

# **Scrutiny Review**

## **Independence without Isolation**

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## 1. EXECUTIVE SUMMARY

*“People with a learning disability are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them”.*

### **Valuing People Now.**

The background to the Panel’s investigation was the link between health and well-being scrutiny and community cohesion, established in ‘*Better Together*’. This theme was developed by the Panel to establish a project looking at the impact of social isolation on people with learning disabilities, particularly when they are living independently.

There are an estimated 10,000 people living in Kirklees who have a learning disability – only a fifth of whom are ‘known’ to the Council. This number is increasing at 3% per year, compared with a national increase of 1%.

Kirklees’ vision is to provide choice and opportunities for people with learning disabilities to live as independently as possible in ordinary community settings. Critical to the success of independent living is the opportunity to feel part of the community in which you live; but, people with learning disabilities are far more likely than the general population to say that they feel isolated and not an integral part of the community in which they live.

The Panel has established that there are a number of factors causing learning disabled people to feel socially isolated and our findings are set out under a number of themes in the report - the transition from childhood to adulthood; further education and employment; transport; leisure; housing; and health. Cutting across all of these is the loneliness and fear felt by so many people with learning disabilities.

The Panel’s investigations point to a significant disparity in the services and support available in the north and south of Kirklees to people with a learning disability – exacerbating health inequalities across the district. This is despite the fact that mechanisms are in place to ensure partnership working – however, these opportunities are not being maximised and information sharing remains patchy.

The Panel’s findings are firmly rooted in the evidence contributed by people with a learning disability and their families and carers. They have been fully involved throughout the Panel’s investigation and this report will also be produced in an easy-to-understand format, so that it can be shared with those who it aims to assist.

The Panel would like to thank everyone who contributed to the review and willingly shared their experiences and expertise.

## 2. BACKGROUND AND CONTEXT FOR THE REVIEW

### 2.1 Background

2.1.1 There are an estimated 10,000 people living in Kirklees who have learning disabilities (approximately 2.5 – 3% of the population) and this number is increasing by an estimated 3% per year. This is significantly above the national increase of 1% per year and Kirklees' Joint Strategic Needs Assessment 2009 highlighted the unquantifiable additional increase that could result from the changing ethnic profile.

2.1.2 Kirklees' vision is to provide choice and opportunities for people with learning disabilities to live as independently as possible in ordinary community settings. The use of residential and nursing registered care provision will decrease significantly over the next decade and will evolve into specialist home care services; people will be supported to live locally, by themselves or with others in their own home. More people with learning disabilities want to enjoy greater levels of independence, choice and control over their lives and want access to a broader range of personalised services, including ordinary community living. However, in Kirklees there is a shortage of mainstream housing/supported living options for people to choose from.

2.1.3 Critical to the success of independent living is the opportunity to feel part of the community in which you live. Social networks are so important to people's general sense of well-being that '*people with good social networks live longer than those with poor networks*' [Kirklees Joint Strategic Needs Assessment 2009 referencing Acheson, D. (1998) *Independent Inquiry into Inequalities in Health Report*]. But, people with learning disabilities who are living in the wider community often have very limited social networks. Both nationally and locally, people with learning disabilities are far more likely to say that they feel isolated and not an integral part of the community in which they live [Joint Strategic Needs Assessment 2009]. This is thought to arise from a number of factors: communication difficulties, unemployment, low skill base, low confidence and self esteem, prejudice, discrimination, and stereotype.

2.1.4 As the number of people with learning disabilities (including those that are more severe and complex) increases, and as the opportunities to live independently in ordinary community settings increase, what will be the effect on social isolation levels? The Panel sought to ascertain what is being done to tackle the social isolation felt by learning disabled people and how learning disabled people can achieve independence and choice over how they live their lives without facing isolation.

2.1.5 In September 2009, Kirklees Council successfully applied to the Centre for Public Scrutiny to carry out an innovative scrutiny review which was required to focus on the link between social isolation and health inequalities.

### 2.2 Legislative Context for the Project

- Human Rights Act 1998
- Disability Discrimination Act 1995

- Valuing People Now 2009
- Valuing People – A New Strategy for Learning Disability for the 21<sup>st</sup> Century
- Our Health, Our Care, Our Say 2006
- Death by Indifference 2007
- Six Lives Report 2009

### **3. TERMS OF REFERENCE AND METHODOLOGY**

- 3.1 The Health Inequalities Scrutiny Panel members were:  
 Councillor Elizabeth Smaje (Lead Member)  
 Councillor Margaret Bates  
 Councillor Roger Battye  
 Councillor Mohan Sokhal  
 Co-opted Members: Ashraf Ali, Kate Cross, and Liz Goldthorpe

For the purposes of the review, Jill Robson, Chief Executive of Mencap in Kirklees, was co-opted onto the Panel.

- 3.2 The Panel was supported by Laura Ellis, Senior Scrutiny Officer, and Jenny Bryce-Chan, Scrutiny Officer.

- 3.3 The causes and effects of social isolation on vulnerable groups had been identified by the Health Inequalities Scrutiny Panel as one of its key work programme objectives for the 2009/10 municipal year. The funding obtained from the Centre for Public Scrutiny enabled the Panel to do a more detailed and focused piece of work exploring aspects of social isolation. Consideration was also given to developing good practice in respect of engaging vulnerable and hard to reach groups in the scrutiny process.

- 3.4 An initial scoping meeting on 6 November 2009, facilitated by Shaun Gordon, expert advisor from the Centre for Public Scrutiny, helped the Panel to clearly identify the remit and scope for undertaking the review. A list of potential witnesses was also identified during the meeting.

- 3.5 The Scrutiny Panel made a conscious decision not to centre its attention on children with learning disabilities, primarily because the key focus was on achieving independence and social inclusion within a community. Until a person reaches adulthood their life is very structured and social isolation less likely.

- 3.6 The Panel made a decision not to focus on people with a learning disability from Black Minority Ethnic (BME) communities. This was because Adult Services had recently commissioned a piece of work which aimed to find out how many people with a learning disability and their carers were from the BME community. This aimed to find out how many of them were accessing services thereby developing a clearer picture of the proportion who are not.

- 3.7 The Panel therefore agreed that the review would focus on adults with learning disabilities and would centre around one sentence that summed up the aim of the project:

**To examine the mechanisms in place to encourage people with learning disabilities to actively participate in the wider aspects of community life and not just those activities that are developed for people with learning disabilities.**

- 3.8 This was further developed to include four key themes - housing, leisure, transportation, and loneliness and fear.
- 3.9 During the course of the review, it became clear that there were other key themes that needed to be explored, and therefore the report also explores: the transition from childhood to adulthood; further education and employment; and health related issues.
- 3.10 The review was carried out between October 2009 and March 2010 and included: interviewing witnesses; site visits; and desk-based research (for a full bibliography, see page 48).
- 3.11 **Witness interviews**
- 3.11.1 The Panel decided to commence with hearing evidence from users and carers, in order to give them an insight into the daily lives and experiences of people with learning disabilities and their families and carers. From this, they progressed to meeting with professionals and service providers.

<b>DATE</b>	<b>WITNESS</b>
<b>24 November 2009</b>	<b>Carers Sub-Group – Learning Disability Partnership Board</b> Members of the Carers Group supported by Tania Webb – Valuing People Lead Officer
<b>30 November 2009</b>	<b>Community Support Workers/Operational Managers (MENCAP)</b> Tina Ewart - Community Support Team Manager Michael Mulkerrin– Community Support Worker Christine Gibson – Community Support Worker Linda Reilly - Operational Manager, Residential Sue Crabtree – Operational Manager, Day Services
<b>1 December 2009</b>	<b>Mencap</b> People with learning disabilities living independently in the community
<b>2 December 2009</b>	<b>Kirklees Information Network</b> Sarah Roberts – accompanied by service users
<b>3 December 2009</b>	<b>Thursday Evening Leisure Group</b>
<b>4 December 2009</b>	<b>REAL Employment Launch</b>
<b>7 December 2009</b>	<b>Kirklees Neighbourhood Housing</b> Paul Buckley - Director of Neighbourhood Housing Linda Spencer - New Business Co-ordinator

	<p><b>Strategic Housing</b> Karen Oates – Commissioning Manager for Access and Support Emma Hanley – Acting Supporting People Manager</p> <p><b>Adult Services</b> Keith Smith – Head of Commissioning and Planning</p>
<b>8 December 2009</b>	<p><b>Gateway</b> David Macdonald – Acting Group Manager</p>
	<p><b>Kirklees Active Leisure</b> Ruth Pawson – Head of Development</p>
	<p><b>Worklink</b> Lynne Howarth – Worklink Manager Pamjeet Kaur – Worklink Manager</p>
<b>10 December 2009</b>	<p><b>Duke Of Edinburgh</b> Denise Bedford – Award Manager</p>
<b>6 January 2010</b>	<p><b>Adult Services</b> Gary Wainwright – Partnership Commissioning Manager for Learning Disabilities</p>
	<p><b>Calderdale &amp; Huddersfield NHS Foundation Trust</b> Amanda Mckie – Matron Complex Need Care Co-ordinator</p>
	<p><b>Adult Services</b> Ginny Holroyd – Team Manager, Shared Lives</p>
<b>8 January 2010</b>	<p><b>Metro</b> Erica Ward – Community Liaison and Accessibility Co-ordinator</p>
<b>29 January 2010</b>	<p><b>Shared Lives</b> Shared Lives Carers Ginny Holroyd – Team Manager, Shared Lives</p>
	<p><b>Mid Yorkshire NHS Foundation Trust</b> Marie Gibb – Strategic Health Facilitator Kate Firth – Assistant Director: Patient Experience and Improvement</p>
	<p><b>South West Yorkshire Partnership NHS Foundation Trust</b> Tim Breedon – Interim District Director</p>
<b>5 February 2010</b>	<p><b>Health</b> Dr Judith Hooper – Director of Public Health</p>
<b>9 February 2010</b>	<p><b>Visit to Brighton Court</b> Niall Roache – Group Manager, Accommodation &amp; Residential Services: Learning Disability</p>

3.12 A press release was issued during the course of the project and the Lead Member was interviewed on Pennine Radio. Members of the general public were given the opportunity to contribute to the review by submitting comments through the Kirklees website, in writing or by telephone. Five members of the public responded and were subsequently contacted by members of the Panel.



### 3.13 Definition of a Learning Disability

3.13.1 The Panel's initial question to all professional witnesses sought a definitive definition of what constituted a learning disability.

3.13.2 According to Valuing People Now 2001, a learning disability includes 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, with a lasting effect on development.*

This definition encompasses people with a broad range of disabilities.

3.13.3 The World Health Organisation (WHO) has defined learning disabilities as; *"A state of arrested or incomplete development of mind. A person should display three fundamental criteria before being diagnosed as having a learning disability.*

- *Assessing any intellectual impairment (IQ)*
- *Assessing social dysfunction combined with IQ*
- *Identifying of early onset of the above"*

3.13.4 Often the term '*learning difficulty*' and '*learning disability*' are used interchangeably, however there is a distinction. Learning difficulty can be used to categorise dyslexia or a specific difficulty with learning and the individual's IQ could be well over the 70 level that has traditionally been set for people defined as learning disabled. The use of an IQ cut off is no longer widely used due to its inflexibility. A learning disability is permanent and substantial.

