplegic  
Severe Fatigue Syndrome  
Sleep Apnea  
Spastic Quadraplegia  
Spinal Cerebella Degeneration  
Spinal Muscular Atrophy  
Spine C5 C7  
Syringomyelia  
Tetraplegia C5/6  
TIA  
Trigeminal Neuralgia

### **Diseases of the Eye and Adnexa (H00-H59)**

Blind  
Cataracts  
Glaucoma  
Poor Eyesight  
Tunnel Vision  
Visual Impairment

### **Diseases of the Ear and Mastoid Process (H60-H95)**

Deaf  
Hearing Problems  
Meniers Disease  
Tinnitus  
Vertigo

### **Diseases of the Circulatory System (I00-I99)**

Angina  
Arrhythmia  
Blood Clot  
Blood Pressure  
Brain Haemorrhage  
Circulation Problems

CVA  
DVT  
Enlarged Heart  
Heart Attack  
Heart Conditions  
Heart Disease  
Heart Problems  
High Blood Pressure  
Hypertension  
Irregular Heartbeat  
Low Blood Pressure  
Lymphoedema  
Pulmonary Embolisms  
Raynards Syndrome  
Stroke  
Tachycardia  
Vascular Problems

**Diseases of the Respiratory System (J00-J99)**

Asthma  
Bronchitis  
Chest Infections  
Chest Problems  
COPD  
Hay Fever  
Lung Problems  
Respiratory Failure  
Rhinitis  
Tracheotomy

**Diseases of the Digestive System (K00-K93)**

Barretts Oesophagus  
Bowel Problems  
Coeliac  
Colitis  
Constipation  
Diverticulitis  
Food Intolerance  
Gall Bladder  
Hernia  
Hiatus Hernia  
IBS  
Illiostomy  
Irritable Bowel Syndrome  
Liver Damage  
Liver Disease  
Liver Failure  
Liver Problems  
Pancreatis  
Stomach Problems  
TMJ  
Ulcerative Colitis

**Diseases of the Skin and Subcutaneous Tissue (L00-L99)**

Chronic Skin Conditions  
Psoriasis

**Diseases of the Musculoskeletal System and Connective Tissue (M00-M99)**

Arthritis  
Back Problems  
Brusitis  
Curvature of Spine  
Degenerative Disc Disease  
Fibromyalgia  
Gout  
Hyper Mobility Syndrome

Joint Problems  
Knee Replacement  
Lumbar  
Osteoarthritis  
Osteoporosis  
Reflex Sympathetic Dystrophy  
Rheumatism  
Rheumatoid Arthritis  
Sciatica  
Scoliosis  
Spinal Curvature  
Spinal Disc  
Spondylitis  
Spondylosis  
Tendonitis

**Diseases of the Genitourinary System (N00-N99)**

Kidney Damage  
Kidney Problems  
Kidney Stones  
Prostate Problems

**Congenital Malformations, Deformations and Chromosomal Abnormalities (Q00-Q99)**

Anglemans Syndrome  
Brittle Bones  
Chromosome 4  
Chromosome 5  
Chromosome Disorder  
Congenital Heart Defect  
Downs Syndrome  
Fragile X  
Gene Problems  
Neurofibromatosis  
Pit Hopkins Syndrome  
Spina Bifida  
Spinal Cord Syndrome  
Tuberous Sclerosis

**Symptoms, Signs and Abnormal Clinical and Laboratory Findings - not elsewhere classified (R00-R99)**

Breathlessness  
Dyslexia  
Dysphasia  
Headaches  
Incontinence  
Seizure

**Injury, Poisoning and certain other consequences of External Causes (S00-T98)**

Allergy  
Amputation  
Brain Injury  
Broken Hip  
Broken Neck  
Burns  
Fractured Spine  
Spine Broken

**Factors influencing Health Status and contact with health services (Z00-Z99)**

Hip Replacement

**ICD 10 Unclassifiable**

Balance  
Body Parts  
Hydrionious Supativa  
Illness due to no spleen  
Immune Deficiency Syndrome  
Not Recorded

Other  
Skin Problems  
Ulcer  
Ulcers  
Urology Problems

**ICD 10 Unclassifiable - Mobility**

Infirmity  
Physical Disability

## Appendix 8

Table A8.1

Reasons for current accommodation being unsuitable (free text)

Reason for unsuitability	No.	%
Stairs	26	36.1%
Bathroom unsuitable	13	18.1%
Too small	9	12.5%
Need privacy/ own bedroom	5	6.9%
Need sheltered/ supported accommodation	5	6.9%
Awaiting adaptations	4	5.6%
Damp/ cold	3	4.2%
Access in/ out home	2	2.8%
Doors not wide enough	2	2.8%
Old building	2	2.8%
Too big	2	2.8%
Too noisy	2	2.8%
Want a garden	2	2.8%
Don't get on with other tenants	1	1.4%
Don't know	1	1.4%
Expensive to heat	1	1.4%
Need a hoist	1	1.4%
Need independence	1	1.4%
Need padding and soft floors	1	1.4%
Want to be near family	1	1.4%
Number of respondents	72	100.0%

## Appendix 9

**Table A9.1** If you had a magic wand, what would you like to see for people with disabilities? (free text)

	<b>Number</b>	<b>%</b>
Equality/ Respect/ Understanding	71	21.9%
Cure/ no disability/ health	56	17.3%
Social activities/ opportunities to meet people	47	14.5%
Other	32	9.9%
Better access/ facilities	23	7.1%
Don't know	23	7.1%
More money/ funding/ grants	22	6.8%
More help/ support	17	5.2%
Suitable Accommodation	15	4.6%
More suitable transport	12	3.7%
Better Health/ Social services	8	2.5%
Happiness	6	1.9%
Help/ support for carers	6	1.9%
Better pavements	5	1.5%
More disabled parking	5	1.5%
More disabled public toilets	5	1.5%
Inclusion/ Integration	4	1.2%
Meet individuals needs	4	1.2%
Unable to answer	4	1.2%
Better information/ access to benefits	3	0.9%
Holidays	3	0.9%
Information	3	0.9%
Suitable respite care	3	0.9%
Employment opportunities	2	0.6%
Fewer forms	2	0.6%
People trained in British Sign Language	2	0.6%
Financial assistance	1	0.3%
Security for the future	1	0.3%
<b>Total answered</b>	<b>324</b>	<b>100.0%</b>

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