

Formal Investigation

The Accessibility of Health
Information in Northern Ireland for
People with a Learning Disability

A Summary

Equality Commission

FOR NORTHERN IRELAND

Formal Investigation

The Accessibility of Health Information in Northern Ireland for People with a Learning Disability

On 1st June 2006 the Equality Commission for Northern Ireland (hereafter, 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. This includes written health information about specific illnesses, health promotion, and the various health services available, as well as the information communicated verbally by a range of healthcare professionals. The investigation is now complete, and this update presents a summary of our findings and recommendations.

Introduction

The Commission has a duty to work towards the elimination of discrimination against disabled persons; to promote the equalisation of opportunities for disabled persons and to take such steps as it considers appropriate with a view to encouraging good practice in the treatment of disabled persons. The Disability Discrimination Act 1995 makes it unlawful to discriminate in providing goods, facilities and services. This includes failing to make a reasonable adjustment to allow a disabled person to use services, which extends to access to and use of “means of communication” and “information services”.

We were aware that:

- Existing research indicates that people with a learning disability are more likely than the general population to experience poorer physical and mental health, and have significant unmet health needs.
- The aim of government policy for people with a learning disability is inclusion “not least in the field of health and personal social services”. (DHSSPS 1995). This means that people with a learning disability must therefore access a

diverse and often complex range of mainstream health services.

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. It identified the main reasons for inferior healthcare 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.

People with a learning disability are entitled to the same standard of service as everyone else. To do so within mainstream health provision, it is imperative that people with a learning disability have access to health information that they can understand.

We therefore decided that it was necessary to examine whether health information, both written and verbal, is accessible for this group. We wanted to identify any barriers that impacted upon the accessibility of such information, and improvements that could be made. On the basis of the evidence produced by the investigation, we made recommendations to the Department of Health Social Services and Public Safety (DHSSPS) which are straightforward, inexpensive, and will, we believe, contribute to better health for people with a learning disability. This will also benefit others in our society with communication support needs, for example, older people or those whose first language is not English.

The Investigation

We collected examples of the written health information that is publicly available from general and dental practices and main hospitals across Northern Ireland. From these, we selected particular pieces of information to be evaluated and assessed in terms of their accessibility to people with a learning disability. We selected material that we considered to be particularly important to people with a learning disability including:

- written material providing information on specific illnesses, health promotion and health services,
- appointment letters sent from the medical records departments of hospitals,
- medicine labels issued by hospitals.

The accessibility of this material was assessed by panels of people with a learning disability and, separately, panels of carers in terms of:

- Style and layout
- Language used
- Use of pictures to explain meaning
- Contact information

A total of 74 people with a learning disability and 178 carers participated in the investigation. Their input on the accessibility of the written information under consideration was obtained through discussion and the completion of questionnaires. Participants also discussed their experiences of verbal communication between healthcare professionals and people with a learning disability within primary care settings, and at hospitals and pharmacies. In reaching our findings, we carried out a thematic analysis of the discussions that took place at the assessment panel meetings, and a quantitative analysis of the questionnaire replies.

Main Findings

Written Health Materials

The written health information that is publicly available at health service settings is not produced in easily accessible formats (such as Easy Read or Makaton) specifically for people with a learning disability. People with a learning disability must therefore use “mainstream” written information, which will often fail to take their specific communication needs into account in terms of style, design, language and use of pictures to explain meaning. Almost all (97%) of panels of people with a learning disability required assistance to understand the health information contained in the written material assessed. Even with assistance, only 80% of these panels indicated that they understood the information. Just over half of panels of people with a learning disability (51%)

indicated that they would not even pick up the written information in the first place. Reasons given included that there was too much writing, the writing was too small, and there were not enough pictures. There is a clear need therefore to provide written health information in accessible formats such as Easy Read or Makaton to meet the specific communication needs of this group. Carers' panels agree that this written information is not accessible for people with a learning disability and are of the opinion that this information is not produced with people with a learning disability in mind.

Verbal Communication

The investigation pointed to many examples of good communication, with the dental sector in particular being identified as being effective in communicating with people with a learning disability. The main barriers to good communication identified were:

- Poor communication: some healthcare professionals do not adjust their communication style to suit the specific needs of the person with a learning disability.
- Familiarity 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 the anxiety levels of the person with a learning disability, and the amount of time available for the consultation itself.

Participants, in particular carers, indicated that their experience suggested that many healthcare professionals had received insufficient training to develop the skills required to communicate with people with a learning disability. However, it was clear from discussions with people with a learning disability that the barriers identified combined to affect their confidence in communicating with healthcare professionals.

Good Practice

The investigation has highlighted a great deal of good practice, which we believe could be used and developed by the Health and Social Care Service in implementing the Commission's recommendations. There are a number of sources of information 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 referred to in the investigation report. Basic guidance would include:

Written Information

- 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 clear and simple.
- Pictures should be used to convey the messages within the text.

Verbal Communication

- Speak to the individual first, not the person supporting them.
- Get the individual's attention, ensure there are no distractions.
- Speak clearly, slowly, and allow time for response
- Use simple language, short sentences.
- Use facial expressions and body language to explain meaning.
- Use signs, pictures or other communication aids where appropriate.
- Repeat what has been said.
- Check understanding with the individual.

Conclusions and Recommendations

Despite the increased emphasis on mainstreaming health provision, much remains to be done to ensure that such services are accessible for people with a learning disability. It is imperative, if the policy of inclusion is to be effective in the field of health, that health information is available in a format which is tailored to their specific communication needs. This includes written health information about specific illnesses, health promotion, and the various health services available as well as the information communicated verbally by a range of healthcare professionals.

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. Our recommendations 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 communication skills to meet individual communication needs. The improvements we are seeking are straightforward and inexpensive and will, we believe, contribute to better health for people with a learning disability.

Key Recommendations

1. Production of Written Information Specifically for People with a Learning Disability.

A strategic approach to the development of a range of accessible written health information should be adopted and led by the DHSSPS. This will require;

- 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 accessed 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.

- Development of a specifically tailored appointment letter across the Health and Social Care Service for use 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 which includes information about the specific needs of people with a learning disability and training in effective communication with those who have specific 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 should be provided to healthcare professionals on how to communicate with people with a learning disability.

The DHSSPS should adopt a strategic approach to ensuring that the Health and Social Services Boards and Health and Social Care 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 robust medical records about people with a learning disability on their practice register.

The current General Practice contract should be reviewed to establish if the existing financial incentives have been 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 a patient identified link person within their Local 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 who have a learning disability, and to facilitate better communication between such patients and hospital staff.

6. Passport System

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

Taking our recommendations forward

Whilst the recommendations we have made will impact across all the Health and Social Care Services, 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 on these at the end of that period. During this phase 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 who will have the opportunity to raise these issues with the DHSSPS to increase support for our recommendations.

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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