

A FORMAL INVESTIGATION UNDER THE  
DISABILITY DISCRIMINATION LEGISLATION TO  
EVALUATE THE ACCESSIBILITY OF HEALTH  
INFORMATION IN NORTHERN IRELAND FOR  
PEOPLE WITH A LEARNING DISABILITY

June 2006 to December 2007

**Equality Commission**

FOR NORTHERN IRELAND



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A summary version and an easy read version of this document are available on request and on the Commission's website



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## FOREWORD

For everyone, health is a vitally important issue. Our state of health makes a significant difference to the kind of lives we lead. Most of us take for granted that we can have easy access to all the information that we need about our health, about any conditions we may have, about treatment and medication. This, however, is not an assumption that can be made in all cases.

That was the starting point of this investigation. Evidence existed that people with a learning disability are more likely than the general population to experience poorer physical and mental health. In these circumstances access to information is even more important and the Equality Commission considered it timely to look at the extent and quality of information available to people with a learning disability.

The fundamental principle is that people with a learning disability are entitled to the same standard of health provision as everyone else. Current public policy is that services, including health services, are offered within mainstream provision to those with a learning disability. They, in turn, address a diverse and often complex variety of services to meet their health needs. The understanding of those needs, the quality of communication from healthcare staff and the availability of relevant and accessible written information are key issues in this context that will require appropriate adjustments from the health service.

The investigation was intensive, carefully conducted, broadly cast and rooted in the practical experiences of those who were at its core. The process involved widespread consultation with, and participation, by people with a learning disability, with their families and carers, with the health service and healthcare professionals and with voluntary and community sector organisations who represent people with a learning disability. These engagements shaped the thinking and the approach throughout. Written health information was evaluated by people with a learning disability and, separately, by panels of carers; verbal communications were assessed through qualitative research; advocacy groups played key roles.

Much good practice was found but much room for improvement was also identified, notwithstanding the reasonable adjustment duty.

The report sets out in a comprehensive, clear and focused way those areas where the needs of people with a learning disability are not being adequately met. Its style is direct and it captures eloquently the voices and experiences of those who are most directly affected. It is written with sensitivity and awareness of the deeply personal impact which relationships with healthcare providers can have.

The findings will speak for themselves. The recommendations are straightforward and inexpensive. They will call for changes of individual behaviour and practice by many in the health service and for organisational responses as well. But they are practical, achievable and will make a difference.

These are real issues. The Statement on Key Inequalities in Northern Ireland, recently published by the Commission, identifies the extent to which health considerations affect many people. The provision of equality of opportunity to benefit from health services is a vital component in any move to redress inequalities. This investigation offers a way to improve the lives of fellow citizens whose independence and dignity can be significantly, and relatively easily, enhanced.

This is the product of much shared and collaborative endeavour. I have already referred to some of those who were involved and the report records more comprehensively those whose assistance contributed so much to this important piece of work. I wish to place on record the Commission's warm appreciation for their generous and wholehearted support. The investigation was formally conducted and overseen by two Commissioners to whom the Commission delegated authority to act on its behalf. Thomas McGrath and Dr Audrey Simpson were nominated for their experience in the area of learning disability and they brought to the work a level of enthusiasm and dedication that merits special thanks. Finally, as ever, Commission staff played no small part in bringing the investigation to the successful conclusion that this report represents. Rosalynd Harkness bore the greater part of the burden and she and Paul O'Neill, who was also intimately involved in overseeing the work, are due special acknowledgment.

Bob Collins  
Chief Commissioner

## EXECUTIVE SUMMARY

On 1<sup>st</sup> June 2006 the Equality Commission for Northern Ireland [the Commission] began a formal investigation under the Disability Discrimination legislation to evaluate the accessibility of health information in Northern Ireland for people with a learning disability. People who have a disability are entitled to the same level of health care as the rest of us. The Disability Discrimination Act imposes a positive duty on all service providers to make any reasonable adjustments that may be necessary to allow people with a learning disability to use that service, and this includes access to and use of means of communication and information services.

In light of evidence suggesting that people with a learning disability have greater levels of unmet health need than the general population, and an increasing emphasis on mainstream service provision, we felt that it was necessary to examine whether health information was accessible for this group. We therefore set out to identify any barriers that impacted upon the accessibility of such information and improvements that could be made to contribute to greater accessibility.

Random sampling was carried out of the written health information literature that is publicly available at general practices, dental practices and the main hospitals. From that sample, we selected particular information to be evaluated by panels comprised of people with a learning disability, and panels comprised of carers. Participants inputted through these assessment panels and by completing questionnaires to obtain their views on the accessibility of the materials. Participants were also interviewed to obtain information about their experience of verbal communication within the Health and Social Care Service.

### Findings

The written health information that is publicly available at health service settings is not provided in accessible formats, such as Easy Read and Makaton. People with a learning disability using these services must therefore use mainstream written information which does not meet their specific communication needs in terms of style, language, and use of pictures to explain the text. Accordingly, our

findings show that only a very small proportion of participants with a learning disability understand the written information evaluated without assistance.

In respect of the verbal communication of health information, the investigation pointed to much in the way of good practice, with the dental sector in particular identified as being effective in communicating with people with a learning disability.

The main barriers to good communication that were identified relate to:

- Poor communication; some healthcare professionals do not adjust their communication style to suit the specific needs of the individual.
- Awareness and attitude; a lack of familiarity with people with a learning disability in general may affect the healthcare professional's interaction.
- Time issues; both in terms of waiting for a consultation which often increases anxiety levels and the amount of time available for the consultation itself.

Despite the increased emphasis on mainstreaming health provision, much remains to be done to ensure that such services are accessible to people with a learning disability. Our recommendations, which are set out at Section 7 of this report, are designed to ensure that accessible health information is produced and is readily available for people with a learning disability, and that all those who work in our health services have the skills to meet individual communication needs.

In light of:

- the statutory requirement that service providers make reasonable adjustments to enable those with a disability to access their services
- the additional statutory duties on public authorities to promote equality of opportunity for this group
- and the increasing emphasis on the use of mainstream health services by people with a learning disability

we consider that it is vital, in meeting the health needs of people with a learning disability, that service providers consider their

specific needs, and ensure these are properly addressed in terms of the provision of mainstream services. It is imperative, if the policy of inclusion is to be effective, that information is available in a format which is tailored to their specific communication needs. This includes written health information about specific illnesses, medication, health promotion, and the various services available as well as information communicated verbally by a range of healthcare professionals.

We also believe that the action we are calling for is overdue. With the return of devolved administration to Northern Ireland, and the drive to modernise and revitalise our Health and Social Care Service, the time is right for change. This investigation has shown that both written health information and verbal communication can be tailored to meet the specific needs of people with a learning disability. The recommendations we have made are straightforward, inexpensive, and will, we believe, contribute to better health for people with a learning disability.

The investigation has also highlighted a great deal of good practice, which is reported at Section 6 of this report. There are also a number of sources of information and guidelines on how to produce accessible written information tailored to the needs of people with a learning disability, and how to enhance verbal communication, that are also referred to in the Good Practice section. We believe that this information can be used and developed by the Health and Social Care Service in overcoming the barriers to the accessibility of health information identified in this report, and in implementing the Commission's recommendations.

Our main recommendations are:

#### 1. Production of Written Information

A strategic approach to the development of a range of accessible written health information should be adopted and led by the Department of Health and Social Services and Public Safety [DHSSPS], and have the following elements :

- A standardised DHSSPS policy and procedure for producing and distributing written information which is accessible for people with a learning disability.

- Identification of priority areas of health information important to people with a learning disability.
- The development of an easily accessible central source for all such information.
- The development of a systematic approach to ensure that people with a learning disability and their representative organisations are involved from the beginning of the process of preparing such accessible information.
- A specifically tailored appointment letter be developed across the Health and Social Care Service and used when inviting a person with a learning disability to a medical appointment. In addition, consideration should be given to providing the person with further accessible information about the service when appointments are made.

## 2. Communication Training

All healthcare staff should receive disability training with emphasis on the specific needs of people with a learning disability and training in effective communication with those who have communication support needs, including people with a learning disability.

Undergraduate and post-graduate training of healthcare professionals should specifically cover communicating with people with a learning disability.

Continuous Professional Development training be provided to healthcare professionals on communicating with people with a learning disability.

The DHSSPS adopt a strategic approach to ensuring that Health Boards and Health Trusts support the use and funding of user groups/advocacy groups. Adequate funding should be provided to fully utilise the expertise of such groups in the provision of communication skills training and ensuring that there are sufficient advocacy groups operating throughout Northern Ireland.

### 3. Health Records

Each general practice should establish comprehensive medical records about people with a learning disability on their practice register.

The current general practice contract should be reviewed to establish if existing financial incentives are sufficient to improve medical records held by general practices in relation to people with a learning disability on their practice register.

### 4. Liaison

Each general practice in Northern Ireland should have an identified link person within their Community Learning Disability Team with whom they will collaborate to facilitate better access for people with a learning disability within primary care settings.

### 5. Patient Liaison Nurses

Each main hospital in Northern Ireland should have a Patient Liaison Nurse to allow for proper preparation for the treatment of people with a learning disability, and to facilitate better communication between such patients and hospital staff.

### 6. Passport System

A passport system be developed to provide people with a learning disability with the option of identifying their particular communication needs when accessing health services.

A key recommendation is that the DHSSPS should adopt a strategic approach to the development of a range of accessible written information. We also identify guidance that is available on how to produce such information, and highlight good practice which we have found in the course of our investigation. We acknowledge, however, that written information is not the only or necessarily the most effective way of communicating information to people with a learning disability. This, however, should not be used as a reason to avoid making written information accessible for this group.

People with a learning disability, particularly those with a more severe disability, will continue to rely on the support of healthcare providers, family and carers. We therefore make a number of recommendations which we believe, when implemented across the board, will improve the accessibility of verbal communication. We also identify guidance that is available on how to improve verbal communication with people with a learning disability, and again highlight good practice identified in the course of this investigation.

### **Taking Our Recommendations Forward.**

Whilst the recommendations we have made will impact across the entire Health and Social Care Service, we believe that the DHSSPS must take a lead role in ensuring that our recommendations are introduced and implemented at all levels.

We shall be reviewing progress on the implementation of our recommendations over the next year, and reporting at the end of that period. During that period we would wish to have regular meetings with the DHSSPS and be regularly updated on progress.

We shall also continue to develop relationships with professional bodies to increase support for our recommendations, and who will have the opportunity to raise these issues with the DHSSPS.

We intend to fully utilise our full range of investigative powers to promote equality of opportunity and eliminate discrimination for people with a learning disability in respect of the accessibility of health information. At the appropriate time we shall report on the extent to which our recommendations have been implemented, and determine whether further action needs to be taken by the Commission in this area.

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## Terms Used In the Report

The Commission (ECNI)	The Equality Commission for Northern Ireland. An independent public body established under the Northern Ireland Act 1998.
Investigating Commissioners	Two ECNI Commissioners with responsibility to oversee the conduct and progress of the formal investigation.
Family carer	Anyone who provides care and support to a family member with a learning disability.
Frontline carer	Anyone who provides care and support to people with a learning disability within a residential supported living or day care facility.
People with a learning disability	The Commission considers this term to be the most appropriate and uses it throughout the report.
Panel members	Those who took part in the investigation through assessment panels.
Healthcare professionals	Professionals such as, doctors, dental practitioners, nurses and pharmacists working within the health service.
HSS Boards	One of the 4 Health and Social Services Boards in Northern Ireland.

## Introduction

This part of the investigation report outlines the reasons for this formal investigation into the accessibility of health information for people with a learning disability, and its aims.

## Summary

The Commission has a duty to work towards the elimination of discrimination against people with a disability and to promote equality of opportunity. The disability legislation empowers the Commission to conduct formal investigations.

It is known that people with a learning disability have greater levels of unmet health need than the general population. Although research has shown that there a number of reasons for this, one of the barriers faced by people with a learning disability is the way in which information about health is communicated. Access to information about health and health services which is easy to read and to understand will empower people with a learning disability and make a difference to their experiences of the Health and Social Care Service.

Public policy and equality legislation promote the inclusion of people with a learning disability in society and this includes the use of mainstream health services. The communication issues experienced by people with a learning disability remain a significant barrier to such inclusion.

This investigation has identified barriers to the provision of information; both written materials and verbal communication. The Commission hopes to encourage the Health and Social Care Service to provide people with a learning disability with the accessible information needed to understand health issues and to negotiate the range of services available to them.

## The Commission and Formal Investigations

The Commission has responsibility for the disability legislation in Northern Ireland. On 1 June 2006 we gave notice of our intention to conduct a general investigation into the accessibility of health information in Northern Ireland for people with a learning disability. Part 3 of the Disability Discrimination Act 1995 renders it unlawful for a provider to discriminate against a person in relation to goods, facilities and services. Discrimination includes failing to make any reasonable adjustment that makes it impossible or unreasonably difficult for the person to use the service. Section 19[3][c] makes it clear that access to and use of both “means of communication” and “information services” is covered by Part 3 of the Act.

## What Do We Mean By “Learning Disability”?

The term “learning disability” is widely used, having replaced the term “mental handicap” in the early 1990s. Other terms such as intellectual disability are increasingly being used. For the purpose of this report we shall use the term “a learning disability”.

The Equal Lives Review<sup>1</sup> used the following definition:

“Learning disability includes the presence of significantly reduced ability to understand new or complex information or 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.”[page 18].

This Review also emphasised the impact of social barriers that may compound biological impairments and increase disability. Importantly, modern definitions stress that the availability of supports can be of considerable assistance in overcoming disability.

Estimates suggest that 50% - 90% of people with a learning disability have communication difficulties<sup>2</sup>. However both written and verbal communication may be adapted to meet the specific needs of individuals to enhance their communication abilities.

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<sup>1</sup> Review of Policy and Services for People with a Learning Disability in Northern Ireland 2005 [Equal Lives]

<sup>2</sup> British Institute of Learning Disabilities-[www.bild.org.uk](http://www.bild.org.uk)

## Aims of the Investigation

- To evaluate the extent to which people with a learning disability can access and use written and verbal health information in Northern Ireland.
- To explore the reasons for any barriers identified by the evaluation.
- To make recommendations to encourage good practice in the provision of healthcare information to people with a learning disability.

The investigation has now been completed. This report presents our findings and recommendations and is published in accordance with Paragraph 7[4], Part 1, Schedule 1 of the Equality [Disability, etc] [Northern Ireland] Order 2000. Our principal recommendations are set out in Section 7 of the report.

## The Need For Action<sup>3</sup>

### The Numbers Of People With A Learning Disability

There are significant numbers of people in Northern Ireland with a learning disability. Based on information held by Health and Social Service Trusts, it was estimated [in 2003] that there was a total of 16,366 people with a learning disability in Northern Ireland [McConkey, Spollen and Jamison, 2003]. Approximately 73% of these people [11,898] had a mild/moderate learning disability, whilst 27% [4,468] had a severe/profound learning disability. Table 1 shows the breakdown of these persons by age.

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<sup>3</sup> As part of this investigation the ECNI commissioned a literature review of relevant research from Professor Roy McConkey of the University of Ulster. In this section we will refer to some of the research detailed in this review.

Table 1: People with a learning disability in Northern Ireland by age.

<i><b>Age band</b></i>	<i><b>Total</b></i>	<i><b>Rate per 1,000</b></i>
0-19 years <sup>4</sup>	8,150	16.30
20-34 years	3,551	10.16
35-49 years	2,438	7.04
50 years plus	2,226	4.54
<b>Total</b>	<b>16,336</b>	<b>9.71</b>

The number of adults with an identified learning disability is proportionally higher in Northern Ireland than in other parts of the United Kingdom and the Republic of Ireland. [McConkey, Mulvany and Barron, 2006]. This research also predicts that the population of adult people with a learning disability in Northern Ireland by 2021 will be approximately 10,050 [a 20.5% increase since 2003]. This compares to an estimated increase of 16.2% in England for the same period. This is likely to produce an increase in age-related health conditions affecting this group.

In addition, those people who are described as having mild or borderline learning disability and who are not known to Health and Social Care Services are included in estimates that place the number of people with a learning disability at around 2% of the population [Foundation for People with Learning Disabilities, 2000].

## Health Inequalities

Significant research, in Northern Ireland, Great Britain and internationally over the last decade has provided a wealth of empirical evidence of health disparities between people with a learning disability and other citizens. Successive research exercises indicate that this group are more likely than the rest of the population to experience:

- Poorer physical and mental health

<sup>4</sup> A proportion of children may be recorded in the Child Health System as possibly having a learning disability but are not known to specialist services

- Increased risk of morbidity
- Significant unmet health needs
- Increased incidence of accidental injuries

The Equal Lives Review highlighted the fact that although the life expectancy of people with a learning disability has increased markedly over the last 60 years, mortality rates remain higher and there are greater levels of unmet health needs than in the general population.

Importantly, however, an increasing number of studies also suggest that health gains can be made by people with a learning disability, and information is becoming more available on methods of enhancing verbal and written communication for this group. Mencap, who campaign for choice, opportunity and respect for people with a learning disability, have identified the accessibility of health information as being of crucial importance in this context [Mencap, 2004]. It identified the main reasons for inferior health care treatment for this group as being:

- Poor communication between healthcare staff and people with a learning disability.
- A lack of understanding of the health needs of people with a learning disability.
- A lack of relevant written information provided in an accessible format.

## Legislative Background

The Disability Discrimination Act 1995 creates a positive duty on service providers [including health service providers] to make reasonable adjustments for people with a disability. The legislation renders it unlawful for service providers to discriminate against people with a disability, which includes failing to make a reasonable adjustment which makes it impossible or unreasonably difficult for the person to make use of any such service. Section 19[3] [b] and [c] makes it clear that access to and use of “means of communication” and “information services” are covered by the legislation.

Designated public authorities in Northern Ireland including the DHSSPS, the Health and Social Services Boards, and Health and

Social Care Trusts and Councils are also required by Section 75 of the Northern Ireland Act 1998, to 'have due regard to the need to promote equality of opportunity' for various groups including persons with a disability. In addition, from 2007 public authorities must also have due regard "to the need to promote positive attitudes towards disabled people and encourage their participation in public life"<sup>5</sup>. The Health and Social Care Service has acknowledged in the context of its statutory duties that some sections of the community, including people with sensory and learning disability, do not enjoy equality of opportunity as regards accessing health service information<sup>6</sup>, and has carried out a Good Practice Review on Access to Information.

### Public Policy Background: "Inclusion"

For some time there has been an emphasis on mainstreaming service provision for people with a learning disability; "The aim of government policy for people with a learning disability should be inclusion...which stresses citizenship, inclusion in society, inclusion in decision-making, participation so far as is practicable in mainstream education, employment and leisure, integration in living accommodation and the use of services and facilities, **not least in the field of health and personal social services**". [DHSS, 1995].

The Equal Lives Review endorsed this aim and identified five core values underpinning its recommendations for service developments:

- Equal Citizenship
- Empowerment
- Social Inclusion
- Working Together
- Individual Support

A particular objective was to:

'Secure improvements in the mental and physical health of people with a learning disability through developing access to

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<sup>5</sup> s. 49 of the Disability Discrimination 1995 as amended by the Disability Discrimination (NI) Order 2006

<sup>6</sup> DHSSPS-5 year Review of Equality Scheme

high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability” [page 8].

The 3 hospitals in Northern Ireland, which provide long-term residential care for this group, have been considerably reduced in size and now concentrate on the provision of short-stay assessment and treatment. In January 2007 the DHSSPS outlined an action plan<sup>7</sup> which envisages that by 2014 no person with a learning disability will have a hospital as their permanent address. It aims to discharge all patients from these hospitals to a community setting within a given timeframe and to ensure that all future patients admitted to hospitals are resettled into the community as soon as possible.

Adults with a learning disability are increasingly being supported to live in the community, and must access an increasingly complex web of mainstream services. Around 60 % of adults with a learning disability live with family members and there has been a major growth in the provision of supported accommodation. This includes housing with staff support, residential care homes, and nursing homes. Government initiatives have also resulted in more people with a learning disability living in their own homes and around 9% of adults with a learning disability live independently with minimal support. [McConkey, 2005a].

If the public policy of support to live in the community approach is to be effective for people with a learning disability, it must be accompanied by a determination to ensure that health information is accessible by this group. Indeed equitable access to health information for all citizens is one of the key values underpinning the DHSSPS strategy ‘Investing for Health’, 2002. Our literature review however suggests that much more could be done to make mainstream health services accessible by people with a learning disability. People with a learning disability are increasingly expected to access a diverse and often complex range of services employing a wide variety of personnel. However, due to a number of barriers, including communication, the reality is that this group has been socially isolated and its opportunities to access and use mainstream services is limited. Individuals may lack the skills required to

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<sup>7</sup> DHSSPS press release –30 January 2007; Goggins outlines action for learning disability hospitals

navigate complex service systems, and there is little evidence that mainstream service providers have adapted in an effective way to respond to the needs of this group.

## Time for Change

The re-establishment of the Northern Ireland Assembly and Executive provides a real opportunity to improve service provision to all our people, including those with a learning disability. Already there has been recognition at ministerial level of the importance of improving health services for people with a learning disability. The Health Minister, Michael McGimpsey, has stated:

“improving services for learning disabled people is one of my key priorities. They deserve the same opportunities as able-bodied people...people with learning disabilities should be part of our society and I am committed to ensuring that they have every opportunity to do so.”<sup>8</sup>

In June 2007 the Minister announced the establishment of a new Mental Health and Learning Disability Board. The Board is charged with the task of ensuring that mental health and learning disability issues are kept high on the agenda, and will be a major force in ensuring that the recommendations of the Equal Lives Review are delivered: The Minister stated:

“I expect the Board to act as champions for people with mental health and learning disabilities. The challenges are to establish strategies and sustain action which will improve the mental well-being of the whole community, prevent mental ill-health and improve support to carers. We must also ensure that people with a learning disability or mental health problems are not isolated but fully included in every part of our society”<sup>9</sup>.

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<sup>8</sup> 12 September 2007- Minister praises work of Learning Disabled Centres in Down and Lisburn areas

<sup>9</sup> 28 June 2007- Minister announces appointments to new Mental Health and learning Disability Board

Prior to the return of the devolved administration, a major reorganisation of Northern Ireland's Health and Social Services commenced as part of a wider Review of Public Administration<sup>10</sup>. We believe that the review of health provision and particularly the establishment of Local Commissioning Groups, demand-led by patients and driven by general practitioners and primary care professionals, will provide a real opportunity to improve services for everyone in Northern Ireland, including people with a learning disability. The new commissioning arrangements should facilitate joined-up community planning and local decision making responsive to local needs.

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<sup>10</sup> Review of Public Administration <http://www.rpani.gov.uk/>

## Section 1: Participants in the Investigation

This Section provides information about the various Groups set up to assist the Commission with the investigation and acknowledges their invaluable input. Those who participated and provided their opinions, comments and experiences during assessment panels and discussion groups are also acknowledged. Details of membership of the various Groups can be found at Appendix 9.

