

**Equality Commission for Northern
Ireland**

**Review of the Formal Investigation into
the Accessibility of Health Information
for People with a Learning Disability in
Northern Ireland**

June 2013

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Introduction

In 2006 the Equality Commission for Northern Ireland launched a formal investigation under the Disability Discrimination Act 1995 [DDA] into the accessibility of health information for people with a learning disability.

The DDA 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 and extends to access to and use of “means of communication” and “information services”.

The formal investigation report published in 2008 highlighted a number of barriers to communication in the health care setting reported by people with a learning disability and made a number of recommendations aimed at improving access to vital health information.

The investigation was conducted at a time when Learning Disability Services were under review and Departmental policies sought to increase the provision of health services to people with a learning disability in mainstream services in the community. Resettlement in the community of all long term hospital residents with a learning disability remains a goal for the Department of Health and Social Services and Public Safety.

At the same time reports such as Mencap’s Death by *Indifference* report¹ were highlighting inequalities in health care provision for people with a learning disability and the barriers preventing their health needs being met within mainstream health services. A follow up report by Mencap published in 2012 noted that some progress had been made in meeting the needs of people with a learning disability, but urged more effective action across health services.²

Following Mencap’s report in 2007 the Department of Health commissioned a Confidential Inquiry³ into the deaths of 247 people with learning

¹ Mencap Death by *Indifference*: March 2007

² Death by *Indifference*: 74 deaths and counting: A progress report 5 years on Mencap; February 2012

³ Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD) March 2013

disabilities in England over a two-year period. The Inquiry reported that on average, men and women with a learning disability die, respectively, 13 years and 20 years earlier than the general population. It found that the most common reasons for premature deaths were problems with diagnosis or treatment together with problems in identifying needs and providing appropriate care in response to changing needs. The Confidential Inquiry recommended that health care professionals become more aware of how they can make adjustments to meet the specific needs of people with a learning disability. It endorsed the implementation of systems which would improve liaison between health services and help to identify people with a learning disability within health care settings.

Such investigations highlight the importance of equality of access to health information for people with a learning disability. Barriers to communication and information provision can make it difficult for people with a learning disability to communicate their health issues and to make their own health choices. Similarly, barriers to communication can make it problematic for health care professionals to identify the cause of health problems and possibly delay appropriate intervention.

Providing health information in a meaningful way to the individual can help to ensure that existing illnesses are diagnosed and treated appropriately. It will help people with a learning disability to be involved in discussions around treatment options and to understand the purpose of treatments. Accessible information can also help to avoid future health problems through health promotion. As such, effective communication may ultimately lead to prolonged and more independent lives.

Policy aims of inclusion and access to mainstream services must be supported by good and effective communication strategies if they are to be successful. This is recognised at policy level and the Department of Health and Social Services and Public Safety [the Department] has committed to improving communication in both the Bamford Action Plan 2009-2011⁴ and

⁴ Delivering the Bamford Vision The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan 2009-2011; DHSSPS

in the Learning Disability Service Framework 2012⁵. Both publications refer to the findings of the Commission's formal investigation.

An evaluation of the Bamford Action Plan 2009-2011⁶ has reported that actions in relation to accessible information have been achieved; although many are ongoing.

The evaluation reported service user concerns regarding future resource constraints and the slow pace of noticeable change. It was noted that the Action Plan 2009-2011 had set in place structures and strategies for improving services and that it may take some time before service users experience real change.

The commitments made in the Bamford Review Action Plan and the standards set out in the Learning Disability Service Framework which aim to improve the accessibility of information for people with a learning disability across Northern Ireland are referred to in this review.

In this report we present the information provided to us by health care organisations and assess progress made in taking the investigation recommendations forward. In addition we report the views and experiences of verbal and written communication in health care settings of with people with a learning disability who participated in focus groups around Northern Ireland.