### 3.14 Definition of Social Isolation

3.14.1 The Panel also sought to ascertain whether there was a definitive definition of social isolation. Each of the witnesses interviewed by the Panel presented different definitions, however, there were common themes emerging:

- Minimal contact with other people such as family, friends or the wider community;
- People who do not interact with others due to barriers of age, gender, language, religion, culture or disability;
- People not being able to access services and opportunities that the rest of us take for granted;
- Feelings of loneliness – little interaction with society as a whole.

3.14.2 The representative from Kirklees Active Leisure put social isolation into the context of the leisure services they provide and said social isolation can be voluntary or involuntary. For example, voluntary in that someone might have an aversion to physical activity and not want to take part; or involuntary in that they want to take part but may not have the support to enable them to participate. The Panel found this to be a very useful definition.

### 3.15 National Context

- About 985,000 people in England have a learning disability; which is about 2% of the population; and 796,000 of them are aged 20 or over.
- The number of adults with learning disabilities aged over 60 is predicted to increase by 36% between 2001 and 2021.
- The number of adults with learning disabilities is predicted to increase by 11% between 2001 and 2021. This would raise the number of people in England aged 15 and above with learning disabilities to over one million in 2021. (*Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, Institute for Health Research, Lancaster University (2004)*)
- There are 55,000-75,000 children with a moderate or severe learning disability in England (*Learning disabilities: facts and figures, Department of Health (accessed online 2007)*)
- There are an estimated 210,000 people with severe and profound learning disabilities in England: around 65,000 children and young people, 120,000 adults of working age; and 25,000 older people (*Valuing People, Department of Health (2001)*)
- Only 20% of adults with learning disabilities are known to learning disability services. (*Note to Adults with learning difficulties in England 2003/4. National Statistics & NHS Health and Social Care Information Centre (2004)*)
- The increase in the number of people with a learning disability may be explained by:
  - Increased life expectancy, especially among people with Down's Syndrome.
  - Growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood.
  - A sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities.
  - Greater prevalence among some minority ethnic populations of South Asian origin (*Valuing People – Department of Health 2001*)

### 3.16 Local Context

- There are an estimated 10,000 people with a learning disability living in Kirklees.
- Of the 10,000 people with a learning disability, approximately 1932 are known to Adult Services.
- Of these, 987 are between the ages of 25 – 44; the age range which shows the biggest increase is 25 – 34.
- 14 people are over the age of 85.
- 325 live in registered accommodation - both residential and nursing.
- 56 people share lives with another family.
- 180 live independently in the community –half live by themselves; the

other half live with friends in a group setting.

- Approximately 1400 live with parents.
- Approximately 291 of those known to Adult Services are from BME backgrounds.
- The annual budget is £25 million, of which £14 million is spent on people in residential care. Some of these have the most complex needs.
- Below is a breakdown of the Council's Learning Disability budget for 2009/10:

<b>LEARNING DISABILITIES - REVENUE BUDGET</b>	
	<b>2009/10 Budget (£k)</b>
<b>OBJECTIVE ANALYSIS</b>	
NET EXPENDITURE	
IS Residential & Nursing	11,499
IS Other Care Costs	3,933
Contracted Services	960
Day Care	2,880
Supported Open Employment	380
Direct Payments	827
Adult (Family) Placements	575
LA Residential & Support	1,965
Care Management	984
Management & Support	918
Support Costs	1,006
<b>Total Net Expenditure</b>	<b>25,928</b>

## 4. TRANSITION FROM CHILDREN'S SERVICES TO ADULT SERVICES

- 4.1 Although transition from Children's Services to Adult Services was not part of the Panel's original remit, issues raised by the Carers Sub Group at the start of the investigation prompted the Panel to seek to gain a better understanding of the transition process.

### Valuing People

*"Transition from childhood to adulthood can be a difficult process for both disabled children and their parents/carers. Our objective is to ensure continuity of care and support and equality of opportunity for young people and their families so that as many learning disabled people as possible take part in education, training or employment".*

### 4.2 Views of Carers

- 4.2.1 Evidence presented to the Panel suggests that for many carers (parents) of children with a learning disability, the transition from Children's Services to Adult Services is not always a smooth process. Most of the carers agreed that from their personal experience, transition was far from seamless; and that once their son/daughter was out of the education system they would often just be sat at home.
- 4.2.2 Of primary concern to carers was the seeming lack of social work involvement in taking up their case, and many said they had to take it upon themselves to seek out and identify relevant services or contact Gateway to Care for help. Other carers stated that when there was social worker involvement, they would often see different social workers and had to retell their stories repeatedly. Furthermore, there appeared to be a lack of knowledge by social workers about what education and training options were available, which further compounded what was already a very difficult time.
- 4.2.3 Carers also stated that getting information was mainly done by word of mouth, as they tended to find things out from other carers.

### Parent

*"There is often no social worker to take up your case and you can find that once your son/daughter is out of the education system they can be just sat at home. As a carer I then had to start at the beginning asking Gateway to signpost me to relevant support services."*

- 4.2.4 Whilst sharing their personal experiences with the Panel, the general view of the carers was that part of the transition process should involve helping a young person learn to live with their conditions. However, it was felt that part of the problem was that they often had to deal with people who did not have the depth of knowledge to help the young person cope with growing up; particularly at a time when they realise that they are different from their peers.

4.2.5 There were also concerns raised about assessments generally, in that if a person's needs changed and a reassessment was necessary it could take months. This view was supported by Community Support Workers who stated that if a problem arose once a case had been 'signed off', a reassessment could take many months. However, it was noted that a safeguarding issue would get an immediate response.

### 4.3 The Transition Process

4.3.1 The transition process is complex and is often very stressful for the individual and families.

4.3.2 From the point of view of the Council, the process usually starts at 14 years of age and can last until a person is 24, with the vast majority lasting a couple of years or less.

4.3.3 There is also a transition period for health provision. Once a young person reaches the age of 16 they are no longer considered a child by health services. In theory, a paediatrician at this point will transfer the medical responsibility to adult health service consultants. However, the Panel was made aware that many paediatricians would continue to care for a learning disabled person beyond this age.

#### **Parent**

*"When my son turned 16, the paediatrician said they could no longer treat him because he was now an adult."*

### 4.4 Adult Services' Transition Team

4.4.1 The Adult Services' Transition Team has the task of implementing Adult Services' transition procedure. The transition process starts at the age of 14, when the Transition Team will be notified of all Year 9 students identified as having special educational needs. This is done via a school census and information will also be forwarded by the Children and Young People's Service (Children with a Disability Team). The Children with a Disability Team also support the transition of Looked After Children, in partnership with the Looked After Children Team, whose remit takes the Team's responsibility past 18 years of age.

4.4.2 The Adult Services' Transition Team consists of; 1 Level 3 social worker, 1 newly qualified social worker, 1 community care officer, 1 social work trainee (until end of 2010), 1 part time administration post, 1 senior community care officer (vacancy), and 1 practice manager.

4.4.3 The transition process begins with the person centred Year 9 reviews and the development of a pathway plan which identifies the hopes, aspirations and dreams of each individual. Children's Services lead on this process but work closely with the Transition Team in planning and detailing how individual needs will be met by Adult Services. In theory the process that is followed is:

**Age 14** Data is collected each year regarding known young people who will most likely need support from Adult Services when they turn 18.

**Age 16** The Transition Team's Practice Manager may start attending Children and Young People's Service reviews, particularly for looked after young people with complex needs. The assessment of their needs may start at this time.

**Age 17** The Transition Team staff members will have been allocated some cases to work in partnership with care managers from the Children with a Disability Team. Meetings with young people and families are arranged on an individual basis based on the complexity of the case, and the anxiety of the family about the transition process. The aim is to ensure Care Plans/Transition Plans are completed for everyone by the time the person reaches 18.

4.4.4 There are 2 key statutes that affect the work of transition - the Children's Act (which states that services provided for children are free but stop immediately on the young person's 18<sup>th</sup> birthday); and the Community Care Act, which has a different set of criteria.

4.4.5 During the transition period, Adult Services will be assessing individuals against the Fair Access to Care Services eligibility criteria (FACS). The FACS eligibility framework specifies which adults are eligible for help and there are four bands: - critical, substantial, moderate, and low. There will also be some people who will fall under the local authorities 'duty of care' or 'statutory duty' and will therefore receive services.

4.4.6 Community and social care services will only be provided for people whose needs are assessed to be in the Critical and Substantial categories of risk. Information, advice and signposting to other services will be given where a person's needs fall in the Moderate to Low bands; and a range of well-being and preventative services are on offer via the third sector and Gateway to Care.

### **Parent**

*"The wheels in Adult Services seem to be slow moving, and it is not the same as when they were younger, and it seems like you're retelling your story over and over again."*

4.4.7 Recognising that transition is a difficult and stressful process, the Kirklees Learning Disability Partnership Board's vision highlights transition as a local priority. The vision states that the aim is to get transition right the first time and also highlights the following priority areas:-

- That people with a learning disability and carers are provided with information about future options available to them in a timely and appropriate manner.
- Transition plans are developed in a person centred way, with the

young person central to the process.

- People in transition and carers are supported through the process.
- Transition planning begins from the age of 14 and detailed plans are in place before a person turns 18. (Kirklees Learning Disability Partnership Board – Our Vision)

4.4.8 The Panel was informed that the data that is collected annually, via the school census, picks up approximately 400 young people with Special Educational Needs (SEN). Of these children/young people the approximate number that will be dealt with by the Transitions Team is 195 and it is likely that these will be those who are approaching their 18<sup>th</sup> birthday.

4.4.9 Information provided to the Panel shows that since 2009, up until the present day, the Transition Team has dealt with a total of 218 cases. This number reflects 195 SEN young people and 23 referrals from Gateway to Care.

4.4.10 The numbers known to Adult Services reflects those people with more profound and complex needs. Adult Services will only provide services for those that fall under the local authorities ‘*duty of care*’ or ‘*statutory duty*’ when the young person turns 18.

4.4.11 The vast majority of people with mild to moderate learning disabilities can lead ordinary lives with the support of family, friends and the wider community. Those with mild to moderate needs do not always want to be badged or labelled and want to be treated like everyone else.

### **Panel Findings**

- Information is collected at Year 9 and at this point the authority knows virtually all 14 year olds with learning disabilities in Kirklees. Approximately 400 are identified each year.
- The Transition Team will focus on those who are most likely to need support from Adult Services at the age of 18 – this will include looked after children and those with complex needs.
- Those who are deemed to have low to moderate needs will not be eligible under the Fair Access to Care criteria to receive support. There are a range of well-being and preventative services on offer through the third sector and Gateway to Care although the Panel has concluded that evidence from service users suggests that this is not well signposted.
- There is an opportunity during the transition period for the authority to maintain a record of all young people identified as having a learning disability. However, this does not appear to happen. Evidence shows that in Kirklees there are between 8000-10000 people with a learning disability, yet the Council is aware of less than 2000. It is clear that the majority of the 400 identified at the age of 14, do not go on to become ‘known’ to Adult Services.
- It is recognised that at the age of 14, many of these may not need to access Council services. However, their circumstances may change in the future, and

it is then difficult to re-access services. This may be because they, or their families/carers, are unable to identify how to access Council services.