### Investigating Commissioners

The formal investigation procedures allow the Commission to appoint one or more Commissioners to conduct the investigation on its behalf. Dr Audrey Simpson and Thomas McGrath were nominated as investigating commissioners due to their experience in the area of learning disability. Their role included:

- Ensuring compliance with legal requirements.
- Advising Commission staff.
- Agreeing terms of reference.
- Adopting a final investigation report for Commission approval.

### Steering Group

Steering Group members have a particular interest and expertise in the area of learning disability. Each of the four Health and Social Services Board Areas are represented. The Group first met before the investigation commenced. Their role was to guide the direction of the investigation, to ensure that the design of the investigation was appropriate and that it dealt with matters which are of importance to people with a learning disability.

Steering Group members:

- informed the key themes of the investigation.
- considered the main health issues and the adequacy of the information collection.
- considered the structure of the panels of people with a learning disability, and ethical issues.
- reviewed a pilot exercise to test investigation methodologies and propose revisions.

Members of the Steering Group provided contacts for groups who would be willing to assist with a Pilot exercise that took place in March and April 2006. The Buzz Group met with the investigation team to provide advice regarding the investigation documents and procedures designed for people with a learning disability. Ballymena Carers Group assisted with the procedures and questionnaires designed specifically for carer groups.

### Focus Group

The Focus Group was an established advocacy group of people with a learning disability. Their role was to complement the functions of the Steering Group from a service user perspective. The Focus Group was particularly helpful in advising on the investigation documents and plans for the assessment panels.

### Reference Group

The Reference Group's role was to assist with and advise on the investigation's recommendations. The Reference Group provided input to the recommendations and how they could be put to practical use.

Group membership consisted of healthcare professionals and others with particular interest in the area of learning disability and the dissemination of health information.

Reference Group members:

- reviewed the results of the investigation and considered the barriers identified for people with learning disability in accessing health information.
- considered the best practice identified by the investigation.
- considered recommendations and how these could be taken forward within the health sector.

## Assessment Panels

- People with a learning disability

74 people with a learning disability took part in the assessment panels which considered sample written health information and provided information about their experiences of verbal communication in the Health and Social Care Service. There were 10 such panels.

- Frontline Carers and Family Carers

178 carers [both family carers and frontline carers] participated in the investigation. 29 carers panels were organised throughout Northern Ireland to allow carers from a variety of caring backgrounds to discuss their experiences of verbal communication between healthcare professionals and people with a learning disability. The carers were also asked to complete and return questionnaires which considered the accessibility of 2 pieces of sample written health information. One carer provided comments and questionnaires independently.

A detailed profile of the assessment panels can be seen at Appendix 3.

## Section 2: Methodology

This Section details the processes involved in the design and conduct of the investigation and considers the fundamental principles behind the identification of priority written health information areas to be assessed.

### Summary

This investigation sought the opinions of people with a learning disability and carers. A focused approach was used to identify participants with a learning disability because of the ethical and practical considerations involved in such an investigation. A random sample of carers was also invited to participate in the investigation.

We collected literature on health information from a sample of general practices, dental practices and main hospitals. The written information used for evaluation was chosen because of its importance to people with a learning disability as identified in a Literature Review commissioned for the investigation.

The views and input of people with a learning disability and carers were obtained through a series of assessment panels and the completion of questionnaires.

Due to the nature of the investigation, a substantial amount of planning was required and so the investigation was necessarily divided into 2 periods which are summarised below.

#### Pre – Investigation Period July 2005 to May 2006

A considerable amount of preparation work was carried out before the official launch of the investigation. During this phase:

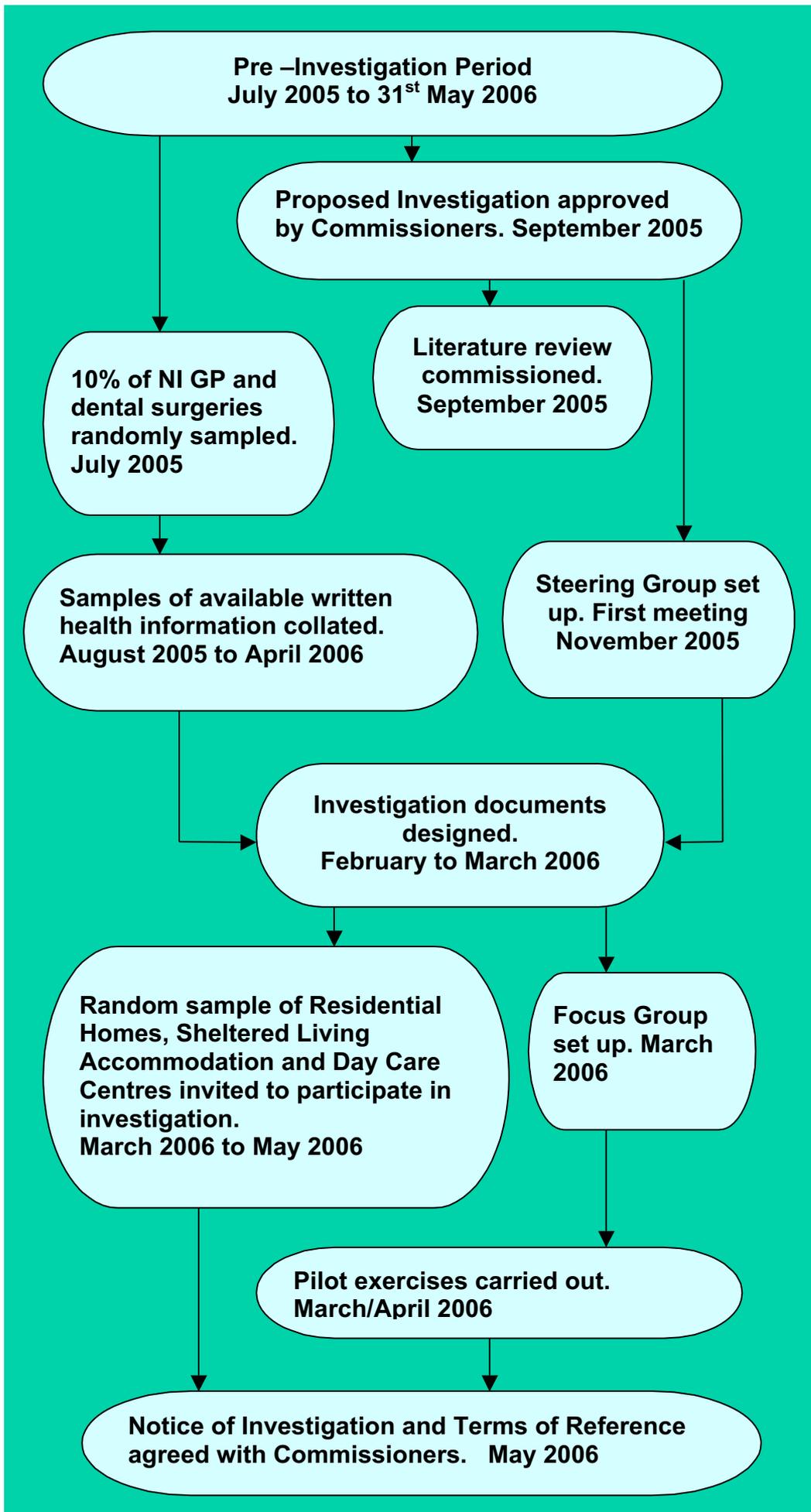
- the scope and purpose of the investigation and terms of reference were prepared and agreed with the Investigating Commissioners, the Steering Group, and the Focus Group. [These documents are available on the Commission's website].

- Samples of available written health information were collected, and assessment panels of people with a learning disability and carers were identified and established.
- A pilot exercise to test investigation tools took place.

### Formal Investigation Period

1st June 2006 to 1<sup>st</sup> December 2007

The formal investigation period lasted 18 months. A total of 178 carers and 74 people with a learning disability participated in discussion groups and assessment panels over a period of 8 months. A quantitative analysis of the questionnaire replies and a thematic analysis of the discussions held were considered by the Reference Group which was convened to assist with developing recommendations.



## Preparing for the Investigation July 2005 to May 2006

### Ethical Considerations

The investigation team ensured that panel meetings of people with a learning disability were facilitated by a person who had obtained POCVA registration.

The Steering Group and the Focus Group advised on the issue of consent and the wording of consent forms for all participants. For those participants of school age where parental consent was also required, a separate consent form was issued through the schools' head teachers.

The investigation team met with carers and people with a learning disability to ensure that all participants were informed of the aims of the investigation and their involvement. All participants were made aware of the confidentiality of the investigations and that all information would be held in accordance with the Data Protection Act 1998.

### Scoping the Investigation

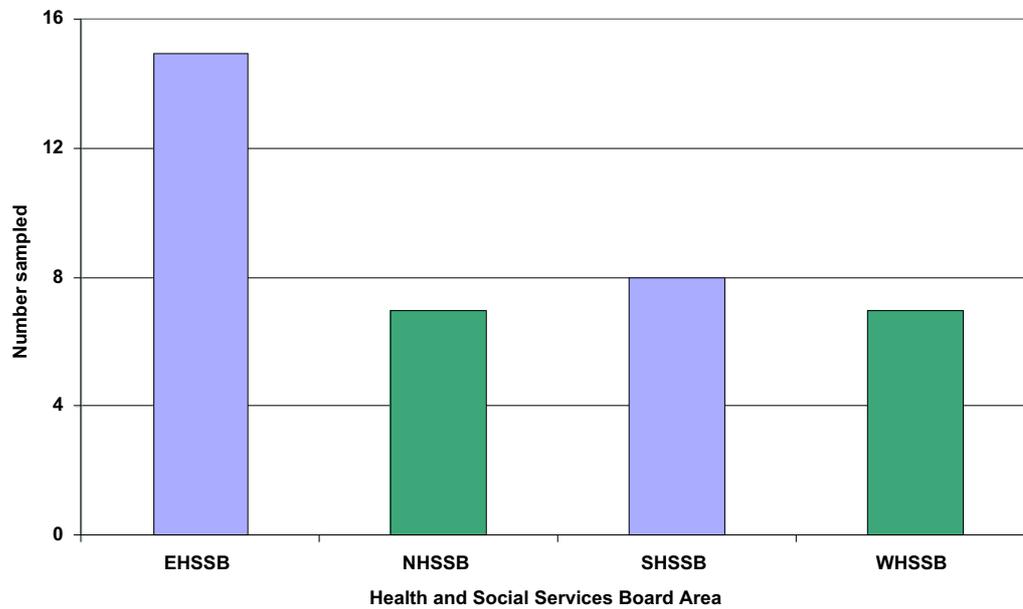
Guidance and advice were sought from a number of sources during the pre-investigation period. Professor Roy McConkey of the University of Ulster prepared a Literature Review to inform the Commission of the issues and topics involved in the accessibility of healthcare information for people with a learning disability and to help identify priorities for the investigation. The Literature Review is available on the Commission's web-site <http://www.equalityni.org>.

### Sample Written Health Information

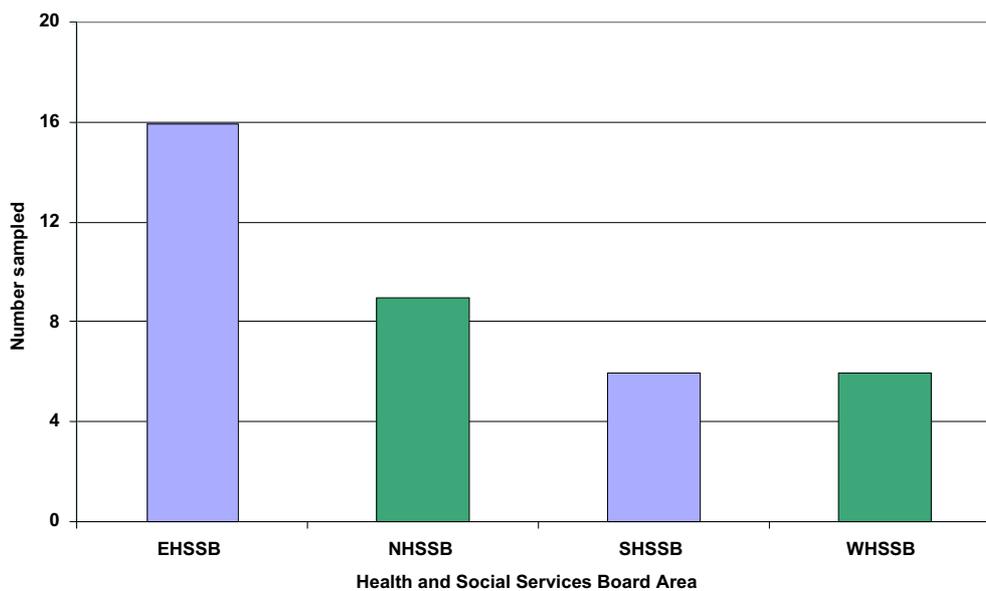
A 10% sample of general and dental practices in each of the 4 HSS Board areas across Northern Ireland was randomly selected. Figures 1 and 2 below show the numbers of practices selected in each HSS Board area. These practices were visited and health information leaflets on display were collected to form the

representative sample of health information generally available for public use.

**Figure 1:** Number of sampled general practices by HSS Board area.



**Figure 2:** Number of sampled dental practices by HSS Board area.



Priority health issue areas were identified from the literature review and agreed through discussion with the Groups involved. These priority areas were:

- Illnesses
- Health promotion
- Health Services

The written health information was catalogued according to health themes.

## Illnesses

Screening studies [Meehan et al., 1995, Barr et al., 1999; Leggett, 2001; Marshall et al., 2003a; McConkey, Barr et al., 2003] have identified major areas of unmet physical health need for people with a learning disability in Northern Ireland, the most common being:

Weight, Oral Health, Ears, Eyes, Feet, Blood Pressure, Skin and Hair, Urinalysis, Testicles, Breasts, Blood Tests, Gastro-intestinal, Continence Problems. It was therefore important to include written health information in these areas.

The Commission's Literature Review [McConkey 2006] identified the mental health needs of people with a learning disability as a particular priority which may not to date have received the attention it merits. This Literature Review suggested that mental health issues appear to be more prevalent in people with a learning disability, with psychiatric disorders in particular not diagnosed. The review also confirmed that a very high proportion of people with a learning disability will have difficulty with verbal communication. The diagnosis of a depressive type illness may depend on the ability of the patient to describe their symptoms to a greater extent than physical conditions, which, by their very nature, may be somewhat more visible. Accordingly, it was agreed that information relating to the promotion of good mental health, with particular reference to relationships, productive work and leisure pursuits would be important to consider, although very little information of this nature was available at the health settings sampled.

## Health Promotion

Health is a positive concept which extends beyond the absence of ill-health, and includes physical, mental and social wellbeing. All people with a learning disability are entitled to equal access to a healthy lifestyle and information to promote same, and this is the stated aim of current Government policy [Investing for Health Strategy]. In simple terms, people with a learning disability, like any other group in society, should be encouraged to achieve their optimum health status. It was therefore important to include written health promotion information.

## Health Services

People with a learning disability are increasingly accessing mainstream health services. A range of written materials are available which outline in broad terms the services that are available from general practices, dental practices and hospitals. This information is required in a format that can be understood by people with a learning disability. Hospital appointment letters were identified as being particularly important in this context.

It was also decided that for the purpose of this investigation the Commission would consider only those health leaflets produced/endorsed by the DHSSPS, the Health and Social Services Boards, the Health and Social Services Trusts and other government sponsored organisations, such as the Health Promotion Agency.

## Other Health Information

We decided to include appointment letters sent from the medical records departments of hospitals as well as medicine labels issued by hospitals and pharmacies. A sample of appointment letters was requested from three hospitals, one in the Western, Northern and Eastern Health and Social Services Boards respectively. Replies were received from 2 of these hospitals. Medicine labels were requested from 2 hospitals; one in the Western Health and Social Services Board and one in Southern Health and Social Services Board.

A list of the health information assessed can be found at Appendix 1.

### Development of Investigation Documents<sup>11</sup>

It was important that all investigation documents were produced in a user-friendly format. Information about appropriate ways to present written information to people with a learning disability to aid understanding is provided through a number of organisations, such as Mencap and the Down's Syndrome Association.

Discussions were held with Mencap and with their assistance the investigation documents providing information for participants with a learning disability were designed in an easy read format.

### Questionnaires

Information about barriers to accessing written information was obtained from the Literature Review and sources such as the Down's Syndrome Association and Mencap. Accordingly, issues such as font size; the appropriate use of pictures; the language used; and the design/style of leaflet were explored using questionnaires. We prepared a straight-forward questionnaire to facilitate discussion with participants, allowing those who wished to complete questionnaires themselves to do so with minimal support.

### Participant information sheet

A participant information sheet was devised for both groups of participants together with a consent form. The information sheet for people with a learning disability was produced in an easy read format and, following discussion with the Focus Group, was also produced in audio format. An easy read consent form was designed for those participants with a learning disability. A separate

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<sup>11</sup> All investigation documents are available on the ECNI website <http://www.equalityni.org>

consent form was also provided for the parents of those participants of school age.

### Interview Schedule

A set of questions about verbal communication with participants was drawn up to steer discussions and assist standardisation across assessment panels.

### Pilot Exercise

A pilot exercise of the investigation documents and the assessment panel procedures took place between March and May 2006 with a group of people with a learning disability and a group of carers. As a result changes were made to the wording of the participant information sheet. In addition arrangements for the assessment panels were reassessed in respect of the time allowed for each session, and the use of the questionnaires.

### Assessment Panels

#### People with a learning disability

The investigation team invited established groups of people with a learning disability, who are used to discussing issues and providing opinions as a group, to participate in the investigation.

A total of 8 assessment panels were originally organised and a further 2 panels were organised on the advice of Steering Group members to ensure that the investigation included people under 18 years. A number of Special Schools were approached through the relevant Education and Library Board and 2 schools participated.

An approximately equal number of males [38] and females [36] took part in the assessment panels and the age ranged from 16 to 80+ years old.

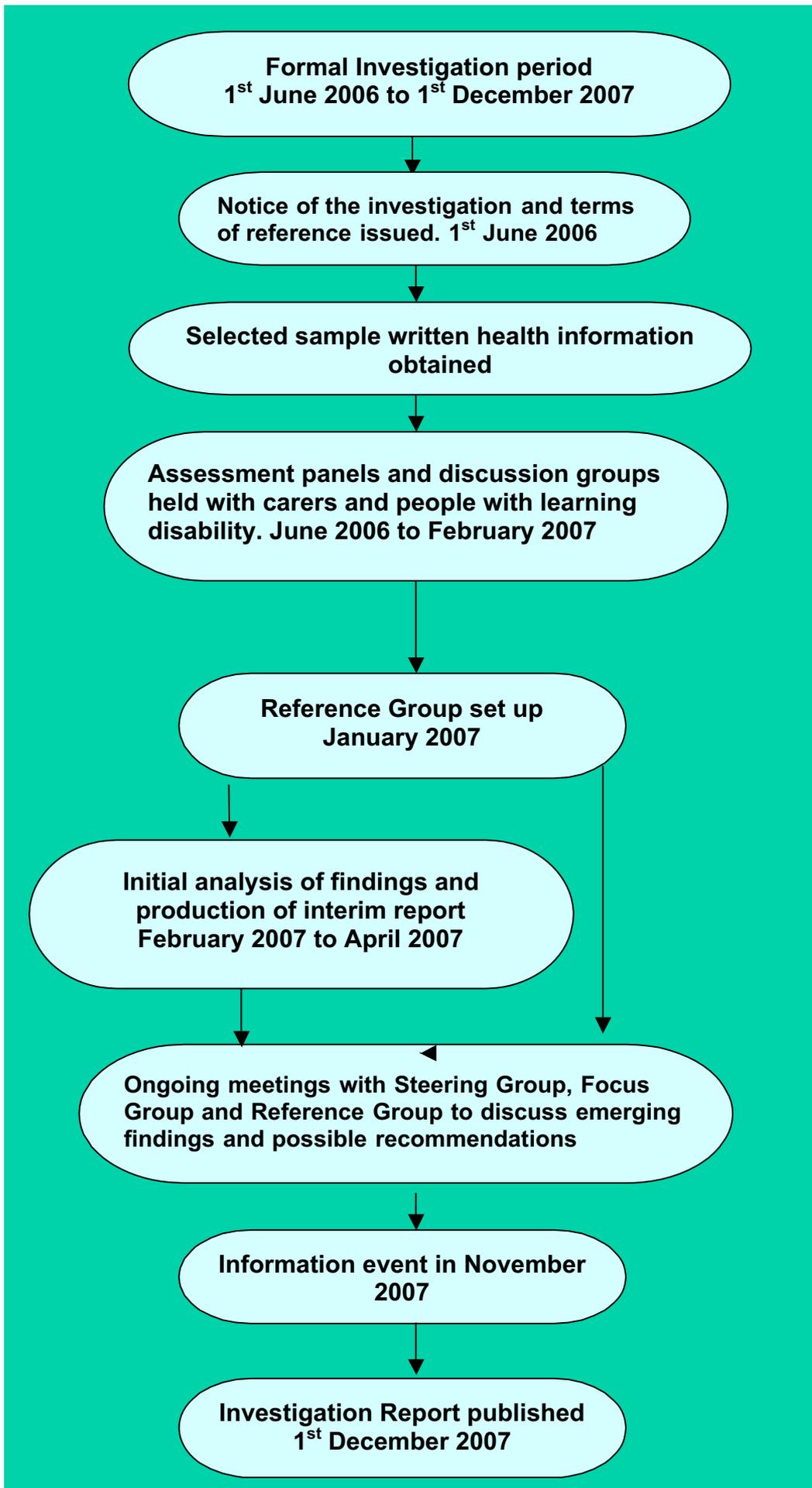
## Carers

A 10 % sample was taken of Residential Homes, Day Care Centres and Sheltered Living Accommodation across the 4 HSS Board Areas. Each sampled establishment was approached and asked if their members would like to participate in the investigation. We also wished to include those who provide care within the family home and approached a number of carer groups to participate in the investigation.

A total of 29 assessment panel groups were organised [see Table 2] with 178 carers taking part in the investigation.

Table 2: Carer Panel location by Board Area

	<b>EHSSB</b>	<b>NHSSB</b>	<b>SHSSB</b>	<b>WHSSB</b>	
<b>Background of Carers</b>					<b>total</b>
<b>Day care</b>	1	1	1	2	5
<b>Private residential</b>	2	1	2	2	7
<b>Housing association</b>	6	2	1	2	11
<b>Trust run accommodation</b>	2	1	1	1	5
<b>Family</b>	1			1	2
<b>Total</b>	<b>10</b>	<b>5</b>	<b>5</b>	<b>7</b>	<b>29</b>



## **Formal Investigation Period 1<sup>st</sup> June 2006 to 1<sup>st</sup> December 2007**

The Formal Notice of the Investigation and Terms of Reference were issued on 1<sup>st</sup> June 2006.<sup>12</sup>

Copies of the written health information to be considered by assessment panels were collated throughout the Formal Investigation period. The panels ran from June 2006 to February 2007.