⁵ http://www.dhsspsni.gov.uk/learning_disability_service_framework_-_full_document.pdf

⁶ Evaluation of the 2009-2011 Bamford Action Plan as at December 2012; January 2012; DHSSPS

Summary of investigation recommendations

The formal investigation recommendations aimed to ensure that communication between health care professionals and individuals with a learning disability is as effective as possible and that accessible written information is readily available. It was recognised that some individuals are likely to continue to rely on others for support when communicating; however, the Commission believed that making health information accessible and tailoring communication to the individual's needs would benefit everyone with a learning disability.

Written information recommendations included:

- Establishing a strategic approach to the development of accessible written health information as essential.
- Involving service users in the development of accessible information.
- Prioritising the health information to be developed into accessible information.
- Making accessible information readily available, ideally in health service locations regularly used by people with a learning disability.
- Creating a central resource for accessible information.

In particular, the investigation recommendations highlighted the need for specifically tailored appointment letters and for more easily understood medication and pharmaceutical information.

Verbal communication recommendations included:

- Disability training for health care staff which includes information about the specific communication needs of people with a learning disability.
- Including specific communication training in undergraduate and post graduate programmes and in continuous professional development for health care professionals.
- Involving service users in the training.

In order to assist health care professionals identify and prepare for the specific communication needs of individuals with a learning disability recommendations also included:

- Establishing robust medical records about people with a learning disability on General Practice registers.
- Improving collaboration between General Practice and Local Community Learning Disability Team.
- Establishing the role of Patient Liaison Nurse at each main hospital in Northern Ireland to facilitate better communication between patients and hospital staff.
- Developing a passport system so that people with a learning disability can identify their particular communication needs when accessing health services.

This review will consider progress against the formal investigation recommendations. The recommendations in full can be found in the formal investigation report at:

[http://www.equalityni.org/archive/pdf/FormalInvestDisability\(Full\).pdf](http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf)

Policies and strategies shaping access to health care and information for people with a learning disability

The most influential review of Learning Disability Services in recent times has been the Bamford Review of Mental Health and Learning Disability completed in 2007. A number of policies and strategies have been developed since the Bamford Review which aim to fulfil the vision of the Equal Lives Report⁷ which considered services for people with a learning disability and related policy.

The Northern Ireland Executive and the Department have stated their commitment to developing services which enable people with a learning disability to live as independently as possible. Effective communication and information provision is recognised as fundamental to achieving this goal.

This section reports on some of the main policies shaping the future of health care provision for people with a learning disability and highlights, in particular, areas which relate to the recommendations of the Commission's formal investigation.

The Bamford Review of Mental Health and Learning Disability

The Bamford Review of Mental Health and Learning Disability [and particularly the Equal Lives Report] provided direction for the reform of policy and services for people with a learning disability in Northern Ireland. The Equal Lives Report provided the vision of how services can be transformed to support people with a learning disability to access the full range of health care services and to participate in decisions about their health.

⁷ Equal Lives: A Review of Learning Disability Services 2005: Bamford Review of Mental Health and Learning Disability: <http://www.dhsspsni.gov.uk/learning-disability-report>

The Bamford Review Action Plans.

A cross departmental Action Plan was published in October 2009 setting out the key actions of the Bamford “vision” to be taken forward over the period 2009-2011⁸. A number of new structures were set up within the Northern Ireland Executive and the health service to oversee and take forward these actions.

Following an evaluation of this Action Plan, published in May 2012⁹, the Department reaffirmed its commitment and published a further Action Plan for the period 2012-2015 in March 2013.¹⁰ The new Action Plan aims to take forward the strategies put in place by the previous Action Plan, to progress ongoing actions and those which were not already achieved.

Communication and information provision play a key role in achieving the Bamford Vision.

The Action Plan 2009-2011 specifically referred to the formal investigation and committed the Department and the Health and Social Care Board [the Board] to implement the “best practice identified in the Equality Commission Report into the accessibility of health information in Northern Ireland for people with a learning disability.”