- Once services have been accessed, if it is not a safeguarding issue, then assessment can take a long time. It is necessary to repeat basic details and background each time the Council is contacted, which is frustrating, in some cases distressing, and unnecessary.

### **Recommendations**

1. That the Council puts in place mechanisms to ensure that all those identified in the Year 9 school census remain 'known' to Council services:
  - a. That a database of all those identified at Year 9 be maintained irrespective of level of need.
  - b. That a Transition Support Network be established, for those identified as having low to moderate level of needs. This will provide a mechanism for maintaining contact and providing information, periodically, on accessing services.
  - c. That a 'Passport to Care' be developed, to be issued during the transition process for those not eligible under Fair Access to Care criteria, providing information on services and contacts both within the Council, and its partners including the third sector.
  - d. That an annual newsletter be issued to service users, and their families and carers, highlighting useful information on services.
2. That a system be put in place to ensure that service users and their families and carers, who ring the Council for help, do not have to go through their history and basic details again. This would include ensuring that IT systems are fit for purpose.
3. That Adult Services publicise more widely the work of Gateway to Care and how it can support people with learning disabilities.



## 5. FURTHER EDUCATION AND EMPLOYMENT

### 5.1 Further Education

5.1.1 The Panel heard from carers that they felt it was important for a young person to have continuing education throughout their lifetime, however they stated that the lack of options and the changes to further education rules were creating problems. They also felt that no-one adequately prepares a young person in terms of careers advice or about life after college, or even gives them a say about their options for the future.

#### **Valuing People**

Many people with learning disabilities make use of further education provision, Local Education Authority, adult and community education and adult work-based training opportunities to develop and extend their skills. They need to have the same access as other people to opportunities for education and life long learning.

5.1.2 There is a statutory duty to provide education for people with Special Educational Needs up until the age of 25, if they have a clearly identified educational need, however the carers felt that most people will have left further education by the age of 19. In the past, it was common for learning disabled people to remain in education for many years. However, changes introduced by the Learning and Skills Council put a stop to this a couple of years ago, and responsibilities have been broken up and passed back to local authorities. In addition, further education funding has over the last few years been cut back nationally.

5.1.3 A full review of the Arrangements for Special Educational Needs in the Children and Young People Service was undertaken in 2008. A number of recommendations highlighted in the report are being taken forward with changes managed by an SEN project board overseeing 5 different working groups made up of parents, primary, middle, secondary and special school heads and also includes representation from health, social care, HE and transport.

5.1.4 This report highlighted issues around the quality and appropriateness of provision and recommended a review of the range and breadth of opportunity provided. It recognised that choices on offer to young people with special educational needs must be developed to ensure they are appropriate and fit for purpose and guarantee equality of access to relevant further education opportunities and the world of work. A consultancy brief has now been prepared to explore the most effective way of meeting identified gaps and to look at continuity of provision which can meet both the curriculum needs and social care needs of this group of young people whose needs are not currently being met.

5.1.5 The recent Government reforms to improve delivery of adult and young peoples' skills have made local authorities responsible for offering young people in their area a full menu of choice and the Council are responsible for ensuring that all young people with SEN have access to a diverse range of opportunities appropriate to their needs. Moving forward, local authorities will have responsibility for the full range of provision including provider

accountability and budget control. In terms of young people with learning difficulties, Colleges receive an Additional Learning Support (ALS) budget which must be used to address the priorities in the Local Area Statement of need as well as National priorities around LLDD (Learner with Learning Difficulties). The Council feel that they are in a position to continue their ongoing dialogue with the College on how this budget can best be deployed to meet the support needs of these young people.

5.1.6 From 1<sup>st</sup> April 2010, the Council will have an additional resource to lead on co-ordinating the planning, development and delivery of provision to meet the needs of LLDD. This will also include supporting the work of the Council to secure effective transition for these young people as well as identifying key vulnerable groups and their requirements for provision in order to inform planning.

## 5.2 Employment

5.2.1 There was an acknowledgement by the Carers Group that employment may work for some people with learning disabilities, and that there have been some success stories, however, the view was that employment would not work for the majority. They informed the Panel that most employers would only look at those at the mild end of the spectrum. In addition, the carers stated that people with a learning disability tend to need routine and may be unable to deal with anything that is a variation to routine.

### **Parent**

*“So many young adults once they leave college there is nothing for them to do, employment is pie in the sky and jobs often end up being tokenistic.”*

5.2.2 The Carers Group felt that another important factor that also had to be taken into consideration was that employment could mean a loss of benefits and many parents did not want that. Mencap’s Community Support Workers said that some of the people they support are in employment, however, they do not get paid very much because of the impact it would have on their benefits. However, they were of the opinion that learning disabled people should be encouraged to work.

### **Case Study**

*Jenny’s\* daughter, when she left education, approached Worklink for advice on employment opportunities. The advice given was that, as she had a learning disability, she would be best to apply for incapacity benefit, which would ensure that she would receive benefits for the rest of her life and not need to seek employment.*

*However, Jenny was insistent that her daughter should have the same opportunities as everyone else to work. They therefore chose to take the option of signing on for Jobseekers Allowance every two weeks. They did this for a number of months before she was successful in gaining part time employment.*

*Jenny was concerned that the only advice received was to follow the incapacity benefit route, reinforcing the perception that someone with a learning disability is not capable of work.*

*\* not her real name*

The Government state “It is likely that less than 10% of people with learning disabilities are in employment.”

Emerson and Hatton have looked at the numbers of people known to services in employment broken down according to ability level. They estimate that:

- **17%** of people with learning disabilities that are known to services are in paid employment.
- **28%** of people with mild/moderate learning disabilities that are known to services are in paid employment. (70% of these people work for 16 or more hours a week).
- **10%** of people with severe learning disabilities that are known to services are in employment. (57% of these people work for 16 or more hours a week).

*Reference Department of Health (2001) Valuing People, a New Strategy for Learning Disability for the 21<sup>st</sup> Century. P.84*

5.2.3 Agencies such as Worklink, REAL Employment and Job Centre Plus all provide advice, help and support for people with a learning disability to gain and be supported whilst in employment.

5.2.4 Job Centre Plus has Disability Employment Advisors (DEAs) who have a number of roles:

- to help people who are looking for work, find suitable employment;
- for those already employed, they can discuss the current situation;
- for those who cannot work, they can offer advice on financial and practical support, or refer to appropriate services offered by other organisations.

5.2.5 Anecdotal evidence suggests that the support from the DEAs is valuable and initial evidence directly from Job Centre Plus has suggested that the DEAs do recognise that there are barriers to employment; however the Panel has not been successful in pursuing this further with Job Centre Plus.

5.2.6 Worklink advised the Panel that they are currently working with 104 people with learning disabilities, 57% of whom are being supported in employment related activities including supported employment and work experience. Part of Worklink’s role is to work with services and organisations to encourage them to offer more work experience and job carving, however they recognise that in this current economic climate it can be difficult for employers to consider initiatives such as job carving (i.e. extracting tasks from a job description that may be suitable for someone with a learning disability).

**Valuing Employment Now**

Employers need to understand the genuine business benefits of employing people with learning disabilities, and the public sector needs to lead by example.

5.2.7 REAL, or Realistic Employment for Adults with Learning disabilities, also work with people who have a mild to moderate learning disability and offer a unique package of support to help learning disabled people gain and maintain employment in the 'open' jobs market. Currently on REAL’s books

are:

- 46 people 'Seeking Work' following referral and a vocational profile.
- 30 people in paid work (which is the target for this year)
- 46 people are existing clients, all in paid employment that are supported by 'call-ins' and monitoring visits.
- 7 people in 'Voluntary work', supported.
- 8 people in 'Work Training'

5.2.8 The jobs that people are undertaking are varied and include: domestics, laundry work, assistant caretakers, librarians, office based clerks, gardeners, and in retail and catering.

### **Parent**

*“As parents it is possible to set your aspirations too high. Having a child that just copes with life and is content is sometimes all that can be asked for”.*

5.2.9 Many people with learning disabilities have aspirations about having a job. One person who spoke to the Panel was currently doing voluntary work but stated that he would like the opportunity to work for money to pay his rent and spend his own money on things.

Elizabeth\* has learning difficulties at the fairly mild end of the spectrum. She went to college but didn't find this a positive experience, as she was in a class with very disabled young people.

Following college, she has felt very isolated, as there is nothing in place for her to access. She goes to Remploy for interviews but has not been successful.

\* not her real name

### **Panel Findings**

- Evidence from carers indicates that changes to further education rules and cutbacks to adult education has had a negative impact on people with learning disabilities in relation to their ability to access further education.
- There is a statutory duty to provide education to people with special educational needs up to the age of 25, if they have a clearly identified educational need.
- Personalised budgets should provide the opportunity for people with a learning disability to fund their own personal development in respect of further education.
- Although life skill classes are still available, there are less of these. This means that the courses that are available are oversubscribed.
- Whilst there is a directive from central government 'Valuing Employment Now' aimed at encouraging employers and people with a learning disability into employment, – the reality is that employment is not a viable option for many.

- On the other hand, there are also a significant number of learning disabled people in Kirklees who would welcome the opportunity to work. This requires employers to be creative and flexible in the way they offer job opportunities, for example, job carving. However, in the current climate, it is recognised many employers are not as willing to make these compromises.
- Whilst employment is an aspiration for many people with a learning disability, their can be an impact on their eligibility for benefits and this cannot be ignored. The eligibility for benefits criteria is not straightforward, and there is anecdotal evidence to suggest that advice from employment agencies can tend towards the easier option of claiming incapacity benefit and not working.
- There is some evidence that the public sector does employ a number of people with learning disabilities. However, there is recognition from the public sector that they do not do as much as they could. Again, the economic situation and the reality of public sector finance impacts upon their ability to provide opportunities.
- Careers advice which signposts learning disabled people to further education courses and employment opportunities is lacking, although work is clearly being undertaken by the Children & Young People's Service, in conjunction with local colleges, and the SEN Project Board.

### **Recommendations**

1. That the Children & Young People's Service work with local colleges to ensure that life skill classes are available for all, but that additional weighting should be given to people with a learning disability who wish to access them.
2. That Job Centre Plus investigate the feasibility of implementing adjustments to their signing on processes for learning disabled people, enabling them to sign on with their Disability Employment Advisor on a less frequent basis. It is recognised that this may involve lobbying central government for a change in rules.
3. That the Council and its partners assess all vacancies, as they arise, to identify if they would be suitable for job carving or more flexible arrangements in order to make them accessible for people with a learning disability.
4. That Job Centre Plus and the employment agencies ensure that they actively promote employment opportunities for learning disabled people, rather than taking the easier option of claiming incapacity benefit.