### **Panels of People with a Learning Disability:**

Although the arrangements for the assessment panels were adjusted to suit the individual needs of each group, certain changes were made specifically for those participants in schools to fit in with the daily running of the school.

- Assessment panels were asked to consider two pieces of written information. As time was more limited each school assessment panel was asked to choose one piece of information to evaluate from 2 pieces of written health information. The reasons for the choice were noted.
- Those who wished to complete a questionnaire were able to do so with some assistance, in other cases responses of panel members were recorded by the Investigating Officer.
- This part of the assessment panel session lasted approximately 1 hour and was followed by a break.

Each assessment panel took part in a discussion about their experience of verbal communication with healthcare professionals in the primary care and hospital setting, and at the pharmacist. This session also took about 1 hour and the prepared set of questions was used to steer the discussion.

Each participant with a learning disability was issued with a certificate by the Commission in recognition of the time and effort given to the investigation.

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<sup>12</sup> These are available on the ECNI web-site. <http://www.equalityni.org>

## Panels of carers

Each session lasted approximately 1 hour and where possible were organised to coincide with regular staff or family carers meetings. A discussion took place during which questions were asked about experiences of verbal communication between healthcare professionals and people with a learning disability within primary care settings, hospitals and pharmacies. The interview schedule previously drawn up was used to facilitate discussion.

Each participant was given 2 pieces of written health information to comment on using the questionnaires provided. Participants were asked to complete these in their own time and to return in freepost envelopes provided. A total of 364 questionnaires were issued and a return rate of 31% was obtained.

## **Section 3: Results - Written Health Information**

This section of the investigation report examines and compares the questionnaire responses of people with a learning disability and carers.

The following issues are discussed:

- Understanding of the information
- Interest in the information
- Language used
- General style and layout
- Contact information
- Use of pictures

### **Making Written Health Information Accessible**

There are a number of sources of information and advice on producing accessible written information. Organisations such as Mencap provide guidelines [available on their website [www.mencap.org.uk](http://www.mencap.org.uk)] on how written information can meet the needs of people with a learning disability.

Guidelines include simple steps to be followed such as:

- Text should be large.
- Sentences should be short, clear and use easy words. Long words should be explained.
- The layout should be clear with lots of space around the text and pictures.
- Pictures should be used to convey the messages within the text.
- Pictures should be clear and simple.

## Summary of Findings

The investigation has identified a number of barriers which prevent written health information being accessible to people with a learning disability.

The assessment panels were provided with selected pieces of written health information and asked to complete questionnaires to assess whether the information was accessible to people with a learning disability.

The assessment panels comprised of people with a learning disability were asked to indicate if they understood the information contained in the written information, and identify the main barriers to accessibility in the piece of information.

The assessment panels comprised of carers were asked to indicate whether or not, in their experience, people with a learning disability would understand the information contained in the written information, and to indicate the main barriers to accessibility in the piece of information.

It is clear from the questionnaire replies that the written health information does not take into account the specific needs of people with a learning disability in its style and design. Features such as the language used, the layout of the information, font size and lack of useful pictorial information, contribute to the fact that only 3% of participants with a learning disability could understand the information without assistance.

The majority of carers thought that the style and design of the written health information does not take into account the needs of people with a learning disability and that this would effectively mean that this group would show no interest in the information.

However, both people with a learning disability and carers stated that the issues covered by each piece of health information would be useful and important to have.

## Responses to Questionnaires from People with a Learning Disability

The assessment panels considered a total of 15 pieces of written health information. All groups, except those in schools, looked at 2 pieces of information. Assessment panels in schools were asked to choose between 2 pieces of information. In each case the chosen piece of information was picked because it was 'more colourful and had more pictures.'

Table 3: Questionnaire Responses: People with a learning disability.

People With a Learning Disability Number = 137		
Question	Yes Percentage	No Percentage
Q1. Do you like the style of the leaflet?	69	31
Q.2 Would you pick the leaflet up to look at it?	51	49
Q.3 Do you know what the leaflet is about?	80	20
Q.4 Did someone help you understand this?	97	3
Q.5 Would you like to have this information?	83	17
Q.6 Is the writing big enough?	28	72
Q.7 Any words hard to understand?	86	14
Q.8 Did pictures help you understand information? [information with pictures <b>N= 89</b> ]	<b>53</b> <b>[81]</b>	<b>47</b> <b>[19]</b>
Q.9 Is it easy to find out how to get more information? [information with contact details <b>N=75</b> ]	<b>30</b> <b>[53]</b>	<b>70</b> <b>[47]</b>

N= numbers of people assessing information which contained pictures or contact information

- **Understanding**

**Q.3 Do you know what the leaflet is about?**

**Q.4 Did someone help you understand this?**

- 97% of panel members require assistance to understand the information they considered.
- 80% of panel members understand the contents of the written information with some support and assistance.

This indicates that the information is not accessible to people with a learning disability because of the way in which it is presented.

The panel members also state that they have difficulty in understanding some pieces of the written information even with assistance. These pieces of information are assessed as having:

- too much text,
- no pictures or pictures that were not easily recognisable,
- difficult language, and
- jargon.

Comments include:

“Words are too hard”

“Too much writing inside”

“Some of the pictures – don’t know what they are”.

However, panel members are able to understand with assistance some pieces of information with similar style characteristics because they are already familiar with the subject matter of the information/leaflet. For example, although they are unable to read the medicine labels, they understand what these are about because they are familiar with instructions for taking medicines. The health promotion leaflets containing information about healthy diet and dental care are also familiar issues. However, information about services, such as the appropriate services to use under various circumstances, is not as easily understood. This may be because people with a learning disability are not used to finding out this type of information for themselves. It is interesting that those who considered the information about podiatry services understood the concept of chiropody more easily because this is the term they are more familiar with.

From the questionnaire responses it seems that unfamiliarity with certain issues and concepts is in itself a barrier to the accessibility of the information even before certain style characteristics are considered. It is important, therefore, to include a good introduction to the information to explain the subject matter of the leaflet. Developing more accessible information will provide more opportunity for people with a learning disability to become familiar with a wider range of health issues.

- **Interest in and Importance of the Information**

**Q.2 Would you pick the leaflet up to look at it?**

**Q.5 Would you like to have this information?**

- 51% of the panel members state that the design of the written health information attracts their interest.
- 83% think that the health issues are important to them.

The attractiveness of the information was determined by style issues such as:

- eye-catching colours
- interesting pictures
- the length of the leaflet.

Panel members indicate that they would not pick up some of the information because it:

- looks dull, [little or no colour or contains few pictures]
- has too much text
- uses a small font size.

Comments include:

“The leaflet does not attract my attention. There are not enough pictures.”

“The pictures are too small. The writing is too small and there is too much writing.”

“Too dull.”

“Eyes get sore looking at the little writing in the little boxes”.

A particular interest in the health issue is also given as a reason for wanting to look at the information. For example, even though some information is not an “attractive” design the panel members

recognise its importance for those who may suffer from a particular condition e.g. diabetes.

Some panel members are not interested in looking at the information contained in the shorter, more colourful pieces of information, because they do not consider this information important to them, or in some cases they say the information would make them worry about their health.

The majority of panel members [83%] think that it is important for them to have access to the information contained in the written material provided to them for assessment. Certain information such as appointment letters, medicine labels and health promotion leaflets about healthy diet or specific illnesses are seen by all panel members as being important. A small number are wary about information regarding safe alcohol limits, healthy eating and skin cancer and see these as less important to have. The reasons given vary, for example, some people do not wish to change their eating or drinking habits and others think that having the information will make them worry about their health.

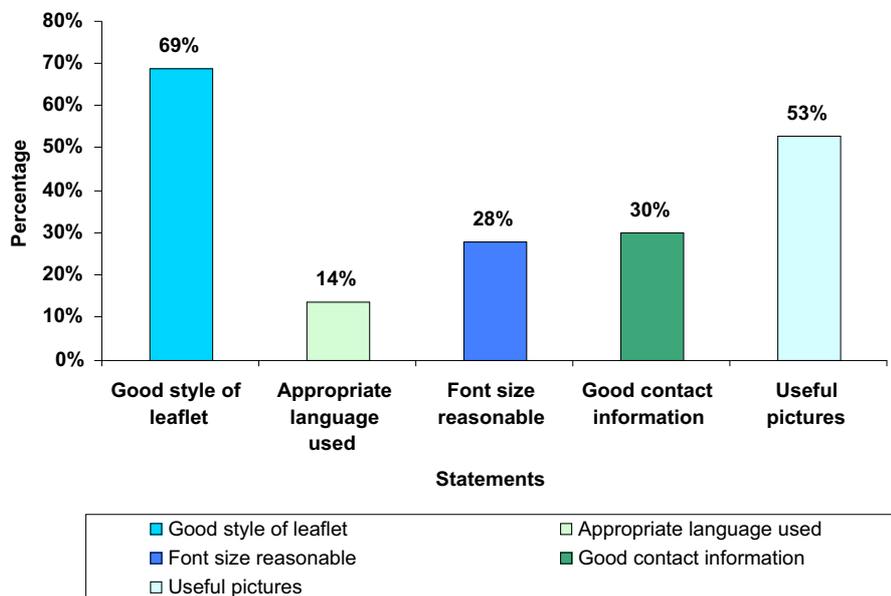
The findings show that although the design of the written information is important in attracting initial interest, there are other important factors which will affect whether or not people with a learning disability will look at the written information. Written information should not only be in an accessible and interesting format but also relate to the lifestyles of people with a learning disability.

- **Style**

**Q1. Do you like the style of the leaflet?**

- 69% of the panel members think that the style of the leaflets is good. However, when this is broken down into specific style elements the picture is less encouraging.

Figure 3: Percentage of people with a learning disability agreeing with statements about the style of the written information.



- **Language**

**Q.7 Did you find any words hard to understand?**

- 86% of the panel members think the language used in the information is too difficult for them to read and understand.
- 14% of panel members think that the language used is appropriate and easily understood.

All of the information is thought to have some difficult words and over 80% of panel members considered the language too difficult in 12 out of the 15 examples of written information. The text in these contains technical jargon or medical language and other words that make understanding difficult for people with a learning disability.

Comments include:  
 “All words are hard to understand.”  
 “I found it hard to understand some of the words like “canopies” .  
 “Can’t read any of it.”

Panel members identify a number of difficult words and phrases, for example; binge drinking, multivitamins, ailments, approximate, chronic disease management, canopies. In addition the wording of

some contact details such as “direct dial number” are not understood and could be made simpler.

The panel members confirm that information using everyday language accompanied by appropriate pictures and simple sentences is more easily understood. Even information which uses some unfamiliar words and phrases [for example, ‘SunSmart’,] is understood because they also use recognisable and appropriate pictures which help to convey meaning.

Panel members describe some pieces of information as “no use”. The words used are too difficult and there are no pictures to assist with understanding. There are 5 pieces of information which do not contain any pictures.

- **Font Size**

#### **Q.6 Do you find the writing big enough?**

- 72% of panel members assessed the information as having small font which is difficult to read.
- 28% of panel members think that the font size of the information is reasonable and easy to read.

Panel members identify other factors which improve their ability to read the font, such as the use of **bold** typeface and good font/background contrast. For the ‘Alcohol Countdown’ leaflet the panel members like the clarity of the **bold black font on the blue background**. The message from panel members, however, is clear; a bigger font size is needed together with more simple language.

Comments include:

“White writing on blue background is hard to make out”

“Can’t see the letters/words. Font size is not big enough for the visually impaired.”

“It is too small and cramped.”

- **General Layout**

In addition to the factors mentioned above, panel members also highlight other details about the layout of the information which improves their ability to read and understand it.

Some of the good examples found in the information are:

- Providing information in short simple sentences in bullet point form.
- Highlighting important information in large bold writing or in boxes.
- Setting out important details separately, for example in letters;
  - appointment date
  - appointment time
  - location

Panel members suggest that it would be helpful if important issues such as health warnings could be highlighted with a red “x”, for example, on medicine labels or in information about unhealthy food and drink.

- **Contact Information**

**Q.9 Is it easy to find out how to get more information?**

- Only 8 out of the 15 pieces of written information provided any contact information.
- Only 30% of panel members think that the written information provides good contact information.

Of the 8 pieces of information which do provide some contact details just over half of the panel members [53%] think that these are clear and useful to them.

As a minimum, panel members state that they would like to see

- a telephone number
- an address

- the name of someone to contact.

The website or email address details provided on some information is useful to some panel members but not everyone has access to the internet.

Comments include:

I would like:

“The name of someone to contact. Like to speak to a person.”

“Telephone number, addresses, information on other formats of leaflets. Maybe Braille or audio.”

Other barriers to the accessibility of contact details highlighted by the panel members include:

- Contact details are not easily identified

In some cases the panel members are unable to recognise that contact details are provided and it would be helpful if these details could be more noticeable. For example; headed paper on letters does not provide sufficient guidance for further contact to be made.

Panel members state that they would like to see contact details provided with pictures to identify the form of contact, i.e. a picture of a telephone instead of the letter “T”. The panel members do not recognise “direct dial number” as a contact number.

- They do not know who to contact

Panel members state that it is important to be provided with the name of someone to contact. Where this is impractical information could provide the job title of the person who will be dealing with the query.

- Contact details are too small

The panels also point out that in many cases contact details are squashed in small font at the bottom of a page, and in some cases at the bottom of an empty back page where more space could have been used.

The panel members also raise the issue that there were no instructions about how to get the information in alternative formats. None of the information provided these details.

- **Pictures**

#### **Q.8 Did pictures help you understand information?**

- 53% of the panel members consider the information to contain useful pictures.
- Only 10 pieces of information contain pictures and of these:
- 81% of panel members think that the pictures used are useful in helping them understand the information.
- However, panel members also think that:
- 8 out of these 10 leaflets need more pictures,
- 6 out of the 10 leaflets contain pictures that are too small and/or unclear.

The percentage of people rating the pictures as good [81%] may reflect more the panel members' enthusiasm for pictures rather than the usefulness of these pictures. It has been noted previously that a high number of panel members need assistance with their understanding of the information and so this high percentage may not be a true reflection of the usefulness of the pictures. During further discussion about the pictures the panel members thought that some were too small, were not easily recognisable and in some cases did not reflect reality. For example, the pictures of food on one leaflet are not the right colour.

Panel members are divided on their preferences for pictures with some stating that they preferred photographic images while others like fun cartoon images. However it is important to note that the questionnaires indicate that for some panel members photographs are sometimes confusing and not immediately recognisable. For example, in one leaflet a photograph of someone cleaning windows is not easily recognisable. Some caution is also needed with cartoon images; although these can be fun and attractive it is clear that some panel members have difficulty identifying their meaning.

In most cases panel members think that the use of pictures can be improved, for example by using;

- more pictures
- larger images,
- pictures of people with a disability.

Comments include:

“There are not enough pictures and the pictures that are in it are confusing and hard to identify, they would be better in their true colours.”

“There are not enough pictures.”

“There are enough pictures but it might be better if they were bigger.”

“Don’t like the colour of the pictures. They are not clear.”

“Some of the pictures. Don’t know what they are.”

## Responses to Questionnaires from Carers

<b>Table 4 Questionnaire Responses: Carers</b>		
<b>CARERS</b> Number = 114		
<b>Question</b>	<b>YES Percentage</b>	<b>NO Percentage</b>
Q1. Do you think the leaflet deals with important health issues for people with a learning disability?	89	11
Q.2 Do you think the leaflet contains useful information about the health issue? [2 no answer]	92	6
Q.3 Do you think the leaflet contains useful and clear contacts information? [information with contact details <b>N=77</b> ]	49 <b>[68]</b>	51 <b>[32]</b>
Q.4 Do you think a person with a learning disability would pick this leaflet up to look at it?	32	68
Q.5 Do you think a person with a learning disability would be able to read and understand this leaflet?	18	82
Q.6 Do you think this leaflet uses words and sentences that a person with a learning disability would find easy to understand? [2 no answer]	27	71
Q.7 Do you think the design of this leaflet takes the specific needs of people with a learning disability into account?	21	79
Q.8 Is the font a reasonable size?	37	63
Q.9 Are pictures used to support and explain the information being conveyed by the writing? [information with pictures <b>N=74</b> ]	25 <b>[36]</b>	75 <b>[64]</b>

N=Numbers of people assessing information which contained pictures or contact information

Carers considered the same pieces of written health information assessed by people with a learning disability plus an additional leaflet. The additional leaflet was required because of the higher number of carer panels.

A total of 114 questionnaires were completed and returned representing a response rate of 31%.

- **Understanding**

**Question 5: Do you think a person with a learning disability would be able to read and understand this leaflet?**

Only 18% of panel members think that people with a learning disability would be able to read and understand the information presented to them. In their view the information contains too much text and information, too few pictures, too many difficult words and complex sentences and too small a font size, making understanding difficult.

Those carers who indicate that the information could be read and understood qualify this with “depends on their ability”, suggesting that they think only those who are of higher ability could do so. Some carers think that the small font size makes it difficult even for those with good reading skills.

Comments made:

“Writing too small.”

“No clear straightforward guidelines.”

“The wording is too difficult.”

“The layout isn’t clear enough.”

“The information is not specific to adults with a learning disability.”

“Too much in depth detail and science.”

“If they could see more pictures of people I feel they could understand.”

- **Importance of and Interest in the Information**

**Q1. Do you think the leaflet deals with important health issues for people with a learning disability?**

**Q.4 Do you think a person with a learning disability would pick this leaflet up to look at it?**

- 89% of panel members agree that the information contains important health information.
- 32% think that people with a learning disability would show an interest in the piece of information being assessed.

Carers who think that the information is not important for people with a learning disability do so because they feel that the information is not presented in a way that people with a learning disability would easily understand or, because the information provided does not reflect their life experiences. For example, some leaflets provided examples of physical exercises and carers state:

“The exercises focus on more able bodied [people].”  
“Not everyone can participate in the exercises stated.”

The lack of relevance to the lifestyles or experiences of people with a learning disability is also reflected in the reasons why carers think people with a learning disability would not be interested in looking at the information.

Two thirds of the panel members think that the information would not be picked up because of the way the leaflet looks. The reasons given are similar to those given by people with a learning disability i.e. the information contains

- too much text
- few or no pictures
- not enough colours
- small font size.

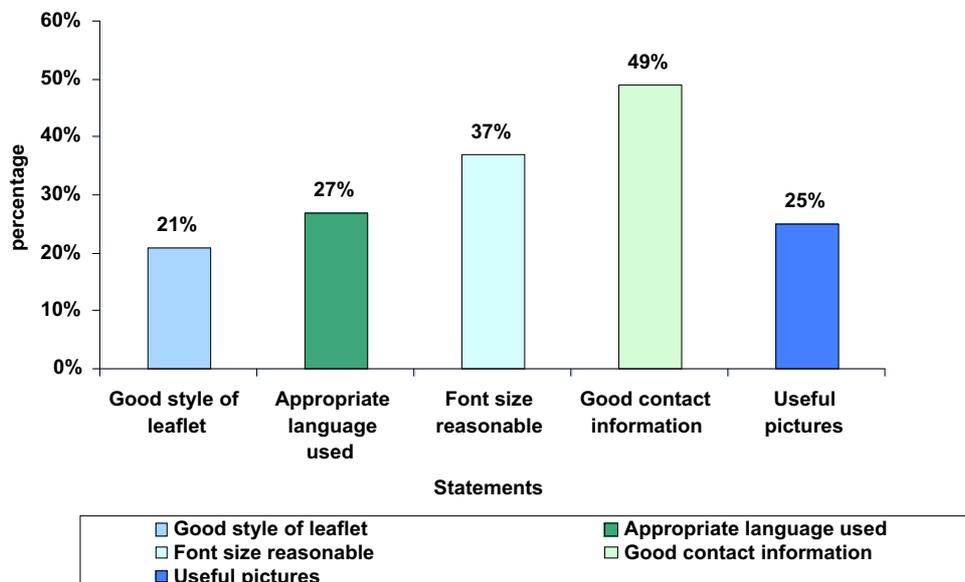
“If you cannot read [there is] nothing to encourage you to lift this leaflet.”

Carers think that people with a learning disability would not look at medicine labels because these are generally dealt with by carers. This concurred with the findings from the assessment panels of people with a learning disability i.e. 75% stated they would not pick them up to look at.

Those pieces of information which are considered to be of more interest are those which have bright colours and large pictures. However, carers raise the issue that although the attractiveness of the front page may encourage interest, the subsequent pages may lose peoples' attention because too much information or text, few pictures and small font sizes make them difficult to read and understand.

Comments made:  
 "Interest would soon wane because of the way the information is presented."  
 "There would be initial interest due to the cover not having too much writing but the inside is much too long winded."

Figure 4: Percentage of carers agreeing with statements about the style of the written information.



- **Style**

**Q.7 Do you think the design of this leaflet takes the specific needs of people with a learning disability into account?**

As demonstrated above the style of the written information not only affects opinion of whether the information is accessible but also whether there will be any initial interest in it. Figure 6 shows that only 21% of carer panel members think that the written information takes the needs of people with a learning disability into account.

For this question carers were asked to consider certain style characteristics which are good practice when developing written information for people with a learning disability.

Carers were asked to consider if the health information:

- Has a reasonable font size;
- Has an introduction which set out what it was about;
- Has highlighted important points;
- Is a good length/ has the right amount of information;
- Contains a reasonable amount of detail;
- Uses pictures to support and explain the information being conveyed by the text;
- Contains technical jargon and if so, whether these technical terms are explained.

For 11 out of the 16 pieces of information assessed over 80% of the panel members consider them unsuitable for people with a learning disability because some do not contain pictures; those that have do not support the meaning of the text; and others use language and/or a font size which is inaccessible for people with a learning disability.

It is not surprising that the statistic is high given that the sampled information is not designed specifically for people with a learning disability. However information which is simple, concise and uses pictures to assist with meaning, for example, 'SunSmart' is considered by some carers to be more accessible to people with a learning disability.

- **Language**

**Q.6: Do you think this leaflet uses words and sentences that a person with a learning disability would find easy to understand?**

- 71% of panel members think that the information uses language which is too difficult, and in some cases the sentences are too complex.
- All 16 leaflets are thought to contain difficult language and complex sentences, while 7 contain technical or medical jargon which people with a learning disability would have difficulty understanding.

Those pieces of information which carers rate more positively contain short, straight to the point pieces of information and use simple, everyday language for example, 'Sugar Free Medicine', 'SunSmart'.

Carer comments highlight the need to ensure that the wording of phrases is not ambiguous or confusing, for example;

- In information about skin cancer the phrase 'Take care not to burn' will not necessarily mean just from sun burn.
- The term 'Out of Hours' could be a confusing concept. A more simple explanation like 'If you need a doctor at night or at weekends' is clearer.
- 'Day procedure' – would not to be understood by people with a learning disability.
- Using the term 'units' would not be understood but talking about glasses or pints might.
- The concepts of times and dates could be better explained with pictures of a clock, or by phrases such as 'after dinner', or 'at breakfast time'.

- Avoid the use of abbreviations for example GP/CPN. More explanation is needed where unfamiliar terms are used – for example the term ‘podiatrist’.
- **Font Size**

#### **Q.8. Is the font a reasonable size?**

63% of panel members think that the font size is too small.

If we look at assessment of font size by leaflet however, carers are divided in their opinion. In particular, 9 pieces of information are thought to have a reasonable font size by half or more of the panel members assessing that piece of information.

It is interesting, however, that only 2 pieces of the information are assessed by over 80% of the carers as having a reasonable font size. For example ‘Against Bowel Cancer’, ‘Stress an ABC of Coping’.

Other issues raised by carers are similar to those made by people with a learning disability. They include the use of bold font to highlight important points and also the good use of contrasting font colour and background colour to make the text easier to read.

- **Contact information**

#### **Q.3 Do you think the leaflet contains useful and clear contact information?**

- Of the 10 leaflets which contain contact information 68% of panel members think that the contact information is good.
- Only one piece of information is considered as having good contact information by all those assessing it. This leaflet provides a wide range of telephone numbers for a variety of local centres. [‘Podiatry Services’]

Carers think that contact information could be improved as follows:

- contact details could be more specific or clearer about who to contact.
- there should be more local telephone numbers or a central number for people with a learning disability.
- medicine labels should contain some details for contacting a local pharmacy or doctor, or as some suggested, should have a space for adding local numbers.

Carers consider contact details to be important for finding out further information, especially local information, and for obtaining further support. They comment that, in most cases, contact details are unclear and would be more useful if they are highlighted in some way.

Comments include:

Contact details “should be highlighted with telephone numbers in very large print.”

There are “no contact numbers for support services to help with alcoholism.”

“It does not say who produced the leaflet and there is no contact number for further questions or concerns.”

- **Pictures**

### **Q.9 Are pictures used to support and explain the information being conveyed by the writing?**

Not all of the information assessed contains pictures. Of the 10 pieces of information which do, only 36% of panel members think that they help to convey the meaning of the text.

The general consensus of the carers is that more pictures are needed in the majority of pieces of information. They think that the pictures used are too small and at times are not clear enough. The pieces of information which are considered to contain useful pictures are those with large clear pictures or those with pictures which help to explain the text, for example ‘Small Changes Big Benefits’, ‘Sunsmart’.

Carers suggest that to help make information accessible pictures should be:

- large
- recognisable
- used as an aid to understanding the text
- photographs of people and situations which people with a learning disability can identify with.

As with the assessment panels of people with a learning disability some carers prefer pictures of fun cartoon images but clarify that these should be recognisable images and in colours that make sense. For example, carers suggest that images of food should be in the correct colour for that food.

Comments include:

“There are too many technical terms. There is too much information presented on the page.”

“It’s dull, too technical and too condensed.”

“Too much writing in a small space.”

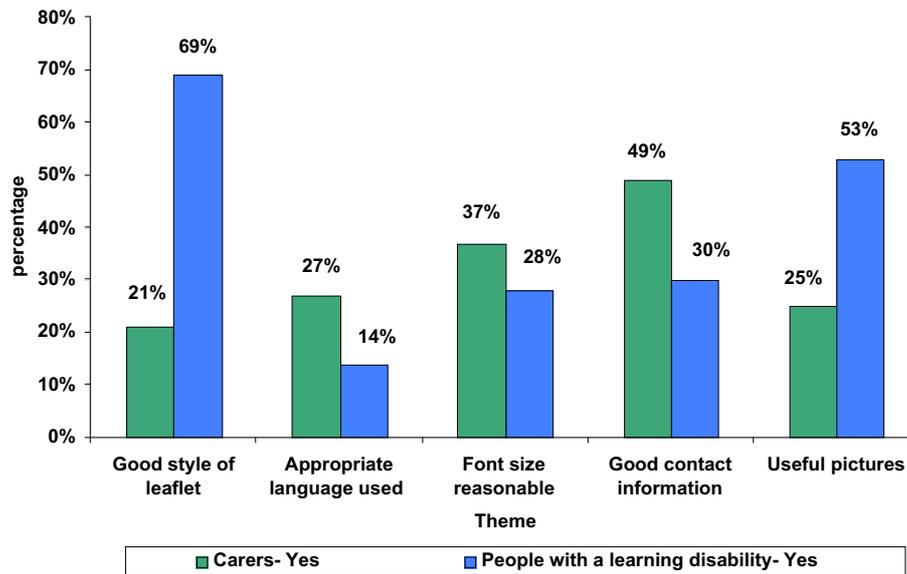
“It is drab and unattractive and uses too much scientific jargon.”

“Pictures are used but are not clear enough to explain the information.”

“There are no pictures in it for someone who cannot read. The information is not explained clearly enough.”

## Comparison of Questionnaires Responses from People with a Learning Disability and Carers.

Figure 5: Comparison of the questionnaire responses from people with a learning disability and carers.



There are some differences in opinion between carers and people with a learning disability in their assessment of the written information. Carers are much less positive about the style of the information. However, the fact that more people with a learning disability consider the style to be good is not borne out by the responses given to the style specific questions. Fewer people with a learning disability:-

- assess the language used in the written information as suitable,
- think that the font size used is reasonable, and
- think that the contact details are useful.

These barriers to accessibility are reflected in the fact that just 3% of people with a learning disability could understand the information unassisted. More carers think the information could be understood; although they did point out that the ability of the individual would be a factor in this.

It is interesting that there is a significant difference between the views of carers and people with a learning disability regarding the

usefulness of the pictures. This may reflect more the enthusiasm that people with a learning disability have regarding information that contains pictures rather than the actual usefulness of the pictures in supporting the meaning of the text.

## **Section 4: Results - Verbal Communication**

This section of the investigation report examines the main barriers to good verbal communication as identified by assessment panels. Assessment panels were given the opportunity to discuss their experiences of verbal communication during consultations with healthcare professionals within primary healthcare settings. It was evident from discussions, however, that some people with a learning disability have more experience of communication within the hospitals, and so these were included.

### **Communicating Well**

Verbal communication can be enhanced to meet the needs of people with a learning disability. In the healthcare situation it is vitally important that communication is effective as a way of obtaining and providing information to ensure equal access to services. Good verbal communication can also be used to build confidence and reduce anxiety in often unfamiliar environments.

Key to good communication is the speaker's awareness of the specific communication needs of the individual and a willingness to adapt their ways of communicating to meet these needs. This may mean using additional aids to explain the meaning of the verbal communication.

Meeting the health needs of people with a learning disability requires good verbal communication skills and using these skills in a busy healthcare setting requires time, patience, training and practice.

### **Summary of Findings**

All panel members have experience of verbal communication within general practitioner and dental settings while some panel members also had experience of communication within the hospital setting. It is noted that only a small number have experienced communication in the pharmacy as many do not collect their own prescriptions.

A number of barriers to good communication were reported by both carers and people with a learning disability in the various health

settings. These barriers were thought to affect not only the patients' understanding of health issues but also the timely identification and treatment of health problems.

The main barriers identified by both the panels of people with a learning disability and carers can be grouped into 3 areas:

- Communication skills and experience

Panel members report that some healthcare professionals do not adjust their communication style to suit the specific needs of the person with a learning disability. This is particularly noted as the experience in hospital settings. It is thought that this is due to a lack of training and experience in communicating with people with a learning disability. People with a learning disability recognise this barrier and also report their lack of confidence in their own communication skills as a barrier.

- Familiarity and attitudinal issues

It is also reported that a lack of familiarity with an individual or people with a learning disability in general, is a barrier to good communication. It is thought that a lack of familiarity may lead to assumptions being made about an individual's ability to communicate or to understand what is being said. Panel members also think that these assumptions and attitudes affect the way in which some healthcare professionals interact with people with a learning disability.

- Time issues

Panel members report that in some healthcare settings lengthy waiting times can increase the anxiety levels of the person with a learning disability and this anxiety can affect his/her ability to communicate during the consultation. They also think that the limited amount of time provided during consultations is in itself a barrier to good and effective communication with people with a learning disability.

One of the outstanding results of the investigation is that panel members are very positive about their experiences of communication with dentists. They have experience of a wide range of dental professionals and not just those who have received

specific training in communication with people with a learning disability. It is encouraging that participants with a learning disability do not identify any barriers to good communication in this situation.

### **Barriers to Good Communication Identified by People with a Learning Disability**

Table 5: Barriers to good verbal communication identified by people with a learning disability.

Barrier identified	General Practitioners	Hospitals
1.	Lack of Self Confidence	Waiting Times/unfamiliar environment
2.	Time Factor	Language Used
3.	GP talking to carer	
4.	No use of other forms of communication	
5.	Language used	
6.	Waiting Times	

No barriers to verbal communication with dental practitioners were identified by people with a learning disability.

Figure 6: Percentage of panels of people with a learning disability identifying each barrier to good verbal communication within general practices.

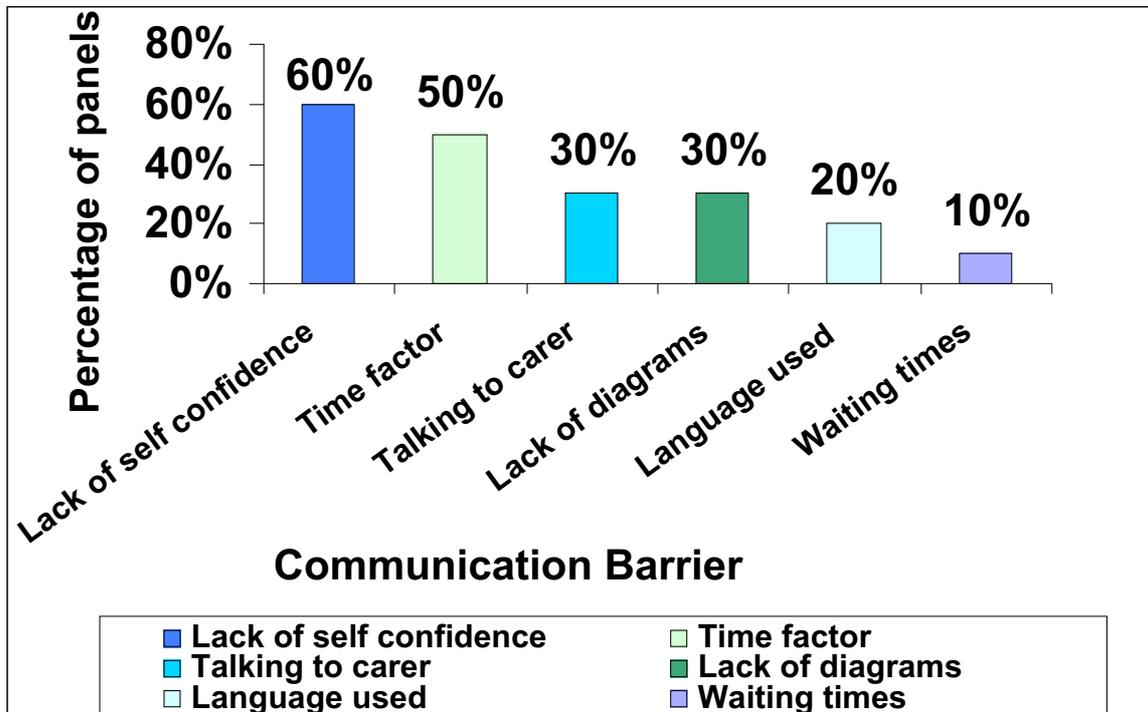
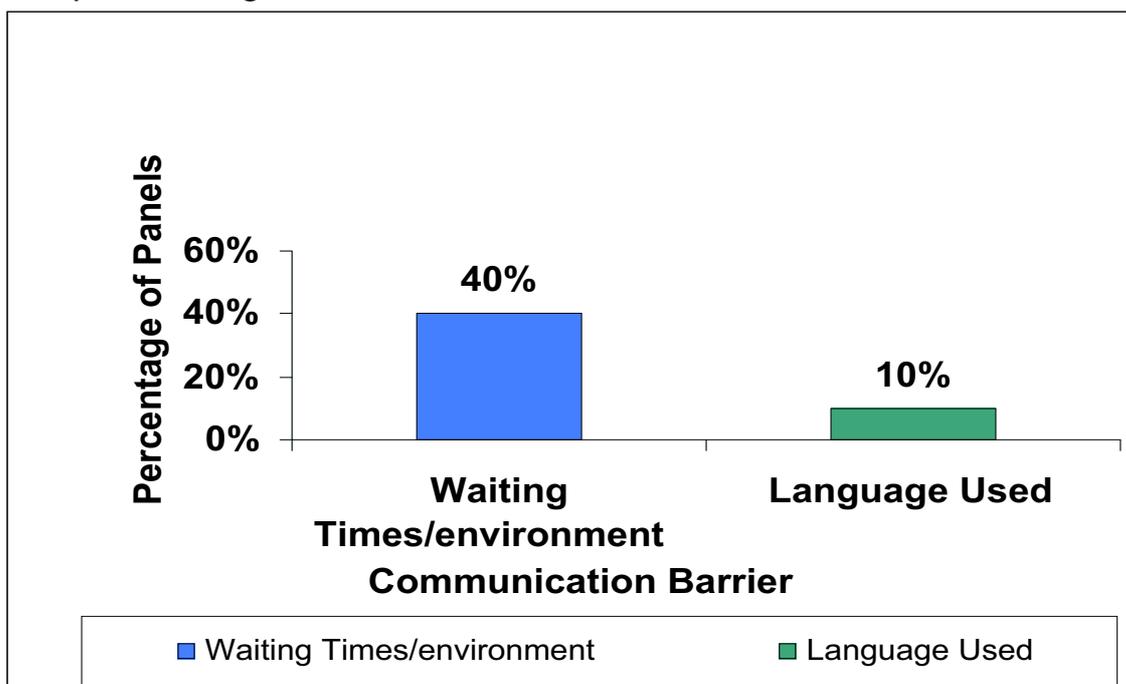


Figure 7: Percentage of panels of people with a learning disability identifying each barrier to good verbal communication within hospital settings.



## Lack of Self Confidence

60% of panels highlight a lack of self confidence as a barrier to good communication when they attend their general practitioner. This was not mentioned as a barrier for other healthcare settings.

Some panel members mention that they do not feel confident that they will understand and remember what has been said during the appointment. As a result some people are content to have someone accompany them to talk and ask questions on their behalf. Those who have speech difficulties are particularly afraid that they will not be understood by the healthcare professional.

Due to this barrier some people are reliant on the carer to speak for them, even those people who would prefer to be unaccompanied during consultations. In addition, the healthcare professional may not attempt to communicate directly with them as they do not feel confident enough to answer questions themselves.

Panel members also state that they do not feel able to ask the healthcare professional questions and as a result leave the consultation not fully understanding what has been discussed. In some cases not having the confidence to speak up about their health issue may mean that they do not fully describe their problem which may have serious consequences for their health.

Comments include:

Some people feel “more confident when someone is doing the talking for them.”

“I worry that the doctor won’t understand me or have time to understand me. I let staff know what is wrong with me before I go to the doctor and they talk for me.”

“I would like to go on my own to the doctor and I have said this to my mum and dad. But I don’t know if I will understand the doctor or remember what he has said.”

“I am glad that someone is with me to explain what has been said.”

“I don’t like to ask. I would be embarrassed”.

Panel members identify this barrier as a lack of self confidence in their own communication skills but there are a number of communication issues on behalf of the healthcare professional which appear to affect the confidence of the person in these situations such as;

- the use of medical terminology during consultations
- the attitude and body language of the healthcare professional
- how familiar the healthcare professional is to the individual
- the time limitations of appointments
- the build up of anxiety during waiting times
- the healthcare professional automatically directing communication to the carer.

The assessment panels provide a number of examples of occasions when healthcare professionals helped to boost their confidence by ensuring that they were the main focus of attention during the consultation. They think that simple actions such as acknowledging and greeting them and beginning the consultation with small talk helps to put them at ease. Panel members state that using simple language gives them more confidence that they will understand what has been said. They are aware, however, that the healthcare professional may need to include the person accompanying them where they are unable to respond. They also report feeling more confident when they are attended by a familiar healthcare professional.

### Time Factor

- Half of the assessment panels felt that the 10-15 minutes allowed for appointment times in their general practice was not long enough for them.
- These participants feel that the time restrictions mean that some GPs do not take time to ask enough questions or to properly explain health problem or medications.

This barrier to good communication is an issue for those who feel that their doctor does not have enough time to explain their health issue simply and fully to them. Some people also feel that the time restrictions mean that the healthcare professional will not

communicate directly with them because it will take longer to convey all the information needed. This barrier is not raised in connection with other healthcare situations by people with a learning disability.

Comments include:

“The GP has no time to try to understand me ...this means I have to go with my mum.”

“The doctor does talk to me but he talks too fast and I can't understand him. I asked him to slow down but he hasn't.”

“I feel rushed and I don't have time to explain why I'm there.”

“I don't like to ask questions even if I haven't really understood”.

There is some evidence that this particular barrier may mean people who wish to attend the doctor on their own are unable to do so because consultations are too restricted and adjustments are not being made to meet communication needs. Panel members indicate that there is not enough time to ask questions even if they do not fully understand what has been discussed. Other people feel that their health issue has not been examined thoroughly enough.

Assessment panels appreciate the fact that some healthcare professionals are prepared to be flexible and take time to try to explain issues to them in a way they will understand. They state that some healthcare professionals, dentists in particular, are very good at explaining the treatment they will be receiving and at taking time to provide information about health issues, using demonstrations where necessary.

## Waiting Times

Figures 8 and 9 show that lengthy waiting times are identified as a barrier to good communication by people with a learning disability when attending hospitals [40% of panels] and general practices [10% of panels].

Panel members report that during lengthy waiting times they do not receive information about how long they are likely to wait and what is going to happen. For some this means that they become anxious and feel nervous. In some cases the unfamiliar hospital environment combines with this uncertainty to create anxiety and confusion. They report that they are more likely to experience

lengthy waiting times when attending Accident and Emergency departments.

Panel members recognise that they become anxious in this situation and their anxiety affects their ability to communicate well. In some cases anxiety leads to unco-operative behaviours which, in turn, may affect the attitude of healthcare staff to them and the effectiveness of communication.

Comments include:

“I don’t like waiting for so long and no-one tells us how long I have to wait.”

“I don’t like the hospital, it’s scary. I don’t know what is going to happen to me.”

One panel member described her experience of hospital. She became very anxious and worried when she was left in an enclosed cubicle where she could not see anyone; did not know what was happening and no-one came to explain what was going to happen. She would have liked someone to have kept her informed and she would have been more reassured if she had able to see outside the cubicle.

Acting to reduce this anxiety and confusion by keeping individuals informed is seen by panels as helping communication and also as good communication in itself.

Panel members state that they appreciate when they are kept informed. Those who attend Accident and Emergency departments say that they are put at ease when a healthcare professional speaks to them to let them know that they may have to wait for a while. They think this is helpful because they then know why they are not being seen and do not become overly anxious.

“A doctor came to speak to me and said that we might have to wait some time.” The individual thought this was good as they knew why they were not being seen quickly.

Others describe how their fears and anxieties are reduced when awaiting results of tests at hospital. This may involve spending long periods of time waiting at hospitals and the panel members

appreciate the nurses taking time to talk with them and keep them up to date with information.

Some panel members describe going to the hospital as a “scary experience” and so this direct communication and provision of information provides reassurance, and this in turn may improve communication with the healthcare professionals.

### Talking to the Carer

- 30% of assessment panels think that their general practitioner talks to the person with them more than to them and that this is a barrier to good communication.
- It is also clear, however, that many people with a learning disability appreciate the role that the carer plays in these situations and rely on them to a large extent.

Panel members who raise this barrier as an issue think that the healthcare professional should speak to them directly and take time to explain things in a way they can understand. Some people feel that although the healthcare professional may ask them some questions the subsequent explanation about the health issue or the medication is given to the carer and not to them.

“I go for check ups every 3 months with my sister. I don’t know why I have to go every 3 months or what the tablets are for”.  
“The doctor tells the person with me about the medicines”.

It has been seen previously that some people with a learning disability rely on the person accompanying them to speak on their behalf and to provide further explanation following consultation. However, where there is little or no effort to include the individual in the consultation this may reinforce their lack of self confidence. In extreme cases this may lead to health issues going unreported and undiagnosed.

### No use of other forms of communication

30% of assessment panels think that the lack of pictures or symbols to assist with understanding is a barrier to good communication of health issues.

Panel members who raise this issue state that the healthcare professional does not use any diagrams or pictures to help explain issues to them and they think it would be helpful if these were used. Some people think the healthcare professional does not have time to explain things properly to them in any case but they would appreciate having verbal communication supplemented with pictures or diagrams. Those people with a learning disability who communicate using Makaton symbols think that their experiences would improve if the healthcare professional was able to communicate this way also.

One participant who visits the doctor unaccompanied comments “I would have liked my doctor to use a picture to explain things better. I asked questions but didn’t really know everything when I left. It makes me feel bad when I leave not understanding what was said.”

Those who experience the use of pictures or diagrams to assist with explanations find that they help them better understand the health issue. For example, they report that pictures can help them see clearly which part of their body is affected, what the health problem looks like, or what treatment will mean for them.

## Language used

People with a learning disability identify the medical terminology used by healthcare professionals as a barrier to good communication

- 20% of panels identified this as being a barrier in general practices
- 10% of panels identified this as a barrier in the hospital setting.

These percentages may appear low, but it is not the case that the remaining panelists considered that simple non-technical language was generally used in these health settings. As reported earlier, panelists are not confident that they will understand what has been said, and many like their carer to be with them. Some assessment panel members state that they have experienced the confusion and lack of understanding caused by the use of medical terminology.

Panel members think it is important that healthcare professionals adjust their language to suit their specific needs.

Comments include:

“the language used is too difficult”

“they don’t break it [the information] down so I can understand”

“the doctor uses words I can’t understand.”

Those with experience of doctors’ rounds as inpatients in hospital comment that they are “confused by the doctors”. Some were fortunate that the nurses took time to explain in simple terms what had been said.

“When the doctors came round I couldn’t understand what they were saying but the nurses took time and helped to explain things.”

As we have noted previously the majority of the panel members lack the confidence to ask questions of the healthcare professionals where there was a lack of understanding. This makes it important for healthcare professionals to ensure that their explanations meet the specific communication needs of the individual.

### Information about medicines

Panel members were asked about their experiences of verbal communication at the pharmacy. Only a small number have experience of collecting prescriptions from the pharmacy either by themselves or accompanied. Those people who collect their own prescriptions from the pharmacy state that the medications are not explained and if they are accompanied they feel that any instructions are directed towards the person accompanying them.

One person comments:

“The pharmacist just hands me the medication and doesn’t go through the instructions.”

Some people say that they read and understand the medication label but others say they “find it hard to read because [the instructions] are so small”.