## 6. TRANSPORT

### Valuing People

Access to transport is essential to enable people with learning disabilities to lead full and purposeful lives. However, they currently face many obstacles using public or private transport. Transport staff and operators may not understand their needs and people may lack the necessary support and training to become independent travellers.

- 6.1 The importance of transport to facilitate access to education, employment, leisure activities, health services, social networks and reduce social isolation was identified as a key theme by the Panel.

John\*, 39, lives in a rural village with his parents, where there are no specific activities that he can access. He is able to travel to town and to work on the bus without support as he has learned these routes; however new routes would have to be learned and his parents have been advised not to encourage this.

John's mum feels that he is financially able to manage because he lives at home (he pays board), he has a part time job, and he qualifies for some benefits. This money enables him to pay for a taxi once a week to take him to a social activity.

However, apart from this he is very reliant on his parents to take him to activities.

\* not his real name

- 6.2 John is not an exceptional case – many of the learning disabled people that the Panel spoke to needed assistance to access activities. Some were fortunate to have parents who were willing to take them to activities and pick them up again. However, those that do not live with parents and have made the step to independent living, face an increased risk of being socially isolated.

- 6.3 What are the options available to those who do not have parents able to give them lifts? None of the people that the Panel spoke to were able to drive. The majority were reliant on public transport, primarily buses.

### 6.4 Public Transport

- 6.4.1 Several of the learning disabled people that the Panel spoke to expressed their fear of using Huddersfield Bus Station, particularly in the evening. They had also had bad experiences with young people, for example, stealing bus passes. Service users of Kirklees Information Network travelled independently but tended to avoid school finishing times. Parents also expressed reluctance to let their son/daughter use the Bus Station on an evening.

- 6.4.2 This was explored with Metro, the West Yorkshire Passenger Transport Authority. Their view was that safety issues were more of a perception than actual reality. Although they were unable to provide a specific breakdown of incident data relating to Huddersfield bus station, or indeed elsewhere

within Kirklees, they advised that the number of actual security incidents compared to the footfall of 35,000 people a day was minimal. Anti social behaviour at bus stations across West Yorkshire has reduced by over 50% since 2003/04 and remains below the target level of 175 incidents per month (across all West Yorkshire bus stations).

#### 6.4.3 There are a number of security measures in place in Huddersfield Bus Station:

- Security staff who wear high visibility jackets – they should be either patrolling or can be located in the customer service office.
- Two Police Community Support Officers, funded by Metro, are dedicated to the bus station and tasked by the Huddersfield Neighbourhood Police Team.
- 16 CCTV cameras, which are monitored 24 hours a day, 7 days a week by the dedicated Metro Control Centre in Leeds. Staff in Leeds and at Huddersfield communicate by radio.
- Emergency help points that enable passengers to speak with the Metro Control Centre in the event of an emergency.
- The Bus Station is part of the 'Shopwatch' radio link with the town centre.

6.4.4 The Bus Station Manager has made an offer to take groups of learning disabled people around the bus station. This is already done for groups from Kirklees College and it involves introducing people to security staff; explaining how to access information and help points; and pointing out CCTV cameras.

### 6.5 On the Buses

6.5.1 Metro do not have control over individual bus companies and it is recognised that individuals may experience difficulties onboard buses, but this will be entirely dependent on individual drivers. It is conceivable that drivers may not realise that someone has a learning disability, and may therefore not offer assistance.

6.5.2 Metro do actively seek to influence driver training to ensure that it includes disability awareness. However, anecdotal evidence suggests that more work needs to be done with drivers.

### 6.6 Concessionary Passes

6.6.1 Free off peak bus travel is available to those with a moderate to severe learning disability, following application for a pass. This pass can be used from 9.30am to 11.00pm Monday to Friday, and all day Saturday, Sunday and public holidays. However, outside of these times, normal fare rules will apply. Where appropriate and necessary, the pass can include a companion to travel with a learning disabled adult free of charge. However, this does not seem to be widely publicised.

6.6.2 Metro are aware that the distinction between on peak and off peak travel, and the different fare rules, is an issue. They acknowledge that this is confusing, and they have looked at introducing a single concessionary card, available for a nominal fee, which would allow travel at all times of the day. However, they have not pursued this at the moment due to time and resources.

## 6.7 Travel Training

6.7.1 Travel training may involve walking and learning to cross the road safely or using buses and trains unassisted. It is the process by which a person learns to travel a specific route, between two different places, on their own and in a safe and responsible way. This trip can be as simple as someone finding their own way to the corner shop or as complicated as learning a difficult journey to another town or city.

6.7.2 Current provision in Kirklees is via Occupational Therapists in the Community Learning Disability Teams at Cullingworth Street and Greenhead Resource Unit. This service is health service led and is offered to very few people. It is also known that Kirklees College and Dewsbury College offer a travel training course.

6.7.3 Adult Services (Day Care Services) employ a part time member of staff to provide a travel training service to service users accessing in-house day care. A community contract of approximately £50,000 was awarded to Share (subsequently taken over by Mencap) who developed a travel training scheme A2B but this was stopped. Overall the approach is ad hoc with no consistent approach.

6.7.4 However, a travel strategy group was put together by the Learning Disability Partnership Board to develop a strategy. This is still in draft form and is awaiting consultation with management and partners, and agreement as to how it can be implemented. This strategy is based on Bradford's travel training project, which is recognised as the best in the area (see paragraph 6.8.2 for more information).

6.7.5 Many families or carers of learning disabled people would be willing to assist with travel training. However the cost of repeated bus or train journeys is prohibitive. A scheme which would enable companions to travel free of charge would take some pressure off services to provide travel training.

## 6.8 Good Practice

### 6.8.1 **Bus Buddies – Leeds**

- A three year project funded by the Department for Transport Urban Bus Challenge between 2002 and 2005.
- Its aim was to help people with disabilities use public transport, and provided 1-2-1 support to give people from socially excluded groups the understanding and confidence they need to use public transport in and around the Leeds area.



- The scheme was open to older people, learning disabled people, people with physical and sensory impairments, mental health service users, and people with long term illness.
- After an initial assessment, trained Bus Buddy volunteers travelled out on the public transport network with their client boosting their self-assurance and ironing out problems as they arose. When they felt their client had gained sufficient confidence to use the public transport network on their own, the Bus Buddy gradually reduced their support. The Bus Buddy Team worked closely with bus companies and other agencies to address some of the barriers which dissuade disabled people from using buses.
- At the end of the scheme, there was no funding available to continue with the project.

### **6.8.2 Bradford College – Travel Training**

- The Travel Training Unit at Bradford College provides mobility training for people with learning disabilities who live in the Bradford area. It is open to all non-independent travellers as well as to those who wish to learn a new route or simply improve their travel skills. They accept referrals for anyone with a learning disability from age 14 upwards.
- The Unit employs a team of Travel Trainers whose job is to ensure that the training is safe and successful. The training is free, conducted on a one-to-one basis and follows a unique learning programme specifically designed to meet the individual requirements of each trainee. The training programme has to be thoroughly planned and well supported, and must take into account all the variables that might occur during the training period.

### **Panel Findings**

- There is clear evidence that bus stations around Kirklees, and particularly Huddersfield, are not seen as safe places to be on an evening. This is despite a range of security measures. Metro believe that it is a perception shared by all sectors of the community rather than borne out by actual incident figures. However there is no doubt that it is deterring people with a learning disability from utilising public transport on an evening.
- Lack of awareness amongst some bus drivers that people with a learning disability may find it difficult to effectively communicate their travel needs, for example stating their destination or providing the correct fare, can make travelling less than a positive experience.
- That the rules on concessionary passes are confusing and that this makes it unnecessarily difficult for learning disabled people to use public transport. There is an opportunity for this to be rectified with the introduction of a single pass for use at all times of day. Clearer guidance could also be provided on whether a companion is eligible to travel free of charge.

- The Learning Disability Partnership Board has developed a travel training strategy, however this is awaiting consultation with management and agreement on implementation.

### **Recommendations**

1. That the Learning Disability Partnership Board work with Metro to develop opportunities for people with a learning disability to tour Huddersfield Bus Station and familiarise themselves with security features.
2. That Metro should review the security arrangements at bus stations across Kirklees to ensure that there is a more visible presence, in order to alleviate the perception of an unsafe environment.
3. That Metro implement a single concessionary pass for people with learning disabilities that can be used at any time, subject to a nominal fee in line with similar arrangements for the off peak concessionary passes. This should include free travel for a companion.
4. That the Learning Disability Partnership Board work with Metro and the bus companies to develop their approach to driver training. This could include using people with a learning disability and their families/carers to raise awareness.
5. That Adult Services progress the travel training strategy as a priority and ensure that there is a clear implementation plan.

## 7. LEISURE

- 7.1 The Scrutiny Panel recognised that essential to tackling social isolation and building friendships and relationships is the ability for people to actively participate in leisure activities and community life. The Panel wanted to explore in some detail just how easy it is for people with learning disabilities to access leisure facilities, not only those specifically aimed at people with a learning disability, such as Day Centres but mainstream community facilities such as pubs, clubs and sport centres; and to identify if there are any barriers to access.
- 7.2 There are many factors which can have a bearing on the types and frequency of leisure and recreational activities that are engaged in, for example: finance, transport, age and level of disability. Evidence to the Panel showed that while many people with learning disabilities are able to participate in some form of activity, in many cases they are unable to access these facilities independently and rely heavily on the support and assistance from their carers, support workers or family members. However, each individual circumstance varied ranging from some people engaging in no social activity on the one hand to someone participating in many activities.

**“people with good social networks live longer than those with poor networks”**

*[Kirklees Joint Strategic Needs Assessment 2009 referencing Acheson, D. (1998) Independent Inquiry into Inequalities in Health Report]*

- 7.3 It is known that social networks are important to health and well-being, and for most people consist of the relationships built with families, friends, work colleagues and team mates i.e. those networks that support everyday life. However, people with learning disabilities often have very limited social networks. Some have no family contact and depending on need may only get a support visit 3 times a week and they can then just be sat waiting for someone to visit. This can have a significant impact on their mental and physical health and increase social isolation and the feelings of loneliness. Depression is a real issue because they are not getting out and about.

### **Valuing People**

The government expects local councils to ensure that their local cultural strategies and service plans to encompass the needs of people with learning disability. This will include a review of physical access to leisure resources and ways to find out about them. Leisure will be an integral part of person centred planning.

- 7.4 Studies have suggested that learning disabled people have up to a third fewer social contacts than their non-disabled peers, and that these contacts are on the whole limited to their family, their carers and other people with learning disabilities. *[R. Pockney, University of Southampton, 2006 'Friendship or Facilitation: People with Learning Disabilities and their Paid Carers' Sociological Research Online Volume 11 Issue 3; citing Wesolowski 1987, Atkinson 1987, Richardson and Richie 1989]*
- 7.5 During their discussions with learning disabled people, the Panel paid

attention to their social networks, the relationships they had, and the opportunities they had to build further relationships.

- 7.6 It was observed by one of the carer's advising the Panel that a learning disabled person will often have a number of acquaintances who they will identify as friends, but rarely have a best friend.
- 7.7 The Panel spoke to a number of people with learning disabilities who were supported to live in the wider community. This support included regular visits from support workers, who were clearly valued by service users. When asked about their friends and the activities they undertook together, it became apparent that for several service users, they were identifying their support workers as their friends.
- 7.8 In itself, this might suggest a naturally close relationship between two people who spend a lot of time together; however it also became evident that for many, this was the total extent of their friendships. This lack of distinction between someone who is paid to support and spend time with you, and someone who chooses to spend time with you, is indicative of the limited social networks enjoyed by learning disabled people. The Community Support Workers said that although it can be difficult there is always a need to maintain professional boundaries.
- 7.9 There are many other factors which can have a significant impact on people with learning disabilities ability to participate in social activities. Mencap's Community Support Workers stated that in some instances many do not seem to want to participate in activities that might increase their social networks because they lack confidence and have very low self esteem. A lack of inclusion in social networks can be the result of factors including: poor social interaction skills, communication difficulties, unemployment, low skill base, prejudice, discrimination, and stereotype. In addition, activities and outings can very rarely be spontaneous as everything has to be planned and organised down to the minute detail.

#### **Parent**

*"I am not entirely convinced that attitudes towards learning disabled people had changed significantly and there is still a lot of learning to do".*

- 7.10 A representative from Kirklees Involvement Network said that although people with learning disabilities want to go to the pub or theatre there are many barriers and they are often reluctant to go out when it is dark because of worries about their safety. Despite a great deal of work being done to reduce hate crime, it is still a major issue. There is general under reporting for all categories, but for people with learning disabilities the figures remain low and an issue is that they do not often see the things happening to them as hate crime because it has been happening to them for so long.
- 7.11 The Panel sought to develop an idea of the types and range of activities and community facilities that people with learning disabilities are able to access.

## 7.12 Day Centres

7.12.1 Day Centres are only available for those people who are eligible under the Fair Access to Care eligibility criteria (FACS) i.e. those people who fall under the local authority's 'duty of care' or 'statutory duty'. There are two levels of charging for day services which participants pay out of their benefits.

7.12.2 For people that are not FACS eligible there are well being and community services, such as luncheon clubs and sport centres. Participants make a financial contribution to these services. It was acknowledged that such facilities for people with a learning disability are limited.

## 7.13 Mencap - Buddies Befriending Scheme

Janet\* is supported to live in her own home within the community, and looks forward to Thursdays when she goes out with her 'buddy' Alison\*. Janet and Alison were matched through Mencap in Kirklees' 'buddies' befriending scheme.

\* not their real names

7.13.1 Mencap in Kirklees run a 'buddies' befriending scheme, which matches a learning disabled person with a volunteer 'buddy', to support them in accessing local community facilities. A 'buddy' forms a one to one relationship with a person with learning disabilities, so that they can share activities such as leisure / sport / social / shared interests. The project helps learning disabled people make new friends through companionship with volunteers during their leisure time.

7.13.2 The project is clearly successful, however, demand far outweighs supply, and the waiting list for 'buddies' is long.

7.13.3 Mencap advertise for volunteers, however they do not get sufficient interest to meet demand and not everyone who applies to become a 'buddy' will be suitable, as it requires specific skills.

7.13.4 The scheme was originally funded by the Primary Care Trust, however this funding is no longer available. Mencap now fund the scheme from donations, however they are concerned that this is not viable in the long term.

## 7.14 Friendship / Dating Agencies

Alan's\* mum spoke to the Panel about her son, his life, and his aspirations. Alan is keen to emulate his siblings and have the same experiences as them. He would really like a girlfriend.

\* not his real name

7.14.1 **Stars in the Sky Yorkshire** - is a friendship agency that is run for adults with a learning disability who want to develop friendships and/or relationships. It currently operates in Leeds, Wakefield, Calderdale and Sheffield. It introduces its members to new friends through a diary of social events such as theatre trips; themed party nights; discos, etc. It also offers

support to members to develop relationships and for people who wish to meet on one to one dates.

7.14.2 **Kindred Spirits** - is a dating and friendship agency run by Jersey Mencap for adults with learning disabilities who live on Jersey. It costs £5 a year to join. The first one to one date is chaperoned by Kindred Spirits and they help to find a place to meet. They also run events throughout the year, for example, a speed dating night.

7.14.3 There is nothing equivalent to either of these within Kirklees.

#### 7.15 Kirklees Active Leisure (KAL)

7.15.1 Kirklees Active Leisure informed the Panel that they have a comprehensive programme of activities, however most of these are not integrated activities. An example was given of Kirklees Disabled Sports Club which is a disability user group which has a variety of activities on Monday nights at Huddersfield Sport Centre. This is a constituted club, which has the sports centre for an hour a week. There is also a special gymnastic club aimed at people with a learning disability and Downs Syndrome. Again, it is a constituted group that hires the facilities, with a lot of support from KAL.

#### 7.16 The Duke of Edinburgh Awards

7.16.1 The young people that attend Duke of Edinburgh have the opportunity to get out and about, and can choose between 8-10 activities to take part in. It provides an ideal opportunity to mix with their peers and make friends. This starts to break down the fear factor felt by some of their non-disabled peers, which in time permeates into the local community. The young people who participate in the scheme get a nationally recognised award, which is something that they may never have been able to achieve whilst at school, where academic qualifications may have been difficult to achieve. This helps to build confidence and self esteem. It is also largely an inclusive social activity.

7.16.2 The Duke of Edinburgh scheme in Kirklees is seen as a flagship for the country, and the Panel felt that this was due to the passion of the individuals who have created such a well regarded scheme. Duke of Edinburgh in Kirklees has no problem attracting volunteers to help run the scheme, but they do experience difficulties with their premises. Their current venue is not big enough for everyone and if they had access to another premise, they could start another scheme.

#### 7.17 Other Activities

7.17.1 One of the issues observed by the Panel was that many groups set up to provide leisure activities for learning disabled people have either folded or are struggling to keep going because of lack of funding.

7.17.2 The Community Support Workers stated that whilst it is part of their role to find different activities for the people they support, this is becoming increasingly difficult. Funding that used to be available has been withdrawn, for example, some of them used to do cooking at the technical college, but the funding has ceased. A local horse riding club has also shut

down. Ten pin bowling used to charge £1, which was affordable, but this has now changed. The reality is that a lot of the activities have dwindled.

7.17.3 Adult Services' Community Liaison provided the Panel with information on some of projects they have funded in the last 12 months and potential projects they are intending to fund in the next 6 months. They did, however, stress that it was important to emphasise that people with learning disabilities attend many of the other projects they fund where the main beneficiary group are not adults with learning disabilities. These projects are led by volunteers and therefore it is very difficult to collect that information from each organisation (approximately 200) as they do not/cannot identify it and some also feel that it's not their role to 'badge' people. The intention is to seek to commission projects that are inclusive. (See Appendix 2 for a list of projects currently supported by Community Liaison.)

### **Key Findings**

- There is a wide range of activities available within Kirklees, both mainstream and specifically targeted at people with learning disabilities, but there are barriers to access. These include:
  - travelling to and from activities;
  - most activities take place during the daytime;
  - fear of travelling at certain times including evenings and school finishing times;
  - financial restraints as not all activities are free or subsidised;
  - inadequate support mechanisms, which may be as they only receive infrequent support visits, or have little or no family contact;
  - lack of confidence and social skills and low self esteem;
  - the need for routine;
  - lack of spontaneity as socialising has to be planned well in advance.
- Hate crime is still a major issue within Kirklees and there is under-reporting of incidents from people with learning disabilities. This is linked to the fact that many learning disabled people do not identify incidents as hate crime.
- That whilst Kirklees Active Leisure offer a comprehensive programme of activities, these are not broadly accessible for people with a learning disability, who may require specific support at least initially to participate. Activities are also not widely promoted to learning disabled people.
- There are specifically constituted groups, for example, Kirklees Disabled Sports Club, who utilise leisure centre facilities. However, there is no evidence of Kirklees Active Leisure providing dedicated sessions for learning disabled people.
- The Kirklees Passport does provide access to leisure facilities for reduced fees.
- Personalised budgets are opening up opportunities for people to choose to access a wider range of activities.
- The Duke of Edinburgh scheme should be seen as a flagship, providing excellent opportunities for learning disabled people to integrate into a

mainstream activity. It is interesting to note that they do not struggle to recruit volunteers, however the capacity of premises remain an issue.

- Funding remains an issue for leisure activities provided by the voluntary and community sector. It can be difficult to maintain the viability of a project when initial funding ceases, or when match funding is required.
- The Adult Services' Community Liaison Team acknowledge that they do fund projects with organisations specifically targeted at learning disabled people. They are also confident that people with a learning disability do access other mainstream projects. However, it is very difficult to identify where this is happening as there are approximately 200 organisations receiving funding.

### **Recommendations**

1. That the Learning Disability Partnership Board commission a scheme similar to Stars in the Sky Yorkshire in Kirklees.
2. That Kirklees Active Leisure nominate a member of staff, who has an understanding of the issues facing learning disabled people, to act as a learning disabilities champion.
3. That Kirklees Active Leisure introduce dedicated sessions in leisure centres across Kirklees, taking into account the specific support needs, at least initially, of people with learning disabilities. This could be in line with sessions provided for other groups, for example, the over 50s.



## 8. HOUSING

### Valuing People

*“Housing can be the key to achieving social inclusion but the number supported to live independently in the community, for example remains small. Many have no real choice and receive little advice about housing options”.*

- 8.1 Housing can indeed be the key to achieving social inclusion and it also presents a real opportunity for people with a learning disability to achieve independence by choosing where they live and who they want to live with.
- 8.2 In Kirklees, an Accommodation Strategy for adults with learning disabilities “A Place to Live” was devised by the Learning Disability Partnership Board in 2008. It was developed through consultation with service users, carers, professionals, third sector providers and key partner agencies including Strategic Housing and Kirklees Primary Care Trust. Consideration was also given to best practice nationally. The Strategy is designed to inform the future direction of housing for people with learning disabilities within Kirklees and it aims to increase the number of, and range of, housing options and support choices.
- 8.3 The Kirklees Learning Disability Partnership Board’s vision for the future is *“to provide choice and opportunities for people to live as independently as possible in ordinary community settings.”*
- 8.4 The Panel has spoken with professionals and housing providers about different housing options; met with front line staff, carers, families and service users; and visited some of the options.
- 8.5 Key Players in Housing within Kirklees
- 8.5.1 The Council’s Strategic Housing Service delivers services to council tenants via Kirklees Neighbourhood Housing, and works in partnership with housing associations and the private rented sector to achieve suitable housing options.
- 8.5.2 The Council’s Adult Services delivers support services to enable learning disabled people to live in the wider community.
- 8.6 Housing Options in Kirklees
- 8.6.1 People with learning disabilities have a number of choices when determining where they will live and how they will be supported. This choice will be informed by a number of factors including: personal preference; availability; and severity of disability.