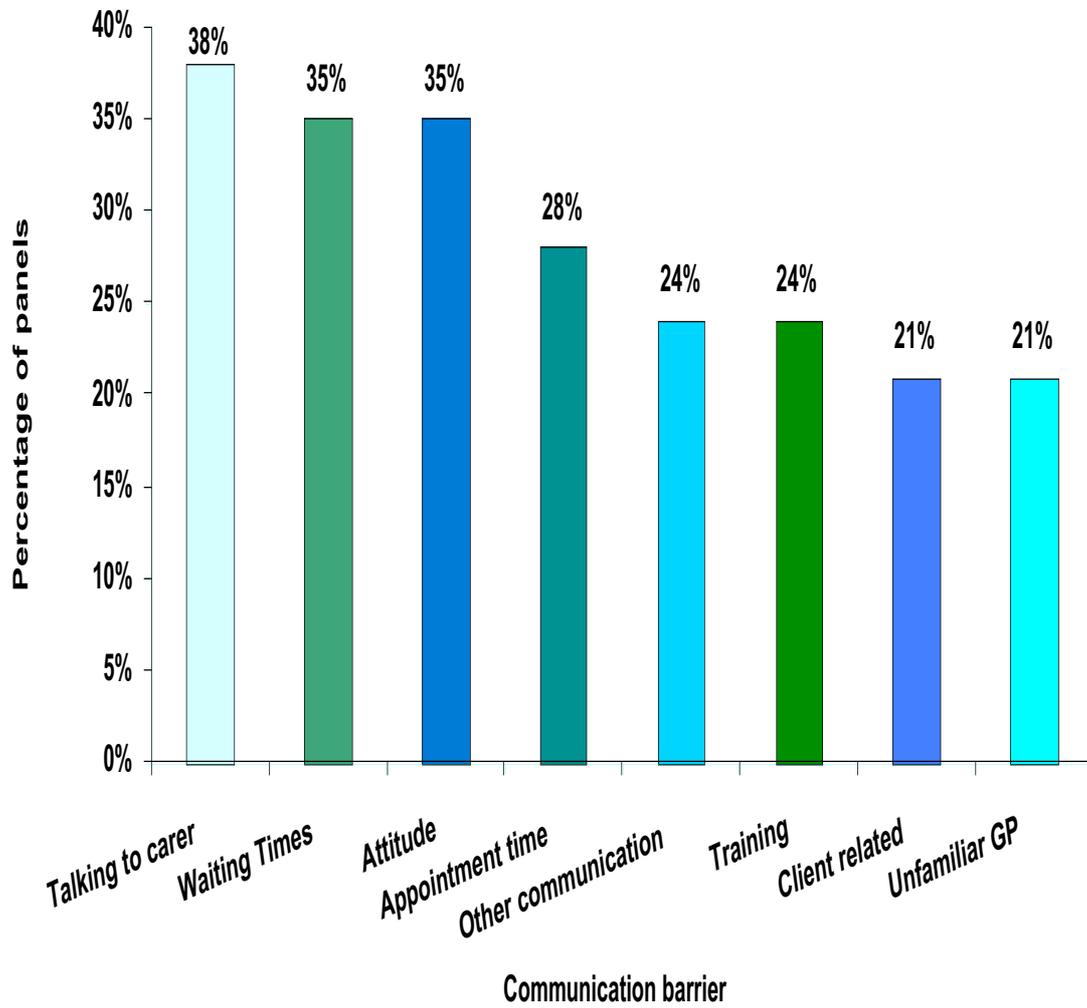
Some people confirm that their doctor explained their medication; why it is being prescribed, how to take it and, in some cases, the side effects. However, it is clear from this investigation that carers are the main support regarding provision of information about and administering medication. Panel members understand the importance of taking their medication and of following instructions carefully and a number of people know their prescribed medication and its affect.

## Barriers to Good Communication Identified By Carers

Table 6: Barriers to good verbal communication identified by carers

	<b>Barriers to good communication</b>		
	General Practitioner	Dentist	Hospital
1	Talking to carer	Lack of training	Lack of Training and Experience
2	Long Waiting Times	Attitude	Attitude
3	Attitude	Other forms of communication not used	Time pressures
4	Length/use of appointment time	Client related [ability/confidence/mood]	Talk to carer
5	Other forms of communication not used	Difficult language used	Unfamiliarity
6	Lack of training		Waiting times
7	Client related – ability/confidence/mood]		Medical language used
8	Unfamiliar GP		Accents
9	Medical language used		
10	GP Accents		
11	Carer's attitude		

Figure 8: Percentage of panels of carers identifying each barrier to good verbal communication within general practices.



Talking to carer	Waiting Times	Attitude	Appointment time
Other communication	Training	Client related	Unfamiliar GP

Figure 9: Percentage of panels of carers identifying each barrier to good verbal communication within the hospital setting.

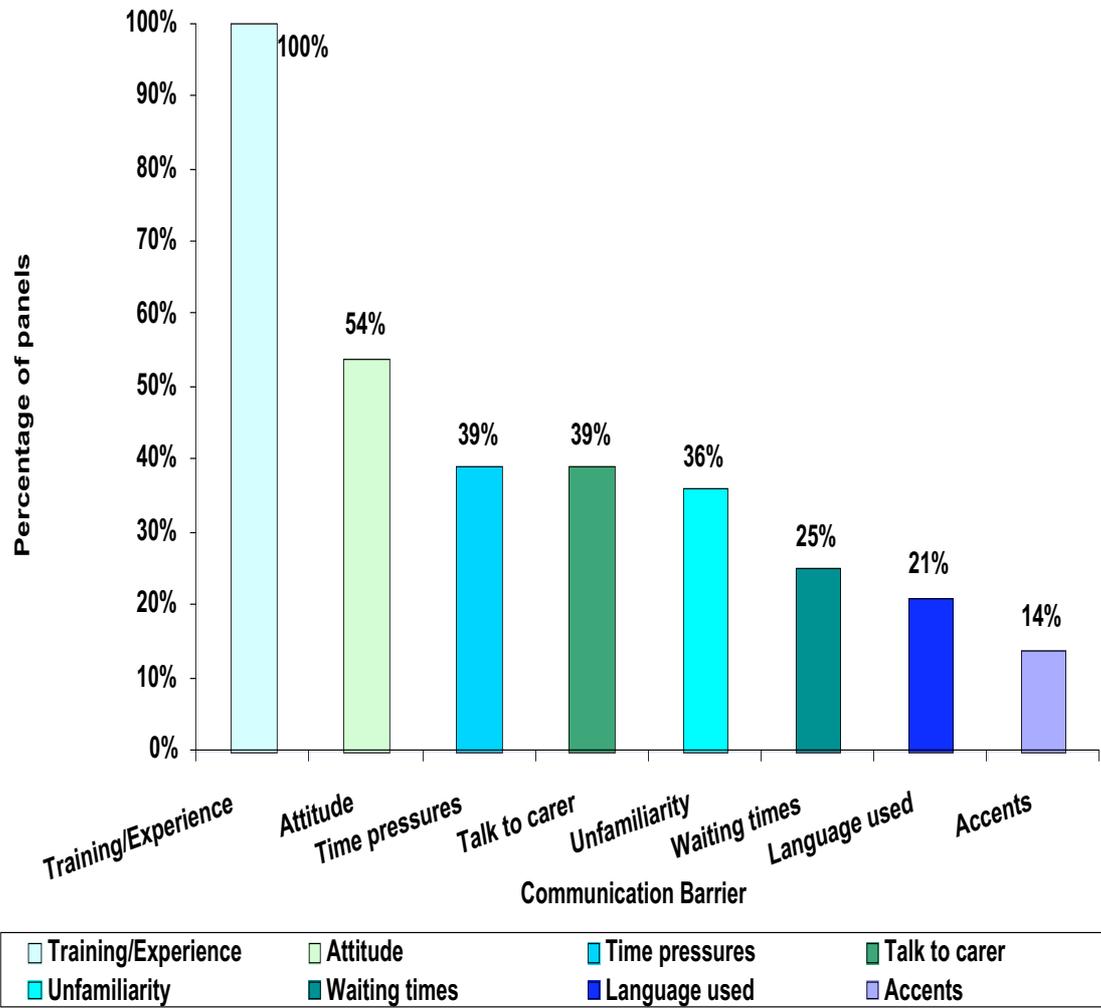
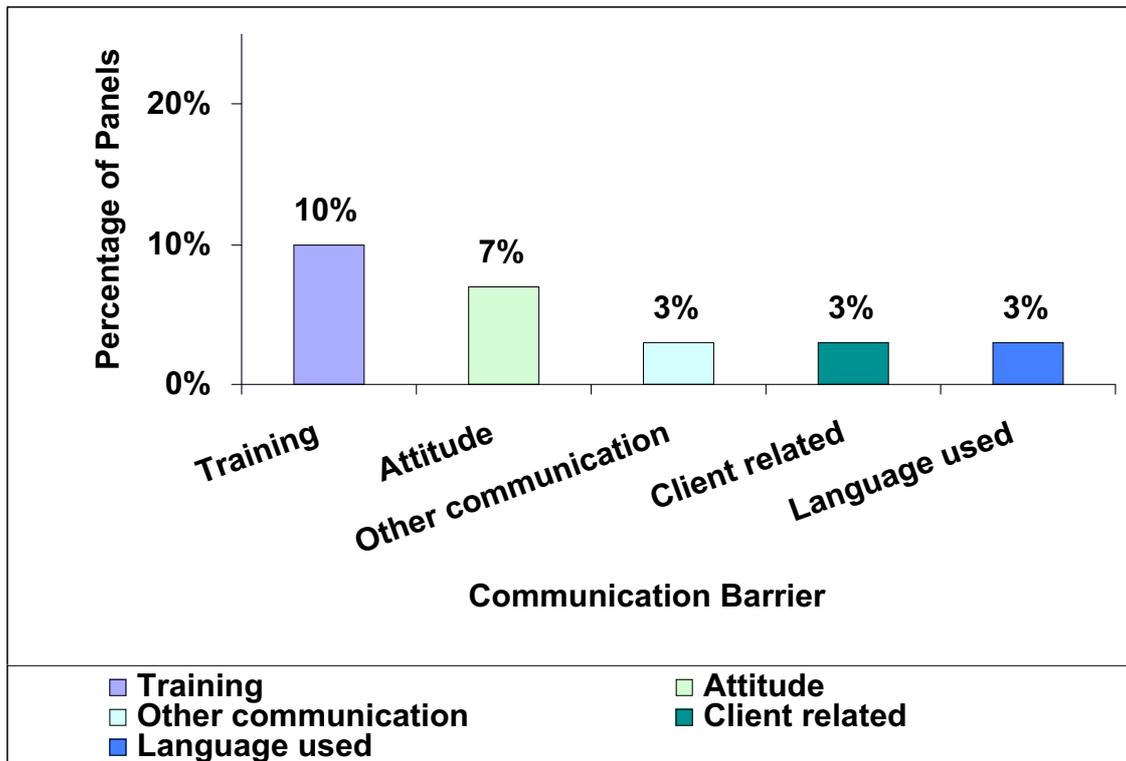


Figure 10: showing the percentage of panels of carers identifying each barrier to good verbal communication within dental practices.



### Lack of training/experience

- 100% of carer panels identify the lack of training and experience as particularly evident in the hospital setting. Panels report this barrier as less evident in general practices [24%] and dental practices [10%].
- Carer panels consider that healthcare professionals have received insufficient training in communication with people with a learning disability and that as a result they fail to respond to the varying capabilities of individuals and their specific communication needs. In addition to training issues, carers think that a lack of experience in communicating and dealing with people with a learning disability leads to little or no attempt to speak with the individual.

Carers recognise that healthcare professionals “make the effort to try to communicate well with the individuals but they would need training... they have limitations in their skills and experience.”

This lack of training, combined with a lack of experience of dealing with people with a learning disability, is believed to lead to poor communication particularly in the hospital setting. Carers mention a number of examples where healthcare professionals are unaware of the abilities of people with a learning disability and how to adjust their communication to meet their needs. They feel that the ability to communicate well is vital in this environment where people with a learning disability may be nervous or agitated.

In one extreme carers think the communication can be oversimplified and patronising to the individual while in other instances language used is not adjusted to suit communication needs. Some report that medical terminology is used when a more simple explanation would lead to better understanding. Carers feel it is vital that healthcare professionals have the skills to enable them to respond appropriately to the needs of individuals.

Carers think that if healthcare professionals had more training and practical experience in communicating with people with a learning disability they would be able to ensure greater direct communication even with those whose ability to communicate is limited. Carers believe that healthcare professionals should have a greater awareness of how good communication skills can assist people with a learning disability.

For example, understanding how the tone of voice used may affect an individual's response or how asking a question in a particular way will enable a person of limited communication ability to answer "yes" or "no" for themselves.

"The doctor thinks they have understood because they nod and agree with him. But once outside they will ask what the doctor was saying."

Carers report that lack of familiarity and experience appear to be a greater barrier to good communication in hospitals where busy staff may not have time to find out about individual communication needs, and staff changeovers can mean that staff do not become familiar with individual abilities. It is the experience of carers that some hospital staff are reluctant to interact with people with a learning disability and think that this may be because they do not know what to expect.

This barrier is not identified by carers for dentists and only a small number of carers have experienced instances where the communication skills of dentists could be improved. In fact 72% of carer panels report that in their experience dentists have received good communication skills training, as compared with healthcare professionals in hospitals [39% of panels] and general practices [35% of panels]. This may reflect, of course, the fact that many of the dentists working with people will be community dentists who have received appropriate communication skills training, but it also emphasises that this is the level of skill required to communicate well and meet the needs of people with a learning disability.

Carers agree that specific training in the communication needs of people with a learning disability can make a great difference to individuals in health settings. In their experience healthcare professionals who have received good training will adjust their style to meet the needs of the individual and will speak directly to the individual. Carers have experienced how communicating well can reassure the individual and help them relax. This in turn makes it more likely that the patient will co-operate, allowing procedures to take place. It also allows the individual to understand issues, treatments and procedures to the best of their ability, and therefore can make more informed choices about their own health. This can make a difference around consent issues where treatment might otherwise be delayed.

## Talking to the Carer

Carers consider that an overemphasis by the healthcare professional on directing the communication to carers is one of the main barriers to good communication. In their experience some healthcare professionals direct all questions and explanations about the individual's health issue and treatment to the carer.

- 38% of panels report this as the main barrier to good communication when attending the general practice.
- 39% of panels experience this barrier at hospitals.

Carers feel that some healthcare professionals make assumptions about an individual's ability to communicate and automatically turn to the carer for information. In the worst cases reported by carers

this means that the healthcare professional does not even acknowledge the individual.

In hospitals, in particular, carers feel that because staff are very busy dealing with large number of patients as well as coping with the daily routine, they do not take the extra time required to communicate directly with the individual.

While carers recognise that they may need to assist the healthcare professional in communicating with some individuals, they feel that the healthcare professional should in all cases attempt to include the individual in the consultation. They feel that some healthcare professionals rely on them unnecessarily in many instances at the expense of the person with a learning disability.

It is recognised that some individuals are able to ensure that they are included in discussions and that some healthcare professionals will realise their mistake if they have not directed their communication to the individual. Carers state that they try to ensure direct communication with the individual but feel that healthcare professionals should always check the individual's capabilities and needs in the first place.

Carers consider that a reluctance to directly communicate with the individual may be related to other barriers identified by panels, such as lack of training, experience, attitude and time pressure.

Comments include:

"The doctor makes no eye contact, no direct communication and no explanation to the individual about treatments. [The individual] is very capable of communicating clearly but the doctor does not even attempt to communicate directly with them."

"The GP doesn't acknowledge her presence and asks us questions about how she is feeling."

"There is no attempt to talk with them and they expect care staff to do this for them."

"They assume they don't communicate and don't ask."

## **Good Practice reported by carers**

Although carer panels agree that barriers to good verbal communication exists they recognise that there has been a great deal of improvement over the years. They have experienced the person with a learning disability being given the opportunity to explain what their health problem is and to answer questions about their condition. Carers state that where healthcare professionals direct their communication to the person with a learning disability they become more confident, more relaxed and more willing to co-operate with the healthcare professional.

Carers agree that people with a learning disability are most likely to be spoken to directly in the dental practice [83% of panels]. A smaller number of panels [61%] report that healthcare professionals in the hospital setting communicated directly with people with a learning disability, while only 38% of panels have experienced this at general practices.

Carers recognise that engaging the individual in this way requires good communication skills and patience, for example in allowing the individual time to respond to questions. They also agree that in some cases they will necessarily be involved to assist with explanations or to confirm information provided by the individual, but only after attempts have been made with the individual in the first instance.

Carers are aware that speaking directly to the individual may not on its own assist understanding of health issues. However, they think that doing so offers the individual dignity and also helps to settle nerves. Carers feel that the healthcare professional should be aware of the individual's ability to understand and retain information and where necessary ensure that the carer is included in information provision.

At times carers have experienced direct communication with the individual but feel that the attitude of the healthcare professional and their communication skills, such as language used and tone of voice, could be improved.

Where direct communication is made in simpler language, and time is taken to explain issues to the person with a learning disability, it can make a difference to the individual's understanding of the

health issue. Direct communication can also be facilitated by physically situating the person with a learning disability in front of the carer in the consultation as this immediately focuses attention on the individual. A specific case was reported where this type of one to one communication enabled the individual to understand the options for treatments for his illness and why the healthcare professional was choosing one option in particular.

One carer describes her experiences of good communication: “The doctor brought the individual to the front of the room and explained that he was the important person in the room. The doctor was aware that the client couldn’t speak but nevertheless directed every question and comment to him. He explained everything to him and went through all the options for treatment and why he had chosen the particular one over the other options.”

## Long Waiting Times

Carer panels think the length of time spent waiting to see the healthcare professional has an affect on the individual’s ability to communicate.

- 35 % of panels experience this barrier at general practices.
- 25% of panels experience this barrier at hospitals
- No panels report this as a barrier at dental practices.

In their experience some carers find that the length of waiting times leads to increased levels of anxiety for some individuals and that this in turn affects their ability to communicate during their consultation. They think that the lack of information or updates about how long they will have to wait and the lack of flexibility to meet individual needs contribute to the problem. [This is confirmed by assessment panels of people with a learning disability]

Waiting times are a particular problem for some clients whose behavioural problems may be highlighted and as a result some carers say that they are reluctant to make appointments unless it is absolutely necessary. Increased levels of anxiety are said to affect ability to communicate and willingness to co-operate during the appointment. In more extreme cases the long waiting times make

individuals so restless and disruptive that the appointment is cancelled or rescheduled.

“They don’t understand why they have to wait so long and it is sometimes difficult to persuade them it is important to wait to see the doctor.”

In other instances the individuals walk about and subsequently lose their place in the queue. A lengthy waiting time may therefore mean that the consultation time is not constructive and there is a possibility that health issues may be overlooked.

In some cases the carers think that where a lengthy wait is unavoidable, the individual may benefit from having more distractions, such as television, to occupy their minds and perhaps a private waiting area.

## Attitude

Carer panels identify attitudes as a barrier to good communication.

- 54% of panels report experiencing this barrier in the hospital setting.
- 35% of panels experience this barrier in general practices.
- 7% of panels report this barrier present at the dental practice.

Panel members feel that certain attitudes result from having little or no experience of dealing with people with a learning disability.

A number of carers indicate that they have found some healthcare professionals unwilling to attempt to communicate or develop any kind of a rapport with the individual. They feel that it is important that the healthcare professional build up a relationship with the individual and gain their confidence as this will help those who may otherwise be anxious to settle down before the consultation begins.

Panel members have experience of some healthcare professionals displaying a poor attitude through their body language. In their experience some healthcare professionals do not acknowledge the individual, for example, by not making eye contact with the person

with a learning disability. They report that some healthcare professionals give the impression of impatience, or that the consultation is a “waste of time”, where they feel the attitude is that “the person has learning disability and there is nothing they can do”. They state that they have experienced some staff physically withdrawing from the individual.

Comments include:

“A bad attitude leads to bad communication”.

Some carers feel that negative attitudes may have built up from experience of the behavioural problems which certain individuals may display under these stressful circumstances. They feel that this may be the only experience of people with a learning disability that some healthcare professionals will have and so they expect others to be disruptive. They state that they feel that the lack of confidence displayed by some healthcare professionals transfers to the individual making them feel anxious and nervous.

In some panel members’ experience the healthcare professional did not take time to explain issues to the individual because they said the individual “didn’t have the mental capacity to understand”. They feel that the healthcare professional assumed this as they didn’t want to take time to try to explain.

Panel members think that at times such attitudes, and the resulting lack of communication, may lead to important health issues going unnoticed. For example, they have experience of individuals being ignored when they have tried to indicate where pain is present. In one particular case the carers feel that the attitude of the healthcare professional that certain symptoms were to be expected because the individual had a learning disability led to a failure to diagnose cancer.

Comments include:

“The GP did not ask many questions or do further tests with the individual; he assumed the problems were constipation related.”

“There is too much emphasis on the learning disability and not enough on the actual person and their health needs....GP’s often make the family feel they are being too fussy.”

## Good Practice reported by carers

Participants also have experience of healthcare professionals who have an excellent attitude towards the person with a learning disability and who are willing to interact with them and become familiar with their particular abilities and specific communication needs. In carers' experience, where the healthcare professional engages the individual and explains health issues in simple terms they gain greater co-operation and understanding. They report that they have experienced good attitudes from healthcare professionals in all areas covered by this investigation.

Comments include:

“The GP shows an excellent attitude towards one patient who has no speech but has devised his own signs to communicate. The GP is willing to interact with him and takes time to understand these signs and to communicate with him. This allows him to indicate his health problems and gives him some control over the direction of the consultation.”

### Length/use of appointment time Time pressures

Carers raise the time limitations placed on healthcare professionals as a barrier to good communication.

- 28% of panels state that the length of the appointment time in general practices provides cause for concern.
- 39% of panels report that the time pressures of a busy hospital are a barrier to good communication.

This is not raised as an issue for dental practices.

Panels agree that the usual time given for a consultation is between 10 and 15 minutes, and they think that in some instances a longer appointment time is required.

"Some clients need a double appointment if the GP is to communicate well with them and put them at ease".

Carers believe that when healthcare professionals feel pressurised they are less likely to attempt to communicate with the individual and can become impatient if the individual's communication abilities are poor.

"The client is not given a chance to explain. The doctor keeps strictly to the 15 minutes appointment schedule."

Carers also think that the time limitations placed on healthcare professionals mean that they want to get to the crux of the matter quickly and so may not take time to settle anxious individuals or attempt to elicit information from those who may have specific communication needs.

"The doctor gives the impression he is in a rush."

Panel members indicate that some individuals do not have the confidence to ask questions of the healthcare professional and when time is limited even those who have good communication skills are less likely to ask, even if they have not fully understood what has been said. As a result many people leave the consultation without fully understanding the implications of the health issue or treatment and so individuals rely greatly on the person accompanying them to explain what has been said to them.

Where there is limited time some carers feel that healthcare professionals are less likely to discuss the health issues further or to perform additional tests. They feel that at times healthcare professionals use consultation time to prescribe medicines rather than to explore health issues with the individual. They also feel that this has had serious consequences for some individuals in their care.