*“Has to be the support – it cannot be accommodation on its own.”*  
Karen Oates, Commissioning Manager – Access and Support.

- 8.6.2 The main housing options are:
- Residential home
  - Shared Lives

- Supported Living
- Renting a council house
- Renting from a housing association
- Renting from a private landlord
- Shared ownership or buying your own home
- Family investment in housing

8.6.3 A breakdown of where people known to Adult Services are living is detailed at Appendix 1. This shows that approximately 75% of learning disabled people known to Adult Services live with parents, relatives or other carers.

8.6.4 Of those who are not known to Adult Services, it must be assumed that the vast majority also either live with parents, relatives or other carers, or are living independently within the community. This assumption is supported by the fact that it tends to be people at the more severe end of the learning disability spectrum who are known to Adult Services.

8.6.5 The national survey conducted by Valuing People in 2005-6 estimated that 62% of adults with learning disabilities lived with parents or relatives, and that 20% lived in registered care provision. However, Valuing People Now placed a greater emphasis on access to mainstream housing services, home ownership and more secure tenancies, and supported living, and this may be reflected in the more recent figures.

8.6.6 The Panel has particularly focused on the following options – Shared Lives, supported living, and renting a council house.

## 8.7 Residential Home

8.7.1 Residential care homes can be large or small homes and are usually for people with high levels of need as support is provided 24 hours a day. Although many people in Kirklees still live in residential homes, this is changing. The aim of Valuing People Now and the Kirklees Accommodation Strategy is to move away from this type of housing and support option.

8.7.2 Most homes are either privately-owned or are owned by charities but a small number are owned by Kirklees Council. All are registered with the Care Quality Commission which makes sure that each service is regulated and of a good standard. In 2008, the Kirklees Accommodation Strategy acknowledged that there was some scope for improvement in the quality of these services.

8.7.3 To live in a residential home, people have to be assessed by the Council's Adult Services Care Management Team, and most of their benefit money will go towards paying for their place in the home and care costs. Residents receive a small personal allowance for their other expenses.

8.7.4 The Panel has made a conscious decision not to focus on residential care, primarily because it caters for those at the more severe end of the spectrum who are more unlikely to be able to explore opportunities to live independently within the community. There is also a move away from this type of housing and support option within Kirklees.

## 8.8 Shared Lives (formerly Adult Placement Scheme)

8.8.1 Members of the Panel met with the Shared Lives Team Manager and a number of Shared Lives carers during the course of the project to explore the scheme and the way in which this housing and support option helps people with learning disabilities live within the community.

8.8.2 Shared Lives aims to keep learning disabled people in the community within a family setting, providing an opportunity for people to maintain their independence and lead the lives they want, with support. It can provide the opportunity to do things that a person with learning disabilities may not usually do – for example, a person in their 30s being cared for by parents in their 70s, will not necessarily have the opportunity to access activities that other people their age enjoy. Shared Lives offers both long term placements and short term breaks. It has a very personalised approach and the Team take time in establishing matches. It is also flexible depending on what a carer can offer and matches can be developed over a period of time.

*“I think this is where the Shared Lives scheme is good because you are not asked to do more than what you are capable of, and you are partnered up, and it is friendships.”*

**Emma\*, home-based Shared Lives Carer**

\*not her real name

8.8.3 All carers have extensive assessment and background checks and are trained to specific national standards which are delivered by the Shared Lives Team and Kirklees Council corporate training. The Shared Lives Team are also responsible for supporting carers, service users in placements, and fulfilling all care standard requirements.

8.8.4 The Shared Lives Team hold publicity events and have a dedicated website publicising the scheme, however it is necessary to be referred by Adult Services who will carry out a Community Care Assessment.

8.8.5 Long term placements offer the opportunity for learning disabled people to live in ‘ordinary’ households, each offering something different. Carers range in age from late 20s to early 70s, and placements may be with families, single people or couples. Shared Lives currently support 32 long term placements.

8.8.6 Short term breaks originally saw learning disabled people going to a carer’s home, to give their regular carers a break. However this has evolved over time, and taken into account that many people said that it was better for their relative to remain at home and the Shared Lives carer come to them. This is particularly important for people with learning disabilities who often need continuity. Many of the short term break carers, or ‘home based carers’, have built relationships over time with service users. Shared Lives currently support 115 people with short term breaks.

Emma\* has been a home based Shared Lives carer for about 6 years, providing respite for carers. At present she looks after 3 different people, who are elderly or infirm, for half a day, or a day, a week. She can also be called upon to provide emergency cover, when someone will come and live with her for a short period of time at very short notice. Emma also provides short breaks for people with learning disabilities and has a lady who stays with her for 6 weeks a year – almost a holiday.

\*not her real name

8.8.7 All the Shared Lives carers acknowledged the importance of having a break, and being able to access respite care.

*“We get a scheduled break for 2 weeks a year and one weekend in every four, which is vital I think when you have got a home and a family as well. You spend so much time focusing on these people that you have invited into your homes, that you take in as part of your daily living, your own home. If you have children, you do sometimes just need a little time out and spend with them.”*

**Kirsty\*, Shared Lives Carer**

\*not her real name

8.8.8 The Panel has been impressed by the dedication of the Shared Lives carers to ensuring that people with learning disabilities get the opportunity to be a part of a family, live within the community, and have choice about how they lead their own lives. The Panel heard about the benefits of long term placements and heard how they can be used to:

- Establish routines and develop social skills, making social inclusion easier;
- Provide a stepping stone to more independent living;
- Provide a supportive family environment and help to develop relationships with the service user’s biological family.

*“The difference between a Shared Lives placement and somebody who lives in residential care is that the biological family is always talking to the same person, they are not talking to different members of staff; so families can talk with the carers and know that their relative is well.”*

**Shared Lives Team Manager**

8.8.9 It was also clear, from the Panel’s interviews with Shared Lives carers, that they maintained contact even after a person had moved on from the placement – just as would happen in a real family. Carers spoke about the need to balance maintaining this contact, with also establishing some distance.

8.8.10 Carers have a slightly ambiguous status, which reflects the national picture. They are not volunteers as they do get paid an allowance. However, they are not classed as employees and do not get benefits such as national insurance, holidays or pension contributions.

8.8.11 Currently, Shared Lives long term carers receive a weekly fee paid by the Council, and the fee is determined by the degree of special needs of service users as identified in their community care assessments. There is also provision to make additional payments, where an individual service user needs intensive support. This structure of payments has been in place

since the 1980s and was based on the rate the Council used to pay for placements in residential care homes. There are no set national rates for payment to Shared Lives carers, and therefore models and rates of payment vary widely.

8.8.12 This current structure is no longer felt to be appropriate and will struggle to meet future needs. It is estimated that the scheme needs to expand to become 8% of the total residential provision in Kirklees and 10% by 2015. Many of the current carers are approaching retirement age and younger carers are indicating that they may have to leave the scheme as they believe that the structure of payments does not fully acknowledge the support that they provide or the costs associated with supporting an individual. Recent recruitment events have not been successful and feedback has pointed to the structure of payments as a significant issue.

8.8.13 A report went to Cabinet on 2 March 2010 proposing a new model of payments to carers and a new system of service user charging – this was subsequently agreed. This directed that:

- A weekly basic fee be paid to the carer by the Council, based on the structure of payments to Kirklees foster carers; together with a weekly contribution from the service user to the carer (i.e. a board payment, funded from the service user's income support or pension).
- A weekly payment from the Council to the carer, for the support they provide to the service user, which will take the form of a 'skills' payment based on the carer's assessed competencies.

## 8.9 Supported Living

8.9.1 Supported living is a housing and support option that is becoming increasingly popular in Kirklees. There are two common forms of supported living:

- Floating support – where a person with a disability has their own home and the support they need visits them in their home on a daily or weekly basis.
- Accommodation based support – where the support provided is based in or tied to a property or accommodation. Support is provided on-site, up to 24 hours

8.9.2 Supported People funding, at any one time, supports around 112 learning disabled adults with floating support and 43 accommodation spaces. Accommodation spaces included those developed by the Council, in partnership with Chevin Housing Association, at Brighton Court and Wilton Terrace. Each scheme provides six self contained flats and provides up to 24 hour support.

## 8.10 Renting a Council House

8.10.1 Renting a house from the Council is a way some people with a learning disability in Kirklees can get an affordable place to live. Most people get a council house by joining the Choose 'n' Move Scheme – the choice based lettings scheme. During the course of the project, the Panel has explored this Scheme and the support available to people with learning disabilities

who need to negotiate the system.

- 8.10.2 Prior to the launch of Choose 'n' Move, stakeholder workshops were held with carers of learning disabled adults and impact assessments were carried out to ensure that information is accessible for people with a learning disability.
- 8.10.3 When an individual identifies that living in a council house may be an option, the first step would usually be for the service user to approach Housing Options, sometimes through their social worker or care manager. Housing Options staff will work closely with an individual to identify the support that they need and the most appropriate accommodation. A person with a learning disability will automatically qualify as at least Band B, and depending on individual circumstances may be awarded Band A, if there were multiple complex needs.
- 8.10.4 Once registered, an individual can look through the property adverts on the website or in the weekly newspaper, and bid for properties. Kirklees Neighbourhood Housing (KNH) do specifically target inactive bidders to check if there is a reason why they are not bidding, and if someone did not understand the choice based lettings scheme, then assistance would be provided. KNH also actively contact vulnerable people if they think that a property might be of interest and would assist in putting in a bid, or put in a bid on their behalf.
- 8.10.5 The Panel was concerned that a strict time limit was imposed for accepting offers of housing, and that this might prove difficult for a person with learning disabilities – for example, if establishing support would be a deciding factor in accepting an offer. KNH advised that, in exceptional circumstances, the Area Housing Manager might allow a limited time extension to the offer period in order to allow a vulnerable person more time. However, this would only be for a matter of days as pressure to avoid rent loss limited flexibility.
- 8.10.6 If an offer was accepted, but the applicant's carer/support worker was seeking more time for them to move in, it would generally be expected that the tenancy would have to commence by the next appropriate start date. However, as long as rent was covered and the property was secured, then the move in date could be delayed for weeks. In respect of the rent, Housing Benefits could be approached about a rent payment overlap, although this would be a discretionary decision.
- 8.10.7 Members of the Panel explored whether there was scope for individuals to try independent living prior to committing to a full tenancy, or a 12 month introductory tenancy. This is not currently available, but KNH were willing to explore this with colleagues in the Strategic Housing Service.
- 8.10.8 Members also felt that there was merit in exploring whether a similar scheme to that aimed at young people, which provided semi-furnished properties, could be used for learning disabled people trying independent living for the first time. KNH do support tenancies with white goods and big pieces of furniture and acknowledged the benefits that such a scheme could have.

8.10.9 Once an individual has commenced a tenancy, support is still available from KNH, who view themselves as a conduit to ensure that tenants receive the right kind of support from the right people. Support could come from Estate Management Officers who handle the day to day management of a group of properties and will support individuals depending on their needs.