“It’s not the length of the appointment but the use of the consultation. It would be more useful if the appointment is used to explore more about the person’s condition rather than the conveyor belt experience with medication.”

In other cases carers feel that consultation time has been wasted asking questions about the individual’s medical history rather than the presenting health issue. They agree it is more likely to happen when the healthcare professional is unfamiliar with the person with a learning disability, where carers consider that it is particularly important to prepare for the consultation.

One carer panel states that they have experienced good communication because there were no time pressures on the healthcare professionals. They feel that the lack of pressure in the less busy hospital department encouraged the hospital staff to take time to speak directly to the individual and try to explain what was happening and why. They feel that this made a huge difference to the experience of the individual and that he was treated with dignity.

Some carers have experience of doctors being very flexible with consultation times for individuals outside the surgery environment when they have made home visits. The individual is given the opportunity to speak alone with the healthcare professional about their health issue before involving the carer to assist where necessary. They feel that this is appropriate and affords the individual dignity and privacy which has enabled the individual to talk more freely about their problems.

#### No use of other forms of communication

Panel members think that where the healthcare professional relies purely on verbal communication and does not supplement this with other forms of communication, such as pictures, that this was a barrier to good communication.

- 24% of panels identify this barrier in connection with general practices
- 3% of panels think this prevents understanding in dental practices.

Panel members consider that not using any other forms of communication during consultation is a barrier to good

communication with people with a learning disability. They think that using pictures, diagrams or where appropriate, Makaton, would be especially helpful where the healthcare professional is not experienced in communicating with people with a learning disability.

Carers report that where the healthcare professional adds to a simple explanation with either pictures or a demonstration, this improves the individual's understanding of the health issue.

“No doctors or dentists have used any diagrams; their first reaction would be to try to verbally explain. One person was given a video about cholesterol which helped to make the problem clearer.”

Panel members state that they have limited experience of healthcare professionals using other forms of communication to assist understanding. However, they also state that in their experience dentists are good at demonstrating dental hygiene to people with a learning disability. They think that dentists are also good at allowing individuals who may be anxious about dental treatment to become familiar with the implements that they will be using and that this has enabled the dentist to treat otherwise unco-operative individuals [31% of panels].

Carers suggest that using technology such as DVDs and CD ROMs is a good way to help people with a learning disability understand health issues and that being given something to take away from the consultation to look at or listen to would assist the individual. These are available from specialist learning disability services, but carers think they should be widely available in all healthcare settings.

## **Further barriers as identified by carer panels**

### **Client related**

Some carer panels think that the barrier to good communication is sometimes due to the individual's own limitations and confidence in communicating. They think that individuals who normally have the ability to communicate well may be unable to do so due to anxiety or behavioural problems highlighted by some of the other factors previously mentioned.

It is thought that this barrier to good communication could be alleviated if the healthcare professional concerned was committed to direct and good communication with the individual.

This issue is not highlighted as a barrier by carers for hospital settings, where more emphasis is put on the perceived poor communication skills and lack of experience of some healthcare professionals in that environment.

Panel members report that for some individuals the anxiety may be caused by the fear factor from past experiences [dental practices 3% of panels] or by long waiting times [general practices 21% of panels]. They feel it is therefore very important that the healthcare professional involved has the communication skills to settle and get the best out of the individual under the circumstances.

### Unfamiliarity

Panel members report that a healthcare professional who is not familiar with the individual is more likely to communicate with the carer. Being unfamiliar with and not checking the individual's abilities or specific needs is said to be a barrier to good communication.

Lack of familiarity with the individual is highlighted as an issue that often causes consultation time to be taken up going over old ground, and therefore leaving less time to deal with the presenting health issue. This is identified as a barrier in hospital settings by 36% of carer panels and by 21% of carers panels in general practices. It was not raised as an issue for dental practices.

Some carers feel that moving services out of local environments is detrimental to good communication as there are no personal connections and the environment is also unfamiliar.

### Medical/difficult language used

Panel members consider that healthcare professionals often do not adjust their language to suit the individual's level of understanding. This makes it more difficult for individuals to answer questions

asked about health issues. Where there is a lack of understanding it is unlikely that people with a learning disability will ask questions to clarify the issue:

- 21% of panels experience this barrier in the hospital setting.
- 14% of panels report this as barrier in general practices.
- 3% of panels experience this in dental practices.

Again carers see this as a communication skills training issue. Some also think that attitudes to people with a learning disability can mean that some healthcare professionals feel there is little point in taking time to explain issues in simpler terms.

“Doctors rounds are particularly bad; they don’t see a person, just an ailment. They don’t listen to them and the terminology used is too medical and technical.”

Carers state that where they experience healthcare professionals adjusting their language they have found that individuals are less likely to be confused and anxious about their health problems. In this way healthcare professionals enable individuals to make their own decisions about treatment options and improve understanding of the procedures which they are to go through.

### Doctor’s accent

A small percentage of carer panels mention that the accent of a doctor can make it difficult for the individual to understand what is being said. This is raised as an issue for hospitals [14% of panels] and for general practices [3% of panels] in the Western Health and Social Services Board Area only.

### Carers’ attitude

A small percentage of carer panels think that healthcare professionals will “take their cue” from the carer. If the carer tends to talk for the individual from the outset and makes decisions on their behalf, this can discourage the healthcare professional from communicating directly with the individual with a learning disability.

This was raised by family carers as experienced at general practices.

Many carers see their role as encouraging direct communication between the healthcare professional and the individual with a learning disability. They are aware that in some instances the barrier to good communication lies in some part with the individual and that carer input is necessary in assisting both the individual and the healthcare professional to communicate. However, carers are keen to emphasise that in all cases there should be some attempt to include the individual in all aspects of the consultation regardless of their specific communication abilities.

#### Information about medicine

Panel members' report that in their experience medication is not often explained to the person with a learning disability at the time it is prescribed. It may be explained to the carer rather than directly to the individual but some carers feel that they have to request an explanation. They feel that it is more likely that newly prescribed medicines are explained in this way while repeat prescriptions are usually not explained.

The importance of ensuring an understanding of medications and often combinations of medications is emphasised by carers as any confusion about these can lead to further health problems.

The side effects of medications are not explained; "not even possible indications of interactions with other medications. This has caused further health problems, leading to more medications."

To prevent this happening, some carers think that if the medication is explained slowly and carefully together with easily read instructions, this will help not only people with a learning disability but also carers who may have difficulty understanding the implications of some medications.

Some carers report that in their experience doctors are good at taking time to try to explain the medications even though they are aware that the individual will receive support when taking them.

Carers confirm that most people with a learning disability in their care do not administer their own medication or collect their own prescriptions from the pharmacist. However, some carers are aware of people with a learning disability who are independent and who collect and administer their own medication. In these cases they are not aware if medication is explained by the pharmacist when it is collected.

In some carers' experience medication is not explained by the pharmacist when collected, and they think that the pharmacist assumes that this has already been done by the doctor. In others' experience the pharmacist is very good with the individual and will go through instructions with them. They feel that the healthcare professionals who are familiar with people with a learning disability are good at explaining medications.

It is interesting that some carers report that they are supporting individuals to administer their own medication and that the local pharmacist has become an integral part in this by visiting and training people.

## Section 5: Conclusions

Being able to obtain and understand information about health issues, health promotion and health services is essential to enable individuals to make choices about lifestyle and options for treatment, and to be informed about the available services.

### Written Health Information

Participants in this investigation were keen to have access to good easy to read health information. It is accepted that many people with a learning disability require support when dealing with written information even if it is in accessible formats, but for many written information may be a useful tool to initiate discussion about topics or questions about options available to them.

- The written information that is available at healthcare settings is not provided in accessible formats such as Easy Read or Makaton. As a result much written information is not accessible to people with a learning disability. Few individuals with a learning disability would be able to read and understand the written information available from general and dental practices and hospitals without support.
- Panel members thought that some of the health information contained good practice by trying to keep text simple and by highlighting important issues. In some cases the information contained pictures which assisted understanding of the meaning of the text. However, most of the information did not take the needs of people with a learning disability into account. Where good written information is developed or already exists it should be shared between HSS Boards and Health and Social Care Services.
- The barriers identified by the panel members relate mainly to the style of the information. Many understand the concept of the health issue when the text is explained to them. Issues such as small font size and using jargon or ambiguous language will limit the utility of the written information even for those individuals of higher ability.

- These barriers can be removed with imagination and effort. Panel members with a learning disability have ideas about how to make information accessible to them. Consulting with people with a learning disability when developing written information is a valuable approach to overcoming these barriers.
- There exists health information which has been designed specifically for people with a learning disability. This accessible information however, is not widely circulated and individuals rely on others to provide them with this information. This is another aspect of 'accessibility'. Panel members were keen to see accessible written information made available at all health services and provided to people with a learning disability in conjunction with their consultation.
- Panel members noticed that none of the information provided guidance on how to obtain the information in other formats which may be an additional barrier to people with a learning disability.
- To encourage the interest of people with a learning disability health information should be made to look attractive and accessible on the front cover, and this should be continued throughout the information if the message is to be understood.
- It is especially important to eliminate barriers to information which is specific to the individual, such as information about appointments and medicines. At present, although these are personal to the individual they are not adjusted to meet the specific needs of the user.
- It is important that people with a learning disability can relate the information to their lifestyles. Panel members with a learning disability showed greater interest in health issues which they are familiar with and which they believe to be important to them. Where new and unfamiliar health issues are discussed during consultation it may be useful to accompany this discussion with written information. However, it is also vital that the information is accessible and relates to their lifestyle.

- Pictures are of considerable importance to people with a learning disability and should be included in health information. These immediately catch interest and make the information more attractive. It is crucial that pictures assist with understanding the meaning of the text and are not simply included to look good. Any pictures included should be clear, unambiguous, and show images that people with a learning disability can relate to.
- Contact information is seen as important by panel members. Having clear and easily recognisable contact details would assist everyone, including people with a learning disability. Where possible local contact information is preferable.
- Although this investigation considers written health information in particular, it is accepted that some people need more support than others when receiving information. Alternative methods of providing information may be preferable to written information, for example, information provided in DVD or CD ROM format may be more useful for some. Irrespective of format it is essential that the information is provided in a simple and relevant way.

### **What this Means for People with a Learning Disability**

- People with a learning disability do not have equal access to the health information.
- People with a learning disability need support when receiving written information which is not in an accessible format, making them less independent.
- There may be less opportunity for people with a learning disability to make decisions and choices about their own health.
- They may not recognise symptoms of illness.
- A lack of accessible information may have serious health consequences, especially in relation to information about medicines.

- Accessing and negotiating health services may be more difficult.
- A lack of information and uncertainty make the experience of health services more stressful for people with a learning disability.

## Verbal Communication

Participants in this investigation are aware that verbal communication is not only an important way of giving and receiving information but that coupled with body language it can greatly affect the experience of the individual. It is especially important that healthcare professionals are skilled communicators and are willing to meet the needs of the individual to ensure that health issues are understood and health needs are met. Although panel members reported many instances of good communication within the Health and Social Care Service, the investigation has identified a number of barriers to good communication which affect the quality of the experience of people with a learning disability.

- People with a learning disability have specific communication needs and these will be particular to the individual. It is important that the healthcare professional is aware of, and adapts to, these individual needs.
- Adapting communication to meet the specific needs of the individual not only assists understanding but is also seen as an important way of building up good relationships with the individual and crucial to gaining co-operation and trust in stressful environments.
- People with a learning disability appreciate communication in simple terms. Using abbreviations or medical terminology is confusing for most people but people with a learning disability may not ask for explanations.
- In some cases the support of a carer is required. For example, carers will assist when individuals are unable to provide an explanation of their health issue to the healthcare professional or when they need support following the consultation. However, the healthcare professional should

always attempt to communicate with the individual in the first instance.

- The investigation has shown that barriers are less likely to be experienced when attending the dentist. Although not exclusive to this healthcare environment, panel members have reported that here communication is more likely to be direct, with less terminology and assisted with demonstrations.
- People with a learning disability are more likely to attribute the barriers to good communication to their own abilities rather than to the skills of healthcare professionals.
- Speaking directly to the individual is seen not only as good practice but also as helping individuals become more confident in their own abilities, and may improve co-operation.
- The main barrier to good communication identified by carers relates to a perceived lack of communication skills training for healthcare professionals, and their experience of using those skills.
- Verbal communication on its own may not be sufficient to gain understanding and using pictures or symbols where appropriate may assist.
- The impact of non-verbal communication should not be underestimated. Where individuals have felt ignored or rushed this has prevented further communication on their part and resulted in them leaving the consultation without fully explaining their condition or understanding the health issue.
- The barriers to good communication identified by the investigation may be overcome through awareness training and communication skills training. Although healthcare professionals in learning disability services receive specialist training there is less training provided for those in mainstream services. However, people with a learning disability often access mainstream services and are entitled to a good standard of service from healthcare professionals in all settings.

## What This Means for People with a Learning Disability

- People with a learning disability may not understand their health problem to the best of their ability.
- They may feel confused and anxious about their health problems or the subsequent treatments.
- Individuals may not have the information to make their own health choices.
- Individuals become comfortable with others speaking on their behalf and are prevented from growing in confidence in their own ability to ask questions etc. As a result some individuals have no confidence that they will understand or be understood.
- Being unable to attend consultations alone may mean certain health problems are not discussed with healthcare professionals due to the embarrassment associated with raising personal issues in front of others.
- Individuals and healthcare professionals become reliant on carers for communication and explanations.
- There may be a lack of co-operation from individuals who are anxious and confused which makes the consultation stressful and unconstructive or examination and treatment difficult.
- Important health issues may not be identified by healthcare professionals in a timely manner.
- Medicines may be prescribed unnecessarily.
- Consultations may be cancelled or missed altogether delaying diagnosis and treatment.

## Section 6: Good Practice

This Section is included in the investigation report to highlight good practice which has been brought to the attention of the Commission during the course of the investigation. We feel it is important to mention the efforts made throughout the Health and Social Care Service and by individuals and organisations to raise awareness and to address the barriers to accessible information for people with a learning disability. Some of the good practice is carried out as project work with limited funding and although there seem to be obvious benefits for people with a learning disability, more work is to be carried out in piloting and evaluating some approaches.

The examples included in this Section recognise that although a high proportion of people with a learning disability may have some form of communication difficulty, they are nevertheless individuals and so awareness of and a willingness to react to individual needs is essential for effective communication.

### Written Information

There are a number of sources of information available on how to produce accessible written information for people with a learning disability. The guidance recognises that working with and involving the target audience at all stages in the development of easy read information is crucially important.

#### Guidance

Organisations such as Mencap have provided detailed guidance on how to make written information meet the needs of people with a learning disability and assist other organisations to produce easy read information.

Mencap's Guide to accessible writing [2000]<sup>13</sup> sets out the following steps in making written information more accessible:-

- Think about [and include] your audience and decide on your key message.

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<sup>13</sup> available on its website [www.mencap.org.uk](http://www.mencap.org.uk)

- Use words that are easy to understand.
- Set out and design your document to make it clear.
- Use drawings, symbols and photographs to support your writing.

Detailed advice is also provided by Government guidance published in 2001. “Let’s make it accessible” was produced to improve the accessibility of government information for disabled people, and stresses the importance of providing information in a format accessible to people with a learning disability<sup>14</sup>.

The Health and Social Care Service acknowledges the importance of consultation with user groups in improving the accessibility of written information. The HSS Boards have all committed to considering the production of information in alternative formats on request. The Northern Health and Social Services Board’s ‘Communicating Information Well Policy’ incorporates much of the advice given. The policy specifically identifies people with a learning disability as a priority group, and accepts that information must be provided in a style and format that is both easy to understand and accessible. It includes “House Style Guidelines” providing specific advice on making written information accessible.

The Eastern Health and Social Services Board [EHSSB] has also recognised the specific needs of people with a learning disability and the need to consult with user groups in order to assess need. The EHSSB has established links with organisations which provide advice on, and produce information in, accessible formats. It has concluded a Good Practice Review on behalf of the DHSSPS. This resulted in the publication of Guidance<sup>15</sup> for all Health and Social Care Service staff who produce or approve the production of information. The guidance emphasises the importance of using plain straightforward language, simple punctuation, and short sentences which cover just one idea. It also highlights the appropriate use of pictures or images to explain the message. This guidance is available on the DHSSPS website.<sup>16</sup>

The Royal College of Speech and Language Therapist’s [RCSLT], Adults with Learning Disabilities Network [July 2007] recognised the

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<sup>14</sup> available on [www.imagesofdisability.gov.uk/docs/lets\\_make\\_it\\_access.pdf](http://www.imagesofdisability.gov.uk/docs/lets_make_it_access.pdf)

<sup>15</sup> The 5 C’s of Information provision- 2003

<sup>16</sup> [www.dhsspsni.gov.uk/econsultation/practice.html](http://www.dhsspsni.gov.uk/econsultation/practice.html)

importance of making written information meaningful to people with a learning disability. Speech and language therapists have a role in advising on appropriate easy read material for individuals at a personal level, as well as providing guidance and encouraging others to develop and promote the use of easy read information.

NHS Quality Improvement Scotland [NHS QIS] was established in 2003 by the Scottish Parliament to take the lead in improving the quality of healthcare in Scotland. NHS QIS sets standards and monitors performance against these standards and aims to ensure that local excellence is shared at a national level. The organization also provides advice and support on effective clinical practice and service improvements, and as part of this process produces best practice statements designed to offer guidance on best and achievable practice in a specific area of care. In February 2006 NHS QIS issued a best practice statement, "Promoting access to healthcare for people with a learning disability- a guide for frontline NHS staff". Communication difficulties are highlighted as a main barrier to accessing health services in the document and guidance is provided on meeting written and verbal communication needs and on systems which should be put in place to ensure that these needs are being met. More detail about the best practice statement can be found at [www.nhshealthquality.org](http://www.nhshealthquality.org).

## Accessible Written Information

There are a number of organisations who produce accessible written information for people with a learning disability, including information about health issues, whose publications are available for purchase. This accessible information is also produced in other formats, such as CD ROMs. Although this information is available, some of these materials can be costly and the investigation has shown that none were generally available from the health service providers sampled as part of the investigation.

The Office for Disability Issues<sup>17</sup> works to co-ordinate disability policy across all government departments in the United Kingdom. The Office has led an information needs project in collaboration with government departments including the Department of Health, aiming to develop a strategy to ensure that disabled people have

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<sup>17</sup> <http://www.officefordisability.gov.uk>

access to the information and advice they need from the most appropriate source. As a result the Office has produced guidelines for public organisations on developing strategies to ensure that information is accessible to disabled people. The guidelines contain five core information principles which are:

- Ensure that disabled people are involved from the start.
- Provide information through a range of channels and formats.
- Ensure your information meets users' needs.
- Clearly signpost other services.
- Always define responsibility for information provision.

In common with all good guidance, the importance of working with people with a learning disability at all stages in the design and evaluation of the written information is stressed to ensure that their needs are being met.

The former Sperrin Lakeland Health & Social Care Trust and Strule/Erne Local Health & Social Care Group worked with Mencap to produce "Be Healthy". The leaflet provides basic yet essential advice in respect of the need to take exercise and looking after your teeth and gums, eyes and ears, and mental health. This information is provided using plain language reinforced by pictures. Size 14 font is used in black type on a yellow background, making the document visually effective and easy to read.

FAIR, an Edinburgh based information and advice service for people with a learning disability, produces excellent health information leaflets accessible to people with a learning disability such as "Keep Yourself Healthy; A guide to examining your breasts". It also produces Guides for Carers, such as "Care of the Oesophagus and People with Learning Disabilities".<sup>18</sup>

Carers working in residential accommodation in the former Homefirst Community Trust [now incorporated in the Northern Health and Social Care Trust] were able to provide accessible written health information which had been procured from FAIR Multimedia for their residents by the Health Promotion Service. The carers found the leaflets a useful aid in providing information to residents.

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<sup>18</sup> information available on <http://www.fairadvice.org.uk/index.htm>

Change<sup>19</sup> is a national organisation led by people with a disability which campaigns for equal rights for people with a learning disability, and has pioneered the production of tools to make information easier to understand. It has produced a Health Picture Bank Book and CD ROM for use, amongst others, by people with a learning disability, and those who work with or support them. These pictures, which can be photocopied from the book or printed off from a PC using the CD ROM version, can be used when developing information. The Book also gives lots of ways on how to make information easier to understand, including drawing your own pictures or adapting the pictures provided and using easy words. Change employs people with a learning disability to develop and run its projects, and they decide on all aspects of the design and delivery of information and training. It has an accessible information team of people with a learning disability who work with its illustrators to ensure the information produced is accessible in terms of language used, appropriate text and font size, adding pictures, and designing the documents.

The Elfrida Society<sup>20</sup> aims “to make it possible for people with learning disability to manage as much of their lives as they wish and feel able to do”. It’s “Access to Health” project aims to help adults with a learning disability use health services, and allow them to learn more about their health. It has provided accessible information on health subjects such as:-

- Medication Labels
- Drug Pack
- Medical Procedure Leaflets
- Healthy Living Services

Again people with a learning disability are involved in the design and production of these materials, and the society uses artists with a learning disability to draw pictures for the leaflets.

The Down’s Syndrome Association has produced “Health - Looking After Yourself” [2002] for people with a learning disability providing advice on diet, exercise and health problems common to people

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<sup>19</sup> information available on <http://www.changepeople.co.uk/>

<sup>20</sup> information available on <http://www.elfrida.com/publications.htm>

with Down's Syndrome.<sup>21</sup> It also deals with the issue of consent, the roles of various healthcare professionals, and provides a personal health record.

The former Homefirst Community Trust has produced specific health booklets for people with a learning disability, which include:

- “Going to the Dentist”, using Makaton symbols which describe the process of visiting the dentist. The aim is to help people with a learning disability to become better informed about visiting the dentist, from the waiting room right through to clinical treatment, with explanations of some of the more common forms of dental care and treatment. Advice is also provided on mouth care after tooth extraction and the issue of consenting to treatment.
- “Fitter Feet”, an interactive health education resource pack, providing information about foot care and footwear. The pack contains a combination of activities, worksheets and flashcards using a combination of photographs, drawings and Makaton symbols. The pack has also been shared with podiatry departments in other Trust areas.

In Britain, The North Tyneside Primary Care Trust has funded a local charity, the Learning Disabilities Federation, to develop a communication tool-kit. “Can I make an appointment please” was provided to every general practice in the area.<sup>22</sup> The toolkit consists of 2 files, one aimed at people with a learning disability, the other aimed at healthcare professionals. The information for people with a learning disability is in an accessible format and includes:

- Information about health, medical issues, making an appointment, questions which may be asked and healthcare services.
- A photographic story board of 13 common medical scenarios to aid communication and modelled by people with a learning disability. The story board can be used to show what happens, the equipment that will be used and how the treatment will feel.

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<sup>21</sup> Available on <http://www.downs-syndrome.org.uk>

<sup>22</sup> Available from North Tyneside NHS Primary Care Trust

- An easy to use CD ROM of the story boards.
- A set of playing cards depicting good and bad health scenarios to support effective communication.

The file for primary care staff contains information and advice about good communication skills as well as information about research, legislation and appropriate terminology, state benefits, and the role of the voluntary sector.

A Health Literacy Officer is responsible for developing and disseminating the toolkit, and works with people with a learning disability through discussion groups, interactive models, drama and video work.

## Verbal Communication

The investigation has found examples of good and effective verbal communication from healthcare professionals which are detailed in the Results Section. The examples given below show how various organisations are attempting to make good communication standard across the Health and Social Care Service through guidance, training and communication aids.

### Professional Guidance

- The Royal College of Nursing, Learning Disability Nursing Forum, has produced excellent Guidance for Nursing Staff<sup>23</sup> which provides detailed practical guidance on communicating with people with a learning disability. It highlights in particular that good preparation is extremely important.
- The Royal College of Speech and Language Therapists emphasises the key role that Speech and Language Therapists can play in assisting people with a learning disability to access mainstream services through:

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<sup>23</sup> Meeting the health needs of people with learning disabilities; 2006, revised 2007. This guidance is available on the Royal College of Nursing Website, <http://www.rcn.org.uk/publications>

- assisting individual communication abilities
- raising awareness of specific communication needs
- influencing policy and practice
- equipping others with the specific communication skills required to communicate effectively.

## Training

The former Ulster Community Hospital Trust [now incorporated in the South Eastern Health & Social Care Trust] fund the Tili Project [Telling it like it is] run by the Association for Real Change [ARC NI]. The project involves men and women with a learning disability in the training [both induction and Continuous Professional Development] of healthcare professionals and staff within the Trust area. The aim of the training is to raise the health service provider's awareness of the specific needs of people with a learning disability in terms of communication, using personal experiences.

In the Down Lisburn Trust area [now incorporated in the South Eastern Health and Social Care Trust] a service development aimed at enhancing communication has resulted in the development of a healthcare communication pack for mainstream healthcare professionals to improve verbal communication with people with a learning disability in healthcare settings. The pack contains good practice guidance and communication aids including picture symbols to assist with understanding. Packs have been sent to all general practices and all wards within acute hospital settings, as well as mental health wards in Downshire hospital.

This Trust has also funded the development of health action plans, targeted initially at persons with a learning disability in residential settings and young people going through transition. The processes and documentation are to be piloted in the Down area. Consent is sought from the individual before taking part in the assessment process and the completion of the health action plan and assessment of key health needs may involve all members of the community learning disability team, key work staff, education professionals and primary care staff. The health action plan booklet will specify clear health improvement objectives, timescales and who has responsibility for the implementation of any action. The

health action plan booklet should accompany the individual to health care appointments and will be regularly updated.

Both projects are aimed at improving health and access to mainstream health services and provide healthcare professionals with tools to help them address the communication barriers faced by people with a learning disability in healthcare situations.

## Specific Initiatives

### Health Surveying

The Commission's Literature Review highlights the level of poor health and unmet and undiagnosed needs for people with a learning disability. On a more positive note, it also points to the fact that there is a great deal of empirical evidence that health gains can be made by people with a learning disability. There is increasing evidence that communication barriers experienced by people with a learning disability can be overcome, and their health improved by, for example, health screening [i.e. a medical examination by a general practitioner in association with a practice or other nurse].

Screening clinics were offered for competitors at the Special Olympics held in Belfast in 2006. Athletes were offered free health checks for vision, hearing, teeth, feet, general fitness, and health promotion. Clinics were held over two and a half days at the University of Ulster Clinic in Jordanstown, during which 306 athletes went through 922 full screenings.

The results were as follows:-

- 58% of athletes failed the hearing test
- 62% had a blocked or partially blocked ear canal
- 29% need to be referred for a hearing test
- 1 athlete had a new hearing aid fitted free of charge
- 22% were supplied with new glasses
- 10% had untreated dental decay
- 24% had gum disease
- 3% needed urgent dental treatment
- 22% needed non-urgent dental treatment
- 39% had a gait abnormality

These figures clearly demonstrate the value of screening as a method of overcoming barriers to better health for people with a learning disability.

In March 2005 the Women's Resource and Development Agency [WRDA], with support from the Eastern Health & Social Services Board and Trusts in that area, Action Cancer, and the Ulster Cancer Foundation developed a programme to encourage marginalised women to come forward for breast and cervical screening. The project was funded by the Big Lottery Fund for a specific time period and was expanded to cover other forms of cancer. The EHSSB deemed the project necessary as they had found that uptake of screening opportunities by people with a learning disability was low for a number of reasons. Research from the Disability Rights Commission in Britain had indicated that only one in five women with a learning disability have cervical screening and therefore this group were targeted in the project.

### Passport System

The Disability Rights Commission has suggested that primary care providers should provide people with a learning disability with the option of having their access needs recorded so that they appear on the patient's records and therefore can be easily identified and met. This information would also facilitate the provider in offering a range of personalised adjustments, including different appointment times and lengths, accessible appointment cards, text or telephone appointment reminders, telephone consultations and specific waiting arrangements, and providing regular health checks and closer monitoring of the effects of medication.

One example of this is provided by the former Ulster Hospital Health & Social Services Trust which operates a 'Passport System' for people with a learning disability to facilitate the provision of these types of adjustments.

### Acute Hospitals

This investigation suggests particular communication difficulties in the acute hospital setting. The Mater Hospital Trust [now incorporated in the Belfast Health and Social Care Trust] has been involved in two initiatives to improve the service it offers to people

with a learning disability and others who may require communication support.

Firstly, it has appointed a dedicated Patient Liaison Nurse to support vulnerable patients who may have particular needs, including those with a learning disability. As well as having this support function and ensuring that appropriate pre-admission planning takes place, the nurse, who is a designated member of the hospital staff, provides communication training to staff, and inputs into the development of policies to ensure that its services are as accessible as possible.

Secondly, the Trust recognised that efforts had to be made to improve the standard of care provided to people with a learning disability in the Accident and Emergency [A&E] setting. It carried out a project which included disability awareness training for all A&E nurses on the nature of learning disability, common medical disorders, the issue of consent, and relevant legislation. This resulted in the production of:

- a resource pack for all A&E staff on the nature of learning disability, common medical disorders and the issue of consent.
- a communication tool made up of pictures and symbols to assist staff communication with people with a learning disability.
- a video/DVD for people with a learning disability to familiarise them with what they are likely to experience and encounter when visiting the hospital. People with a learning disability feature in the production.

The South and East Belfast Health and Social Services Trust [now incorporated in the Belfast Health and Social Care Trust] produced “Equality Vision” in video/DVD which uses language that is easy to understand to explain equality legislation to people with a learning disability. The aim is to help individuals learn more about their rights in respect of health and social care services. The Junction Club, an independent organisation representing adults with a learning disability advised on the project, and people with a learning disability feature in the production. The video/DVD is also supported by a booklet produced in an accessible format.

## Section 7: Recommendations

This final section of the investigation report sets out the Commission's key recommendations for improving the accessibility of both written health information and verbal communication for people with a learning disability. The recommendations are based on the main findings of this investigation and were developed in discussions with the Groups advising the investigation team. These key recommendations provide direction on action required to improve access to vital health information for people with a learning disability.

Our recommendations are consistent with the commitments of public services, including the Health and Social Care Service, to meet the needs of people with a disability and their legal obligations under the disability legislation.

It is clear that for some time there has been an increasing emphasis on mainstreaming service provision for people with a learning disability. However, much remains to be done to ensure that mainstream health services are accessible to people with a learning disability, including the provision of accessible information which is tailored to meet the specific needs of this group.

It is also clear that both written health information and verbal communication can be tailored to meet the specific communication needs of people with a learning disability.

Our recommendations aim to ensure that:

- accessible written health information is produced and provided to people with a learning disability and
- those working within the health and social care services are provided with the skills to meet specific and individual communication needs.

Undoubtedly, those who have more severe disability will continue to rely on the support of others, whether they be healthcare professionals or family members, to assist their communication needs within the Health and Social Care Service settings. However, we believe that our recommendations will improve the standard of

health provision and benefit all people with a learning disability, including those with moderate to severe learning disability.

In making these recommendations, we welcome the Health Minister's commitment to improve health services for this group as a key priority<sup>24</sup>.

We would also remind health providers that people with a learning disability are entitled to the same standard of provision as everyone else, and that failure to make reasonable adjustments (including access to and use of information services) which makes it impossible or unreasonably difficult for a disabled person to make use of a service, will amount to unlawful discrimination.

We would also wish to emphasise the clear links between our recommendations and those of the Equal Lives Review. We believe that our recommendations would be supported by the approach set out in that Review. We therefore welcome the role of the Mental Health and Learning Disability Board in acting as champions for people with a learning disability, and ensuring that the Equal Lives Review recommendations are implemented.

### **Summary - Written Health Information**

It is clear from this investigation that the trend towards the mainstreaming of health and social care service provision to people with a learning disability has not been accompanied, as one might expect, with a determined and strategic approach to the production and dissemination of accessible healthcare information designed to meet the needs of this group. The written material that has been mass produced and is available in local surgeries or main hospitals has not been produced in easily read formats suitable for the vast majority of people with a learning disability. The investigation has shown that the materials that are generally available are often not appropriate for this group.

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<sup>24</sup> 12 September 2007- Minister praises work of Learning Disabled Centres in Down & Lisburn areas

Therefore:

- The Commission firmly believes that it is imperative that health information is produced in easy to read formats taking account of the evidence provided at Section 3 of this investigation report and in line with the good practice guidance contained in Section 6. These formats should be readily available in general and dental practices, in hospitals, and at all health and social care service providers.
- We recognise that for some people it will often be wrong to rely on written information alone. The provision of information to people with a learning disability may need to be supported by other media and by professional support. Nevertheless, we consider that this should not be used as a reason for not making written health and social care information as accessible as possible for this group.
- We suggest a progressive approach to the development of accessible written materials, which have been specifically developed to meet the needs of people with a learning disability. This should be done in conjunction with the development and use of other formats to support written information, for example DVD or CD ROM formats. The Health and Social Care Service may also wish to explore new technologies, such as providing information on MP3's or portable DVD's. The internet should also be used to provide information in an accessible way to people with a learning disability, carers and others to download.
- We agree with the recommendations of the Equal Lives Review and particularly that all generic health strategies should specifically refer to the needs of and impact upon people with a learning disability." [Recommendation 38].

Having equal access to information about health issues and health services is a crucial step in the process of improving the mental and physical health of people with a learning disability. Empowering individuals in this way will assist them to make informed choices about their health and the services they receive.

## Key Recommendations – Written Health Information

**A strategic approach to the development of a range of accessible written health information should be adopted by all Health and Social Care Agencies and led by DHSSPS, and have the following elements :**

- A standardised DHSSPS policy and procedure for producing, distributing and monitoring the quality of written information which is accessible for people with a learning disability.
- Identification of priority areas of health information important to people with a learning disability.
- The development of an easily accessible central source for all such information.
- The development of a systematic approach to ensure that people with a learning disability and their representative organisations are involved from the beginning of the process of preparing such accessible information.
- The development of a specifically tailored appointment letter across the Health and Social Care Service to be used when inviting a person with a learning disability to a medical appointment. In addition, consideration should be given to providing the person with further accessible information about the service when appointments are made.

We believe that the various elements of the Health and Social Care Service in Northern Ireland [for example HSS Boards & HSS Trusts] led by the DHSSPS, should collaborate in adopting a strategic approach to the production and dissemination of pamphlets, leaflets and other Health and Social Care Service literature in easily read formats which are more accessible to people with a learning disability. The DHSSPS have a responsibility to “champion” this issue to ensure the participation of service providers at all levels. The Strategy should include the following elements.

## 1. Standardising Policies and Procedures

The Commission considers that the DHSSPS should have a standard policy of developing written communication specifically for people with a learning disability. It is suggested that this policy should take the importance of the following into account:

- Working with the user groups in the development of policies and procedures.
- Ensuring that those who make key policy decisions have received appropriate disability and equality awareness training with specific training on the communication needs of people with a learning disability. User groups and healthcare professionals with specific expertise should be involved in the design and provision of such training.
- Involving people with a learning disability in the development and production of accessible information. People with a learning disability are able to advise not only about the style characteristics and language that should be used, but importantly are able to provide guidance on how to make the information relevant to their lifestyles.
- Sharing good practice information across the Health and Social Care Service and making accessible information available to all.
- How the accessible information is made available. There is a need for this information to be made widely available and not just through learning disability specific services. Accessible information may be distributed through user groups and places attended by people with a learning disability, including surgeries and hospitals.
- Good contact information. This is essential for those who wish to find out more about a health issue or health service. Therefore procedures should be in place for dealing with queries by people with a learning disability and those who will be dealing with these should receive appropriate communication skills training.

## 2. Identifying priority health information

We accept that, due to resource limitations, the Health and Social Care Service may initially need to adopt a targeted approach to the production and dissemination of such information. Information about the following health issues, related services and preventative health promotion information should be a priority. In addition, health information which is not considered a priority should be available on request in an easy to read format.

### a. Leaflets providing information about illnesses or conditions which particularly affect people with a learning disability.

The Commission's Literature Review identified the fact that various screening studies in Northern Ireland have shown high levels of poor health and unmet or undiagnosed health requirements in the following areas:

Weight:	Obesity, overweight, underweight.
Oral Health:	Poor oral hygiene, loose teeth, tooth decay, gum infection.
Ears:	Excess ear wax, hearing difficulties.
Eyes:	Cataracts, reduced vision.
Feet:	Corns, verucca, fungal infection, damaged nails/ toe beds, poor circulation.
Blood pressure:	Hypertension, hypotension.
Skin / Hair:	Dry scalp, dandruff, varicose veins, eczema, psoriasis, acne.
Urinalysis:	Glucose, protein and blood present.
Testicles:	Undescended, swollen, underdeveloped.
Breasts:	Inverted nipple, skin tags, breast lumps, male breast enlargement.
Blood Tests:	Hypothyroidism, diabetes.
Gastrointestinal:	Pain/discomfort, reflux problems, peptic ulcers, constipation.
Incontinence:	Reduced continence, urinary tract infections, pain/discomfort.

The Literature Review also highlighted mental health as a particular issue, and one which is often undiagnosed in this population.

Similarly, the Royal College of Nursing in its guidance to nursing staff, has highlighted a number of health problems which may particularly affect this group, such as:

Gastrointestinal cancers  
Coronary Heart Disease  
Epilepsy  
Thyroid disease

## **b. Information about health services and entitlements**

There should be accessible information for people with a learning disability providing comprehensive information about the services they are entitled to receive, and how to access these services. Such a package of information should include guidance about:

- what to expect when attending health and social services,
- questions to ask of healthcare professionals,
- advice about how to obtain relevant accessible information.

The DHSSPS should work with other organisations in the production of this information involving user groups as suggested.

## **c. Appointment letters**

The investigation has identified a particular problem concerning the extent to which appointment letters are capable of being understood by people with a learning disability. The standard form of letter currently issued by most medical records departments is not appropriate for people with a learning disability; they are too formal, do not have straightforward language that is easily understood, and do not use pictures to clarify the meaning of the text.

We consider that a tailored appointment letter should be used for people with a learning disability, using larger font, with a simple and clear message confined to the important details. In particular contact details need to be easily recognised, and instructions about re-arranging appointment dates or requesting reasonable adjustments should be as clear as possible.

Accessible information about the service and what the patient can expect should be included with each appointment letter.

Again this is an approach that would be supported by the Equal Lives Review which recommended [Recommendation 41] that every acute general hospital in Northern Ireland [as well as each general practice facility] should have, with immediate effect, clear and formalised arrangements in place to facilitate equity of access to services for people with a learning disability.

#### **d. Information on medication/pharmaceutical information.**

The investigation confirmed that in many cases the administration of medication was supervised and regulated by carers. However, for those people who independently administer medication and who purchase over-the-counter medication much could be done to improve instructions for taking medication and to provide general information. The Disability Rights Commission has highlighted the need for healthcare providers to offer patients information and choice around medications, particularly in respect of allowing the patient to make an informed choice, and to explain how the medication will affect them, and any side-effects it may have.

Medication in itself is a vast area to cover and again a gradual approach would be advised in terms of producing easy to read versions of literature on medications. However we consider that it would be relatively straightforward to make prescription labels more understandable in line with the guidance set out at Section 6, and to introduce less medical terminology to replace terms such as “to be taken twice a day”.

### **3. The development of a central source for accessible information**

The DHSSPS, HSS Boards, and Trusts should develop an extensive library of resources available for healthcare professionals, carers and people with a learning disability to access. This resource should be widely publicised through user groups, Patient Public Information Forums, and other services used by people with a learning disability. In addition, as expertise in producing accessible information is developed, the DHSSPS should ensure that this knowledge is shared and that the production of such information remains a priority within the Health and Social Care Service.

#### **4. Working with others to improve the style of written health information**

One of the aims of this investigation is to identify barriers to good communication. For the written information the barriers identified by people with a learning disability and carers were numerous in respect of the style and language used. For example:

- Complicated and technical language
- Too much written detail
- Font size
- General layout
- Poor contact information
- Lack of useful pictorial information

Section 3 provides an overview of how written communication can be enhanced to meet the specific needs of people with a learning disability. There are a number of organisations who can assist and provide guidance on accessible information and this advice should be built into standard procedures for the communication of written information. Working in partnership with organisations who produce accessible information and tapping into the wealth of guidance available would enable the Health and Social Care Service to progress the production of information in accessible formats.

#### **Summary - Verbal Communication**

A high proportion of people with a learning disability will have difficulty with verbal communication, which may be due to limited vocabulary, understanding, and speech difficulties. However this investigation has identified a number of barriers to good verbal communication which the Health and Social Care Service and healthcare professionals can address, such as a lack of personal familiarity with the individual, time factors and the environment.

Section 4 provides an overview of how verbal communication can be enhanced to meet the specific needs of people with a learning disability. This investigation has identified much in the way of good practice in all areas of the Health and Social Care Service in terms of verbal communication with people with a learning disability, for example, dentists in particular were identified as effective communicators.

Therefore:

- The Commission considers that the specific barriers experienced by some people with a learning disability can be reduced by the use of good communication skills on behalf of the healthcare professional.
- We believe that good preparation for the consultation can alleviate the impact of other communication barriers, by ensuring the environment is conducive to effective communication. However, in circumstances where there is limited opportunity to plan in advance, for example in emergencies, good communication skills are even more essential to improve the experience of people with a learning disability in the Health and Social Care Service.
- We consider that good verbal communication is particularly important to ensure that medications are properly explained in respect of the need for treatment, administration and side effects.
- Our recommendations focus on ways to assist healthcare professionals to meet the specific communication needs of people with a learning disability.

## **Key Recommendations – Verbal Communication**

### **Communication Training**

- All healthcare professionals and support staff should receive disability training with emphasis on the specific needs of people with a learning disability and training in effective communication with those who have communication support needs, including people with a learning disability.
- Undergraduate and post-graduate training of healthcare professionals should specifically cover communicating with people with a learning disability.

- Continuous Professional Development training be provided to healthcare professionals on communicating with people with a learning disability.
- The DHSSPS adopt a strategic approach to ensuring that HSS Boards and Health Trusts support the use and funding of user groups/advocacy groups. Adequate funding should be provided to fully utilise the expertise of such groups in the provision of communication skills training and ensuring there are sufficient advocacy groups operating throughout Northern Ireland.

### **Health Records**

- Each general practice should establish comprehensive medical records about people with a learning disability.
- The current GP contract should be reviewed to establish if existing financial incentives are sufficient to improve medical records held by general practices in relation to people with a learning disability.

### **Liaison**

- Each general practice in Northern Ireland should have an identified link person within their Community Learning Disability Team with whom they will collaborate to facilitate better access for people with a learning disability within primary care settings.

### **Patient Liaison Nurses**

- Each main hospital in Northern Ireland should have a Patient Liaison Nurse to allow for proper preparation for the treatment of people with a learning disability, and to facilitate better communication between such patients and hospital staff.

## **Passport System**

- A passport system should be developed and linked to individual health action plans, and cards issued to all people with a learning disability known to services. Use of this system should be monitored on a regular basis.

### **1. Communication Training**

This investigation points to the importance of ensuring that all healthcare professionals and staff receive specific training in effective communication with those who have communication support needs, including people with a learning disability. In this way good practice for people with a learning disability should also assist others in our society who may have communication issues, for example, older people and those whose first language is not English. This training includes professional training at undergraduate and post-graduate levels and should also be incorporated into appropriate NVQ awards. It is vital that those who provide health services recognise their personal responsibility to ensure that they are equipped with the skills to effectively communicate and meet individual needs and that these communication skills are enhanced through Continuing Professional Development.

In line with policies of mainstreaming services for people with a learning disability it is not only healthcare professionals and staff who wish to specialise in learning disability who will come into contact with this group, and it is therefore essential that there is an awareness of the skills required to communicate effectively amongst all healthcare professionals and staff. Therefore, all those who work in the health and social care service should be made aware, through disability awareness training programmes, of the specific needs of people with a learning disability. The Health and Social Care Service should use the expertise of its own professionals and staff to deliver communication training and to highlight its importance.

Ideally, to avoid an informal approach to training, the DHSSPS should establish a working group to identify communication training needs, determine necessary content, and make training mandatory and accredited.

The Commission considers that the use of advocacy groups of people with a learning disability to be a particularly effective way of improving verbal communication. User groups are particularly good at expressing their needs and raising awareness of their experiences of verbal communication. It is also helpful that healthcare professionals can meet and ask questions of those who have first hand experiences of the Health and Social Care Service. For example, advocacy groups are currently used in some Trust areas to raise awareness of the needs of people with a learning disability by healthcare professionals and support staff. Unfortunately advocacy groups receive limited public funding and the funding that is provided is often piece-meal and ad hoc.

## **2. Health Records**

Recommendation 42 of the Equal Lives Review states:

“Each General Practice should establish robust medical records and health details about people with learning disability on their practice register.”

The Commission endorses this recommendation and considers that the current GP contract should be reviewed to establish if existing financial incentives are sufficient to improve medical records held by general practices in relation to people with a learning disability.

People with a moderate to profound learning disability and those with a mild learning disability who have complex needs, will generally be known to the Community Learning Disability Team, and this information should be used as a starting point to improve medical records.

## **3. Liaison between Community Learning Disability Teams and General Practitioners**

The vast majority of people with a learning disability live in the community and access mainstream health and social care services. However, specialist services are often needed to provide additional support. Community Learning Disability Teams have developed in each Health Trust area, employing a range of specialists including

community learning disability nurses, occupational therapists, physiotherapists, psychiatrists, psychologists, social workers, area managers, and speech and language therapists. People with a moderate to profound learning disability and those with a mild learning disability who have complex needs, will generally be known to the Team.

The Equal Lives Review has recommended [Recommendation 43] that:

“with immediate effect each General Practice should have an identified link person within their Local Community Learning Disability Team with whom they work collectively to facilitate better access for people with learning disability within primary care settings.”