8.10.10 KNH are also in the process of developing a toolkit 'People First' which is designed to identify people's individual needs and how to access help if necessary. A package of work is being specifically designed for adults with learning disabilities.

8.10.11 It is recognised that the cluster properties at Pennine Crescent are working well and provide a supportive community for people with learning disabilities. Support is available for these tenants through MENCAP.

8.10.12 KNH maintain a database of information on all their tenants, which flags up particular needs. If, for example, repairs were needed to a property and it was known that the tenant had learning disabilities, then special arrangements would be put in place.

#### 8.11 Renting from a housing association

8.11.1 Housing associations are independent not-for-profit organisations that provide low cost social housing, and they are major providers of new homes for rent in Kirklees. Much of the accommodation for supported living services for people with learning disabilities in Kirklees is currently provided by housing associations.

8.11.2 In the first instance, anyone who is interested in renting from a housing association would be directed to have an assessment with their social worker or care manager who could discuss support arrangements.

#### 8.12 Renting from a private landlord

8.12.1 It is known that many people with a learning disability choose to rent a home from a private landlord because this can be a quick and easy way to find suitable housing.

8.12.2 In the first instance, service users are advised to contact Kirklees Housing Options and Support Service who can discuss support arrangements, eligibility, and whether benefits payments are sufficient to meet the costs of rent. The Council does have a Landlord Accreditation Scheme, which private landlords can sign up to indicating that they have agreed to meet certain standards of accommodation.

#### 8.13 Shared ownership or buying your own home

8.13.1 More people with a learning disability now buy their own homes, and many are able to do this through shared ownership. There are a few specialist mortgage advisers who arrange mortgages for people with learning disabilities. As with most housing options, the first step for a person with learning disabilities would be to approach a social worker or care manager through Gateway to Care.

## 8.14 Family investment in housing

8.14.1 Family members could help a person with a learning disability to get a home of their own, and there are a number of ways of doing this:

- Outright purchase
- Shared ownership
- Joint ownership
- Company ownership
- Buy to rent
- Inheritance
- Property in a discretionary trust

## 8.15 What's missing?

8.15.1 When the Learning Disability Partnership Board were putting together the Accommodation Strategy in 2008, they conducted a survey of service users. This identified the following gaps in provision:

- a lack of choice in living options;
- too little supported living accommodation within ordinary communities, especially for people with high support needs;
- a lack of accommodation targeted at people with specific additional needs including: older people with dementia, young people with profound and complex needs, people with physical disabilities and people with behaviours that challenge services;
- a need for more support to help people access mainstream housing;
- too much reliance on registered nursing and social care home placements.

8.15.2 The Panel has not found substantial evidence that this picture has changed, but recognise that it will be a phased process.

8.15.3 Service providers recognise that not everyone with a learning disability will access their services, but their aim is to ensure that where people need and wish to access services, they are able to do so as efficiently and easily as possible.

## 8.16 Additional areas of investigation

8.16.1 The Panel questioned whether the Housing Options and Support Service used the Board Talk scheme that is used successfully elsewhere within the Council. It was observed that this does not currently happen but officers agreed to discuss it at the next Learning Disabilities Housing Sub Group meeting, with a view to asking the group to work with Housing Options to put a scheme in place.

8.16.2 Staff receive training around specific client groups and the needs of customers. New staff are given the opportunity to 'shadow' partners and providers working with people with learning disabilities.

## **Key Findings:**

- The Kirklees Accommodation Strategy's vision is to provide choice and opportunities for people to live as independently as possible in ordinary



community settings. There is evidence that all Council services are signed up to this approach and that it forms the basis of their approach to housing. However, it is recognised that whilst the emphasis may be on choice, it simply is not possible to provide housing that meets everybody's choice all of the time.

- Suitable accommodation is critical, particularly its location which may be influenced by a number of factors including: physical location in relation to accessing shops, transport routes, families and friends.
- However, suitable accommodation on its own is not sufficient to meet the needs of people with learning disabilities. An appropriate package of support is also imperative.
- Three quarters of those known to Adult Services live with their parents, families or carers. It must also be assumed that of those who are not known, that the vast majority either live with parents, relatives, carers or live independently within the community.
- There are a wide range of housing options available to people with a learning disability. However it is recognised that it can be a big step for someone to go from living with their parent/carer to living independently (irrespective of the living and support arrangement). Parents can also be very apprehensive about allowing their child to take this first step towards independence.
- Shared Lives is an excellent scheme, providing a valuable opportunity for people with learning disabilities to be part of ordinary family life and providing a welcome respite break for carers. The Shared Lives carers are to be commended for their commitment and dedication.
- The Panel is pleased to note that a recent report to Cabinet has recognised the contribution of Shared Lives carers and has put in place a new model of payments.
- In North Kirklees, Brighton Street and Wilton Terrace provide supported living accommodation in partnership with Chevin Housing Association. There is no similar scheme in South Kirklees.
- A strict time limit is imposed on people accepting offers of housing through Kirklees Neighbourhood Housing, which places people with a learning disability at a potential disadvantage. Although it is recognised that the timescale is enforced to minimise rent loss, it fails to recognise the difficulties that may be faced by a learning disabled person. For someone who struggles with spontaneity, needing to make a decision of this magnitude under tight time constraints is very difficult. There is also a need to ensure that support arrangements are established, which may be critical to the success of the tenancy.

## **Recommendations**

1. That Adult Services and Kirklees Neighbourhood Housing work together to develop a scheme which would enable learning disabled people to trial independent living, prior to committing long term to such an arrangement.
2. That Adult Services and Kirklees Neighbourhood Housing work together to develop a scheme, similar to that in place for young people, where a first property would be part-furnished.
3. That a report be brought to the Health Inequalities Scrutiny Panel in September 2010 explaining the impact that the new model of payments has had on recruitment and retention of Shared Lives carers.
4. That the Council look to develop a similar scheme to Brighton Street and Wilton Terrace across the rest of the district.
5. That Adult Services and Kirklees Neighbourhood Housing work together to develop a scheme, similar in style to older people's sheltered accommodation, which would enable learning disabled people to live independently within a safe environment. This would provide their own living space but also communal areas and activities.
6. That the Learning Disability Partnership Board work with the Housing Options and Support Service to implement the use of Boardtalk by this service.
7. That Kirklees Neighbourhood Housing should extend the timescale available to people with learning disabilities when asking them to make a decision over accepting a tenancy.

## 9. HEALTH

9.1 The Scrutiny Panel heard evidence which showed that people with learning disabilities can often be predisposed to a wide range of health problems; such as epilepsy, mental health problems, and dementia (particularly for those people with Down's Syndrome).

9.2 Information from the 2009 Joint Strategic Needs Assessment for Kirklees, makes reference to research carried out by the Disability Rights Commission, which highlights the scale of inequalities faced by people with learning disabilities in England and Wales. For example:

- *People with learning disabilities were 58 times more likely to die before the age of 50 than the general population.*
- *People with learning disabilities were 2.5 times more likely to have health problems than other people.*
- *Four times as many people with learning disabilities died of preventable causes as people in the general population.*

### Valuing People

Few people with learning disabilities access health screening services with uptake for breast and cervical screening being especially poor.

9.3 The Scrutiny Panel wanted to explore what was being done to address the health inequalities being experienced by people with learning disabilities; and what action was being taken to ensure that they were accessing health screening programmes. The Panel met with representatives from: Calderdale & Huddersfield Foundation Trust, South West Yorkshire Foundation Trust, and Mid Yorkshire Hospitals NHS Trust.

### 9.4 Learning Disabilities Register / Health Action Plans

9.4.1 Evidence heard by the Panel showed that the Government introduced the Direct Enhanced Service (DES) which requires GPs to keep a learning disabilities register. The DES is aimed at targeting the provision of health checks towards adults with a learning disability who have the most complex needs and therefore are at the highest risk from undetected health conditions and will benefit most from receiving an annual health check. This health check should include health screening as a way of preventing illness.

9.4.2 In addition, the Government intended that from June 2004, all people with learning disabilities should be registered with a GP; and by June 2005, should be offered a Health Action Plan (*DOH 2001*). Health Action Plans require a medical health check and thorough assessment of health needs. Health Facilitators should also be identified for each individual. For everyone on the GP's register, the GP receives £50 plus an additional £50, for completing the Health Action Plan.

9.4.3 A representative from Calderdale & Huddersfield Foundation Trust informed

the Panel that the expectation is that information from the DES registers will enable them to find out how many people are going for cervical screening and breast screenings. However, at the time of this review this information is not known.

9.4.4 The Panel was unable to ascertain with any certainty the extent to which GPs are keeping a register or whether this is being monitored. It was observed that this had an impact on the inequalities agenda as some practices will complete the register; whereas other practices won't. The GP practices that do not complete the register tend to be in the areas where the greatest health inequalities already exist.

9.4.5 A representative from Adult Services initially suggested that completing the register does not get the same priority as some of the other registers GPs have to complete, so the numbers of people known to the GPs in Kirklees is less than the numbers of people known to Adult Services. However, this has not been borne out by other evidence (which suggests that the GP registers are identifying large numbers not known by Adult Services). This may be due to Adult Services actively working with GP practices, which should all now be signed up to completing the register.

## 9.5 Information Sharing Protocols

9.5.1 Information to the Panel suggested that within the Children's Act there are information sharing protocols; however, the same duty does not apply to adult safeguarding. While the local authority is able to share the information it holds with health organisations, it appears that this arrangement is not reciprocal. The Panel's understanding is that the GPs register can be shared with other health bodies but because of data protection, a small number of GPs have asked that information from the register not be shared with the local authority.

9.5.2 It is known, for example, that health partners are aware of 600 people in the South Asian community in Kirklees with learning disabilities, who are not known to the Council. Information cannot be shared and therefore the Council is unable to ascertain if these individuals are in need of support.

9.5.3 Questions were asked by the Panel, but members remain unclear as to whether there is sharing of information between the various partners involved in the health and social care of people with learning disabilities.

## 9.6 Appointment Letters

### **Case study**

Despite sending repeated appointment letters, health professionals failed to understand why Peter had not turned up for his hospital appointments. It was to later transpire that Peter was unable to read or write.

9.6.1 The Panel was concerned that one of the reasons why people with learning disabilities were not accessing health screening programmes was that many are unable to read the appointment letters they are sent. Having failed to respond to appointment letters, they may then be taken off the list.

It is not believed that any follow up work is done by screening services to check why an individual has not responded to an invite for screening. The Panel raised this issue with each of the Trusts and their response it outlined within each of the following sections, dedicated to the individual Trusts..

## 9.7 Calderdale & Huddersfield Foundation Trust

9.7.1 The Panel was informed that Calderdale & Huddersfield Foundation Trust is served by a Matron, and when a person with a learning disability is admitted, the Matron receives an e-mail alert to inform her of the admission or pending outpatient appointment. For all patients who have an alert, the Matron can then support the individual and carers as necessary, and make any adjustments in the pathway of care as necessary.

9.7.2 The Matron will have access to the completed GP learning disability registers from April 2010, and this will be cross referenced with their records to advise staff if someone has a learning disability. There are plans in place to put an alert on all patients on the PAS and EDIS (A&E system).

9.7.3 Calderdale & Huddersfield Foundation Trust informed the Panel that work is being done with clinical records to look at how appointment letters are sent out and other ways of communicating with patients including telephone calls and text messages.

9.7.4 The Trust has developed Vulnerable In-Patient (VIP) Cards, which are pocket sized cards which contain vital personal information. It is hoped that everyone with a learning disability will have one of these. This practice has been shared with Mid Yorkshire Hospitals Trust, who are responsible for people living in North Kirklees.

## 9.8 Mid Yorkshire Hospitals NHS Trust

9.8.1 The Strategic Health Facilitator for people with learning disabilities at Mid Yorkshire is funded by NHS Wakefield Commissioners and is employed by South West Yorkshire Foundation Trust.

9.8.2 The Trust has, over this last year, delivered a training package on learning disabilities to key staff. This was delivered with the help of carers. There are now 45 Learning Disability Champions across Mid Yorkshire Trust – this includes consultants and anaesthetists.

9.8.3 If the Trust is aware that someone has a learning disability, then when they come into the hospital that will have a patient with a learning disability form. They are then case managed by the Matrons.

9.8.4 At the moment, in day surgery, a person with a learning disability would be identified at the pre-screening assessment. The day surgery sister would then advise the Community Team Learning Disabilities and the Strategic Health Facilitator. A person would then be offered support. Mid Yorkshire acknowledge that work needs to be done to 'flag' patients when they enter the system.

9.8.5 Although once a person is in hospital the duty of care rests with Mid Yorkshire, the hospitals do recognise the expertise of carers in working with

a person with a learning disability.

- 9.8.6 The Panel was concerned about the potential impact of the forthcoming Mid Yorkshire reconfiguration and the impact this could have on learning disabled people. The Trust has acknowledged this, and intends to undertake awareness raising of reasonable adjustments.
- 9.8.7 The Trust acknowledges that when the Strategic Health Facilitator is not on site there is a gap in support. There is recognition that a Learning Disability acute liaison nurse service is needed. A business case has been submitted to both NHS Wakefield and NHS Kirklees to fund this service, this was submitted last September and as yet no decision has been shared. The benefit of this approach would be that the nurses could be a resource on wards, whereas the Strategic Health Facilitator's focus should be at a strategic level.
- 9.8.8 Mid Yorkshire Hospitals NHS Trust advised that they are unable to send out appointment letters in a different format at this present time. This is currently being worked on.
- 9.8.9 The Trust's Patient Experience Group had identified that information on common procedures in hospital was not readily available. Work had been undertaken to produce information in a pictorial format – for example, to explain the process of having a blood test.
- 9.8.10 There have been efforts to bring the support for learning disabled people into the mainstream. This has included, for example, revisiting the pathway for epilepsy care. Traditionally, a learning disabled person would have been supported by a psychiatrist, whilst the general population would have been treated by a neurologist. This has now been rectified so that treatment is through the neurologist, but with additional support in place.
- 9.8.11 Mid Yorkshire have also confirmed that they have adopted the VIP cards, developed by Calderdale & Huddersfield Foundation Trust.

## 9.9 South West Yorkshire Foundation Trust

- 9.9.1 The Trust provides services across Kirklees, Calderdale and Wakefield and provides a specialist learning disability health service. There are two key strands to this.
- 9.9.2 The first strand is a community nursing scheme. The second, for someone who needs more support, is a specialist healthcare service. The specialist healthcare service has three strands – inpatient services; community based assessment and treatment; and working with other organisations to help provide support. The Trust also provides low level secure services locally, and has access to medium secure services on a regional basis.
- 9.9.3 Services provided include: providing formal assessments; support to carers; psychology services including anger management and basic behavioural analysis; speech and language services; diet and weight management; occupational health; aids and adaptations; physiotherapy services for those who cannot access mainstream services; interventions; and treating mental health issues that accompany learning disabilities.

9.9.4 The Trust recognises that transition is a difficult period. Once a person is 18 they will largely be supported by their GP, who may have a limited understanding of their needs. There is a big difference in resources for children and those available for adults.

9.9.5 The Trust do face pressure to provide services focusing on highly complex needs, although they do support GPs to offer certain health checks, for example.

9.9.6 The Trust also send out appointment letters in alternative formats, for example pictorial, if required. However, the emphasis is on providing information in other formats and a letter would usually only be sent as a reminder to the carer.

### **Key Findings:**

- People with learning disabilities are often predisposed to a wide range of health problems such as epilepsy, mental health issues, and dementia.
- Uptake of health screening services, such as breast and cervical screening, is particularly poor amongst people with learning disabilities. This is due to a number of factors including: irregular attendance at doctor's surgeries; limited understanding of the purpose of screening; and difficulties in reading and understanding appointment letters.
- Although GPs are required to complete a learning disabilities register, it has been impossible to ascertain with any certainty whether this is happening in practice.
- Information is not flowing between the Council and its health partners. Although there are information sharing protocols for children's services, the same duty does not apply to adults. Whilst the local authority does share the information it holds on people with learning disabilities, this is not reciprocated by health partners. This has been attributed to data protection legislation by some health partners; however the Panel remain unconvinced that this is correct.
- It is recognised that in some cases, GPs are respecting the wishes of parents by not sharing personal information – but in removing this aspect of the information, it renders it of little use.
- The Health Action Plans are a valuable tool in assessing the health needs of people with learning disabilities. However, the Plans are not fully implemented across all of Kirklees and awareness of them is limited.
- The means by which health partners communicate with learning disabled people is inconsistent and does not always take into account their individual situation. Although there are examples of letters being sent in easy read formats or telephone calls – this is patchy and appears to be dependent on the compatibility of computer systems. This is of particular concern in respect of health screening, where if appointments are missed, individuals can be taken off registers.

## **Recommendations**

1. That NHS Kirklees introduce early screening for dementia, for people identified as having a learning disability.
2. That the Director of Public Health, in her dual role with the local authority and NHS Kirklees, develops an information sharing protocol based on reciprocal arrangements.
3. That NHS Kirklees put in place promotional activity around the Health Action Plans, to raise awareness and increase the take up of this valuable resource.
4. That the Director of Public Health facilitate the sharing of good practice amongst health partners in respect of appropriate communication with learning disabled people. This will help to minimise health inequalities, whereby those in North Kirklees receive one service, and those in South Kirklees receive another.



## **10. CONCLUSIONS**

Whilst sufficient evidence has been presented to the Scrutiny Panel to show that there are certainly mechanisms in place to enable people with a learning disability to participate in the wider community, this is not without its challenges. Social isolation and loneliness/fear remain prevalent, and there are significant and substantial barriers to inclusion in practice.

### **Transition**

- It is recognised that the carers' experience of transition in Kirklees has been less than positive in the past, and that it can be a difficult and stressful time.
- There has been some acknowledgement by the Council that there needs to be improvement and it has been given priority locally. The aim is to get it right first time.
- The Panel remain concerned that to deliver this requires adequate resources in the Transition Team.
- Those not eligible for statutory services are at risk of 'falling off the radar' and the Panel believe that better management of information would mitigate this.

### **Further Education and Employment**

- Whilst further education and employment may not be suitable or feasible for everyone, this cannot be assumed to be the case for everyone.
- The public sector has a responsibility to lead by example in respect of employing learning disabled people.

### **Transport**

- Transport facilitates access to education, employment, leisure activities, health services, social networks and reduces social isolation.
- It is therefore of concern that many learning disabled people say that they are frightened of using Huddersfield bus station, particularly in an evening and at school finishing times.
- Opportunities for travel training are currently very limited in Kirklees and this needs to be seen as a priority by the Council.

### **Leisure**

- The ability and opportunity to participate in leisure activities is essential to tackling social isolation and building friendships and relationships.
- There are a wide range of activities within Kirklees, but there are also significant barriers to access. Activities seem to start and stop due to funding restrictions.
- Personalised budgets and changes to the rules regarding support packages, present an opportunity to engage in a wider range of leisure activities.

### **Housing**

- Although the vision is to provide more choice on housing options for people with a learning disability, in reality this choice remains limited.
- Housing on its own is insufficient to achieve independence; a strong support package is also required.

## Health

- There are pockets of good practice, but this is not consistent across the district and in some cases is contributing to health inequalities in Kirklees.
- Information sharing between the local authority and local health partners is poor, and it is hard to see how a coordinated approach to support can be achieved whilst this barrier remains.

The Panel's work has centred around key themes, however one of the emerging issues that cuts across all of these, is the very real fear that parents have about the future for their children. As carers get older, and people with a learning disability live longer, a new set of challenges are emerging. For example, carers may no longer be able to cope with the demands of supporting a learning disabled person.

Families will find themselves having to make difficult and fundamental decisions about the future. Many do not wish to pass on the 'burden' to siblings, but are unsure whether services will provide the same level and quality of care. There is also the increasing possibility of people who have not previously been in contact with services, suddenly requiring a comprehensive package of support. It is impossible for services to plan adequately.

In order to adequately address health inequalities across Kirklees, there needs to be a partnership approach. It is apparent that there is disparity in the service and support available in the north and south of the district. The mechanisms for good partnership working are in place, through the Learning Disability Partnership Board's Health Sub Group, however these opportunities are not being maximised and information sharing remains patchy.

Part of the Panel's initial remit was to develop scrutiny good practice in respect of engaging a vulnerable and hard to reach group in the scrutiny process. The Panel's findings are firmly rooted in the information provided by people with a learning disability and their families and carers. They have been fully involved throughout the Panel's investigation and the Panel intends to share its findings by producing an easy-to-understand version of this report. The Panel also intend to meet with those who contributed to the review to share their findings.

An Action Learning Group will be established at a local level, with key commissioners and service providers, to meet at key intervals. It is envisaged that this group will meet immediately after the conclusion of the project to review findings and share learning. The Group will then continue to meet at regular intervals to share implementation of the recommendations and the impact of this.

The Panel would like to extend their thanks to everyone who has contributed to the review.

## **Bibliography**

### National

- Valuing People Now – 2009, Department of Health
- Valuing People – A New Strategy for Learning Disability for the 21<sup>st</sup> Century – 2001, Department of Health
- Death by Indifference – March 2007, Mencap

### Local

- 'A Place to Live' – Accommodation Strategy for adults with learning disabilities living in Kirklees
- Joint Strategic Needs Assessment 2009 – Kirklees
- Making services better for people with Learning Disabilities from Black and Minority Ethnic (BME) Communities – Gurmit Singh Jauhal
- 'Get Going' – A handbook of services and opportunities for adults with learning disabilities in Kirklees – March 2009, Kirklees Council
- 'A Home of my Own' – A guide to housing in Kirklees for people with learning disabilities – February 2010, Kirklees Council
- 'Keeping you in the Picture – Day Opportunities in Kirklees' – Summer 2008, Kirklees Council