Again the Commission fully endorses this recommendation, and considers that it should be actioned as a matter of urgency. We believe that this approach would also facilitate the recommendations contained in this report, for example it would help general practices to establish more comprehensive records of people with a learning disability on their practice register, and help ensure that general practitioners and staff obtain appropriate training on communicating with people with a learning disability. Improved liaison with Community Learning Disability Teams will also enable primary health services to make the reasonable adjustments which may be necessary, such as, flexible or longer appointment times for those with communication support needs and or behavioural problems.

Community Learning Disability Teams will also play an integral role in the implementation of Individual Health Action Plans. This investigation has pointed to the potential use of regular health screening to identify and treat previously undiagnosed health issues, and thereby improve the health of people with a learning disability. Our Literature Review indicated:

“There is increasing evidence that a health screen (that includes a medical examination by a GP in association with practice nurses) does identify a range of conditions that are amenable to treatment which had previously been undiagnosed or unnoticed in people with learning disability.”

The Equal Lives Review recommendations envisaged a person-centred planning process being developed in Northern Ireland by 2008, with

- Collaborative working between mainstream Health and Social Care Services and Community Learning Disability Teams.
- People with a learning disability to be able to access mainstream services with support from specialist services when required.
- Mainstream healthcare staff to receive adequate training on the needs of people with a learning disability.
- People with a learning disability to be registered with their general practitioner.
- Offering people with a learning disability an individualised Health Action Plan and have a nominated “Health Facilitator” to develop and implement the plan.
- Ensuring that people with a learning disability are offered regular health checks and are included in health screening programmes.
- Health promotion materials are made accessible to people with a learning disability.

The Equal Lives Review made the following specific recommendation [Recommendation 40]:

“By December 2008 a Health Action Plan will be developed as part of the ‘Person Centred’ planning process, which is to be set in place for all those with a learning disability in contact with health and social services agencies.”

It is essential that those carrying out health assessments and also any subsequent treatment as part of this process are properly equipped with the necessary communication skills.

#### **4. Patient Liaison Nurses**

This investigation has pointed to there being particular communication problems when people with a learning disability come into contact with Acute General Hospital services [see for example pages 27-28 of the Commission's Literature Review].

We believe that each main hospital in Northern Ireland should have a Patient Liaison Nurse as part of its team to allow for proper preparation for examination and treatment, and to facilitate better communication between the patient and hospital staff. We believe that it is important that the Patient Liaison Nurse is an integral part of the hospital team, and not part of the Community Learning Disability Team attached to hospitals, and that systems are put in place to ensure that they are properly notified of admissions in advance. This approach will require co-operation between the Community Learning Disability Teams and Acute Hospitals.

We would also suggest that a standard pre-admission planning policy in line with the guidance contained in Section 6 be produced. We believe that this would help ensure that the specific needs of patients with a learning disability are assessed, and necessary adjustments to standard practice are put in place prior to admission.

#### **5. Passport System**

The Commission believes that the DHSSPS should develop a system to allow people with a learning disability to disclose that they have this disability when accessing health and social care services should they wish to do so. This will allow the individual to make known that they have specific communication requirements when they do come into contact with healthcare professionals and staff. The information contained in the 'passports' will be additional to ordinary patient records and will summarise how communication with them can be enhanced. It will also assist the healthcare professional make any required reasonable adjustments.

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## **Appendices**

### **Appendix 1**

**List of sample written health information**

### **Appendix 2**

**Random Sample of general and dental practices throughout Northern Ireland**

### **Appendix 3**

**Profiles of the assessment panels**

### **Appendix 4**

**Comments from questionnaires completed by people with a learning disability about written health information.**

### **Appendix 5**

**Comments from questionnaires completed by carers about written health information**

### **Appendix 6**

**Comments from discussion with people with a learning disability about verbal communication**

### **Appendix 7**

**Comments from discussion with carers about verbal communication**

### **Appendix 8**

**Participants**

### **Appendix 9**

**Group Membership**

**Appendix 1: The information presented to assessment panels for assessment.**

<b>Leaflet</b>	<b>Health Issue</b>	<b>Produced by:</b>
Appointment letter	Service	Trust
Balance of good health	Health promotion	Trust
Bowel cancer	Illness	UCF/DHSSPS
Care in the sun	Health Promotion	Cancer Research UK
Diabetes and exercise	Illness	Trust
Get a life get active	Health Promotion	HPA
Healthy eating	Health Promotion	Trust
Make the first Move	Health Promotion	HPA
Med labels	Service	Trust
Out of hours	Service	Board
Podiatry	Service	Trust
Safe snacks	Health Promotion [dental]	
Small Changes big benefits	Health promotion	HPA
Stress an ABC of coping*	Illness	Board
Sugar free medicine	Dental	Regional Oral Health Promotion Group
Sugar and your teeth	Dental	Regional Oral Health Promotion Group

\*assessed by carers panels only

## Appendix 2: Random Sample of general and dental practices

Number of general practices randomly sampled from each HSS Board Area

Board area	No of GP Practices	10% sample
EHSSB	154	15
NHSSB	74	7
SHSSB	76	8
WHSSB	68	7
Total	372	37

Number of dental practices randomly sampled from each HSS Board Area.

Board area	No of Dental Practices	10% sample
EHSSB	160	16
NHSSB	85	9
SHSSB	56	6
WHSSB	63	6
Total	364	37

## Appendix 3: Profile of assessment panels

### People with a learning disability Assessment Panels

Number of panels	10
Number of people attended	74
Number of questionnaires provided	137
Percentage return rate	100%

#### People with a learning disability: Age Range

Age range	Number of people
16-19	16
20+	23
30+	9
40+	8
50+	8
60+	7
70+	2
80+	1

#### People with a learning disability: Gender

Gender	Number of people
male	38
female	36

#### Number of Assessment panels held in each Health and Social Services Board Area

Board Area	EHSSB	NHSSB	SHSSB	WHSSB	Total
Number of panels	3	2	3	2	10

### Carers Assessment Panels

Number of panels	29
Number of carers attended	178
Number of questionnaires provided [8 extra given out]	364
Number of questionnaires returned	114

### Number of sample facilities catering for each age range

Age range	Number of facilities
Under 18's	2
18-19	7
20+	18
30+	24
40+	26
50+	27
60+	23
70+	10
80+	6

### Number of carer assessment panels in each HSS Board Area [10% sample]

	Board Area				Total
	EHSSB	NHSSB	SHSSB	WHSSB	
Type Of Facility					
Day care	1	1	1	1	4
Private residential	2	1	2	2	7
Housing association	6	2	1	2	11
Trust run accommodation	2	1	1	1	5
Family	1			1	2
<b>Total</b>	<b>12</b>	<b>5</b>	<b>5</b>	<b>7</b>	<b>29</b>

#### **Appendix 4: Comments from questionnaires completed by people with a learning disability about written health information.**

##### **What panel members don't like about the written health information**

"There are not enough pictures and the pictures that are in it are confusing and hard to identify, they would be better in their true colours."

"Unless you can read you would have no idea what the leaflet is about."

"Small writing. Needs more pictures."

"The leaflet does not attract my attention. There are not enough pictures."

"Can't read any of it. "

"Writing is too small."

"It is too small and cramped."

"I found it hard to understand some of the words like 'canopies' or skin cancer'. I don't know what wraparound sunglasses are."

The pictures helped to understand the information "but they were a bit hard to clearly see them."

"There are enough pictures but it might be better if they were bigger."

"Too dull. Don't like the colour of the pictures. They are not clear."

"The pictures are too small. The writing is too small and there is too much writing."

"White writing on the blue background is hard to make out."

"Eyes get sore looking at the little writing in the little boxes."

“The size is handy but they should have used both sides of the leaflet and had less writing on both sides.”

“Words are too hard.”

“It might be hard to read. It might take too long to read.”

“Too much writing inside.”

“Can’t see the letters/writing. Font size not big enough for the visually impaired.”

“All words are hard to understand.”

“Some of the pictures – don’t know what they are.”

“Direct dial number. Don’t know what this is.”

### **What panel members like about the written health information**

“It is short and to the point.”

“The colours are very bright and eye catching.”

“The information is good and the writing is big. It is very interesting.”

“It is colourful and there is just one page.”

“Colours.”

“It has big writing.”

“Picture of food.”

“Sets out important details at the top.”

“Short, only two pages.”

“Well set out and easy to understand.”

“Like the bullet points and short sentences.”

“It can help people learn.”

## **What panel members would like to see in the written health information**

“The name of someone to contact. Like to speak to a person.”

“Bigger writing for the contact details and pictures to help identify the ways to make contact.”

“Simpler words. Bold black writing. Photos.”

“How to get information in different formats for example, DVD, CD, video. ”

“Important bits should get their own space and be in a different colour. Eyes would be drawn to it more if it was big and bold.”

“A map.”

“More pictures.”

“A bigger leaflet”

“Telephone number, addresses, information on other formats of leaflets. Maybe Braille or audio.”

## **Appendix 5: Comments from questionnaires completed by carers about written health information**

### **What panel members don't like about the written health information**

"The wording is too difficult and the layout isn't clear enough."

"It contains very useful and important information but is no use if you cannot read."

"There are no obvious contacts provided in the leaflet."

"No numbers or address on information sheet."

"Too formal. Big words. Maybe too complicated."

"There are too many technical terms. There is too much information presented on the page."

"It is not colourful. Do not visually recognise things on it. Should be more photos and colour."

"Whatever the design a doctor or carer would need to spend time explaining the content."

"Very complicated looking - opening instructions hard to follow for a person with a learning disability. ... information overload. It only needs to give appointment details."

"The writing is too small. There are no pictures on it for someone who cannot read. The information is not explained clearly enough."

"For someone with reading and comprehension difficulties it needs to be structured with possibly additional pictures and full explanations."

"It's dull, too technical and too condensed."

"Jargon. Bullet points are often not understandable sentences."

“Whilst the information is important this leaflet would be too detailed and complicated for most people with a learning disability to absorb. It is also drab and unattractive and uses too much scientific jargon.”

“Too much writing in a small space and may confuse them.”

“Too long, jargon, print needs to be bigger.”

“Boring, dull, colourless article. Nothing to draw attention to it.”

“The design of the information needs to be made much more interesting. The size of print is too small for most people with learning disability to read. The information would be difficult for people with learning disability to understand unless interpreted by a carer.”

“If you cannot read there is nothing to encourage you to lift this leaflet.”

“The bright red colour would be attractive. Interest would soon wane because of the way the information is presented.”

“The picture initially looks interesting – it may initially “grab” the viewer but will quickly lose them in seconds.”

“Too much writing. Needs bigger lettering and more vibrant colours to attract attention.”

“Pictures are used but are not clear enough to explain the information.”

### **What panel members like about the written health information**

“Colourful and straight to the point with key issues highlighted.”

“Use of bold print to highlight important points.”

“Large title, pictures and diagrams.”

“The information is clear to understand. It is simple and to the point.”

“Bright and colourful. Words are in interesting and relevant format. Those who had a reasonable level of reading skills would certainly understand the information/advice. Important information is simple clear and to the point.”

“Picture of telephone. Telephone number good and visible.”

**The improvements panel members thought should be made to make written health information more accessible.**

“Accept that many will not be able to read and simplify the information for those with “average” ability.”

“Have pictures available along with words and make the wording easier to understand.”

“It would be useful to have a space allocated for specific telephone numbers.”

“Given out at special appointments the person attends not just left on tables in doctors where often ignored or posted out to certain people.”

“Leaflet could be more attractive with a greater variety of colour. It should get to the point highlighting important points and situations and cutting out the scientific jargon. .. it could be issued to all organisations dealing with people with learning disability.”

“A booklet with brief statements and simple wording. Pictures describing the content. The contact numbers on the front cover. Made available in doctors, dentists. Posted to healthcare providers.”

“Colour coded highlighting would be beneficial.”

“Leaflets should have more pictures and symbols than words.”

“Telephone [contact details] should be made clearer if appointment cannot be made or if need special requirements.”

“There should be a picture of where it [the appointment] is, a picture of a calendar for date and picture of a clock for time. And a picture of doctor.

A booklet should be enclosed that could be used to explain to patient what it is about which should include pictures of doctor, receptionist, place, room, time they will be there and what will happen them, so they fully understand.”

## **Appendix 6: Comments from discussions with people with a learning disability about verbal communication**

### **Talking to carer**

“The doctor talks to the person with me. I like having someone to talk for me”.

“I go for check ups every 3 months with my sister. I don’t know why I have to go every 3 months or what the tablets are for”.

“The doctor tells the person with me about the medicines”.

### **Talking to the individual**

“The dentist talks to me even though mum goes in with me. The dentist is very good at telling me what he is going to do and how to look after my teeth. He shows what [tools] he is going to use before he uses them.”

“The dentist is good at telling me how to look after my teeth and at letting me know what they are going to do.”

“The nurse in the surgery takes time and tells me what she is going to do.”

“The doctor asks me if he can look at me and tells me what he is going to do.”

### **Appointment time**

“I don’t have time to talk to the doctor about things”.

“I go to the doctor with my mum but I would like to go on my own. The doctor doesn’t ask me what is wrong. She doesn’t take the time to try to understand me.”

“I feel rushed and I don’t have time to explain why I’m there. The doctor is too quick to repeat the medicines instead of taking time to ask questions.”

“I don’t understand what is being said but I don’t have enough time

to ask questions. I go to the doctor on my own.”

### **Confidence**

“I worry that the doctor won’t understand me or have time to understand me. I let staff know what is wrong with me before I go to the doctor and they talk for me.”

One person did not feel confident enough to ask GP about why she got asthma “I don’t like to ask. I would be embarrassed”.

“I would like to go on my own to the doctor and I have said this to my mum and dad. But I don’t know if I will understand the doctor or remember what he has said.”

### **Waiting times are a problems**

“I don’t like waiting so long and nobody tells us how long I have to wait”.

“I don’t like the hospital, it’s scary. I don’t know what is going to happen to me.”

### **Waiting times are not a problem.**

“We are given a number when we arrive. I’m happy to chat or look at the magazines until my number is called.”

### **In casualty**

“A doctor came to speak to me and said that we might have to wait some time”

The individual thought this was good as they knew why they were not being seen quickly.

“I had to go to hospital for tests. I was waiting all day and was very worried about [the results of] the test. But the nursing staff kept me up to date with what was happening and this made it easier. A staff member was with me all the time and the nurses had time to chat.”

## **Familiarity**

“I like to see my doctor. I know the doctor knows me”.

“The doctors know me and they know how to talk to me. Individuals like to see the same GP all the time as they know their circumstances.

## **Communication skills**

“I would have liked my doctor to use a picture to explain things better. I asked questions but didn’t really know everything when I left. It makes me feel bad when I leave not understanding what was said.”

“The doctor does talk to me but he talks too fast and I can’t understand him. I asked him to slow down but he hasn’t.”

One person found that as an inpatient when “doctors came round I couldn’t understand what they were saying but the nurses took time and helped to explain things.”

“When I go to the doctor she doesn’t look at me”. This makes the individual feel the doctor isn’t interested.

“The doctor will talk to me and ask questions – they will talk to [the carer] sometimes.”

“I sit in a chair in front of [the carer] and the doctor talks to me.”

“I told my doctor that I couldn’t understand what she was saying and she now uses words I can understand.”

Operations: “The doctor told me that he would give me something that would make me sleep and he told me what would happen. The nurses talked to me. I wasn’t so scared then.”

Following an accident “The ambulance men helped me to relax. They talked to me. The nurses were very good and told me what was going to happen and why I had to get new teeth.”

## Appendix 7: Comments from discussions with Carers about verbal communication

### Talking to carer

“The GP has no eye contact, doesn’t speak directly to him and doesn’t explain treatments to him. He is very capable of communicating but the doctor does not even attempt to talk to him.”

“The GP doesn’t acknowledge her presence and asks us questions about how she is feeling.”

“They get little reassurance from hospital staff and they become agitated. Staff think that they will be disruptive”.

“There is a “fear factor” with hospital staff... There is no attempt to talk with them and they expect care staff to do this for them.”

“They tend to ignore residents because they don’t know what to expect and how to deal with them.”

“They ignore them and don’t attempt to talk them at all. When he was an inpatient and had bought a TV card, it lay in the drawer. No-one had spoken to him or asked if he needed help with it.”

“There is no communication with them. They expect the carers to do this”

“They assume they can’t communicate and don’t ask. One nurse tried to straighten her legs even though she had been told that her legs didn’t straighten and she was in pain. She could communicate but was talked over the top of and no-one asked her questions directly.”

“The staff at the A&E would talk to the carers and usually not the resident.”

“Hospital staff will talk to the carer rather than the person. They don’t check out their ability.”

“The hospital doctor [A&E] saw her as a child and ill and directed everything to me even though she could speak for herself.”

“Consultants come round hospital beds with student doctors - they will say “hello” to the individual and then turn to talk straight to us. Other doctors are being taught this is good practice.”

## **Waiting Times**

“The waiting times are too long. A lot of anxiety is caused by the waiting as they don’t know what is wrong and what the outcome will be.”

“They don’t understand why they have to wait so long and it is sometimes difficult to persuade them it is important to wait to see the doctor”.

## **Attitude**

“A bad attitude leads to bad communication.”

“The doctor said she didn’t have the mental capacity to understand.”

“The doctor gives the impression that he is in a rush.”

“He was referred by the GP to the optician but the doctor didn’t go through why he was being referred, what would happen or why it would be good for him. This was because his skills are limited, but he was confused and scared.”

“Some GPs still have the attitude that the person has learning disability and there is nothing they can do”.

“They use terminology such as ‘mentally handicapped’.”

“It’s easier to prescribe medication than to talk through the problem with the client.”

“Nurses in particular are anxious about dealing with people with learning disability. Some physically withdraw. A nurse came to put a dressing on her and physically drew back; the client said to her “I won’t touch you.””

“Attitudes can be a problem especially if they have behaviour difficulties ...one nurse had taken offence that she had called her a

pig and said she wasn't trained to deal with people with special needs."

"Staff are very dismissive of residents in hospital and they don't get the same treatment and consideration as other people. You feel that they are not 'worthy of the effort'. They don't provide information to carers or relatives."

"Doctors rounds are particularly bad – they don't see them as a person just an ailment – they don't listen to them and the terminology used is too medical and technical."

"Carers are not afraid of talking directly to the client – some professionals give the impression that they are."

"Sometimes past experiences affect the way they are treated. Clients with behavioral problems get a negative reputation at hospitals. There have been some "not him again" comments."

### **Appointment times**

"Some people need a double appointment if the doctor is to communicate well with them and put them at ease."

"The GP will say hello to her but will turn to the carer to explain why she is there."

"They are not given a chance to explain. The doctor keeps strictly to the 15 minutes appointment schedule."

"It's not the length of appointment but the use of the consultation. It would be more useful if the appointment is used to explore more about the person's condition rather than the conveyor belt experience with medication."

### **Other forms of communication**

"No doctors or dentists have used any diagrams; their first reaction would be to try to verbally explain. One person was given a video about cholesterol which helped to make the problem clearer."

## **Training/ Skills**

“The doctor thinks they have understood because they nod and agree with him. But once outside they will ask what the doctor was saying.”

“GPs make the effort to try to communicate well with the individuals but they would need training... they have limitations in their skills and experience.”

## Appendix 8: Participants

### 1. Assessment panels of people with a learning disability

Dr B's Project	Belfast
Elmbrook Special School	Enniskillen
Funkie Advocacy Group	Dungannon
Garryduff House	Ballymoney
Happy Talkers	Portadown
Killadeas Day Centre	Lisnaskea
Lisanally Special School	Armagh
Skyway Club	Belfast
The Buzz Group	Omagh
The User Council Compass Advocacy Group	Ballymoney

### 2. Carer Assessment Panels

Autism Initiatives	Newcastle
Belmont Cottages	Londonderry
Bowens Close	Lurgan
Creamery House	Kesh
Down's Syndrome Association	Londonderry
Downe Residential Project	Downpatrick
Drumary House	Derrygonnelly
Duncreggan	Portrush
Edgcumbe Day Centre	Belfast
Fairview PRH	Londonderry
Garryduff House	Ballymoney
George Sloane Day Centre	Ballymena
Grange Avenue	Bangor
Hebron House	Markethill
Killadeas/Omagh Day Centre	Enniskillen
Lynwood Hostel	Newtownabbey
May Street	Bangor
Manor/Eden Centre	Portadown
Mertoun Park	Belfast
Mount Oriel	Belfast
Mourne Grange	Kilkeel
Naroon House	Crumlin
Orchard Grove	Clough
Prospects	Lisburn
Railway Court	Omagh
Shaw's Avenue/ Trench Park	Belfast

The Firs  
Tower House  
Triangle -Sandown Road

Ballygawley  
Ballymoney  
Belfast

## APPENDIX 9: Group Membership

### Membership of Steering Group

Dr Owen Barr	Head of School Nursing	University of Ulster
Sam Bell	Carer	Family Carer
Anne Blake	Carer	Family Carer
Stella Cunningham	Chief Officer	Southern Health & Social Services Council
Julie Dickenson	Deputy Service Manager	Positive Futures
Donna Lynch	Regional Manager	Down's Syndrome Association
Aiden Murray	Assistant Director Social Services	Eastern Health and Social Services
Clare McCaughey	Children's Services Manager	Dr B's Project
Prof. Roy McConkey	Professor of Developmental Disabilities	University of Ulster
Catherine McCrory	Project Coordinator	Equality 2000
Dr Paschal McKeown	Policy and Information Manager	Mencap
Linda McKendry	Manager	Compass Advocacy Group

Rosalind Patterson	Community Learning Disability Team	Causeway Trust
Mrs Pat Smyth	Senior Manager	NHSSB
Jacqui Walsh	Community Learning Disability Team	SHSSB
Morag Wylie	Tenant & Service User Participation Co-ordinator	Triangle Housing Association

### **Membership of Focus Group**

Gareth McKenna  
Nauman Hassan  
Rodney Johnston  
John-Francis Carey  
Kevin Davidson  
Cheryl Glendinning  
Patrica Corr  
Gerald O'Neill  
Lynn Cordner  
Rosie Kennedy

Facilitator's of this group:

John Diamond  
Martin Gunn  
Julie Dickenson

## Membership of Reference Group

<b>Name</b>	<b>Position</b>	<b>Organisation</b>
Anne Basten	Equality Unit	Central Services Agency
Maurice Devine	Nurse Consultant	EHSSB
Anne Friel	Director of Pharmacy	WHSSB
Siobhan Gallagher	Snr. Health Promotion Officer	NHSCT
Heather Robinson	Head of Learning Disability Unit	DHSSPS
Ruth Knowles	Publications Development Manager	Health Promotion Agency
Alison McCullough	Country Policy Officer	RCSLT Speech Language Therapy
Jude Anderson	Senior Dental Officer	British Dental Association
Dr Terry Bradley	Medical Adviser	EHSSB
Dr Paschal McKeown	Policy and Information Manager	Mencap
Paula McKeown	Public Relations Manager	SHSSB



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