The Action Plan 2009-2011 also contained further Key Actions consistent with recommendations contained in the Commission’s formal Investigation, including:

- A register of clients with a learning disability to be developed and maintained in GP practices and the development of health facilitation posts
- Provision of information in easily accessible formats

⁸ Learning Disability Action 58 page 130; Action Plan 2009-2011; DHSSPS (see page 4, footnote 4)

⁹ Evaluation of the Bamford Action Plan: DHSSPS (see page 5, footnote 6)

¹⁰ Delivering The Bamford Vision, The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability: Action Plan 2012-2015, November 2012: DHSSPS

- Training for staff in contact with those with a learning disability in disability awareness and communication skills including undergraduate and postgraduate training for dental care professionals.
- Improving information provided to people with a learning disability to ensure appropriate health care is given where needed.
- Establishing a Passport system for both children and adults.

Learning Disability Service Framework

The learning Disability Service Framework¹¹ was published in October 2012. It advocates supporting independent lives for people with a learning disability and recognises that effective communication is necessary for the delivery of health and social care, including the provision of information in a way in which the service user can understand.

This Service Framework builds on the approaches proposed in the Bamford Review Action Plan and includes the implementation of GAIN Guidelines¹² as a key performance indicator. The Service Framework recognises that there are areas where communication can be improved within health care organisations: it highlights the importance of effective liaison between services; and it identifies the training of health care staff as an integral part of ensuring that individual communication needs are met.

There are 34 Standards contained within the Service Framework. Standard 7 relates to communication with people with a learning disability. A number of other Standards relating to equality of access to health services assume effective communication.

Standard 7: “people with a learning disability should receive information about services and issues which affect their health and wellbeing in a way that is meaningful to them and their family”.

¹¹ http://www.dhsspsni.gov.uk/learning_disability_service_framework_-_full_document.pdf

¹² GUIDELINES ON Caring For People with a Learning Disability in General Hospital Settings: Guidelines and Audit Implementation Network: June 2010:
<http://www.gain-ni.org/images/Uploads/Guidelines/Gain%20learning.pdf>

There is reference to the Commission’s formal investigation report as part of the evidence base for some Standards. Specific actions which correspond closely with the recommendations of the formal investigation are provided at Appendix 1.

The Service Framework does not specify how these actions are to be met by health care organisations, but it is clear that the Board remains at the forefront of driving changes. The Standards are measurable and so will provide a basis for evaluation of progress against the formal investigation recommendations.

Transforming Your Care

Transforming Your Care¹³ sets out the Department’s plans for the future shape of health and social care services in Northern Ireland. In implementing the new model the Department’s stated aims include tackling health inequalities and ensuring greater personal choice and control for service users.

“every individual will have the opportunity to make decisions that help maintain good health and wellbeing. Health and social care will provide the tools and support people need to do this.”¹⁴

Transforming Your Care reflects the vision of the proposed new 10 year public health framework for 2012 -2022, Fit and Well – Changing Lives where “all people are enabled and supported in achieving their full health potential and well-being”¹⁵. Both strategies incorporate the implementation of the Bamford Action Plan 2012-2015¹⁶.

¹³ Transforming Your Care: A Review of Health and Social Care in Northern Ireland December 2011 DHSSPS

¹⁴ Ibid page 6

¹⁵ Fit and Well Changing Lives 2012-2022; A 10 Year Public Health Strategic Framework for Northern Ireland DHSPSS 2012, page 11

¹⁶ Action Plan 2012-2015 (see page 9, footnote 10)

In particular, for people with a learning disability, Transforming Your Care works towards enabling and supporting people with a learning disability to live in the community and to access mainstream and local services.

The Transforming Your Care review publication identified a need for improving clinical staff awareness of the specific communication needs of people with a learning disability and for reasonable adjustments to be made to meet to those needs. In particular, the review identified allowing more time for consultation with people with a learning disability as one such reasonable adjustment¹⁷. This was also recommended by the formal investigation. The Transforming Your Care review proposed that Direct Enhanced Services be further developed and that an information resource about services be made available for people with a learning disability.

¹⁷ Transforming Your Care; DHSSPS page 94 (see page 11, footnote 13)

The Investigation Review

The Commission has regularly sought information from the Department about action taken to progress the investigation recommendations. In the first instance discussions were held with the Department's Learning Disability Unit and, more recently, the Board has provided information on request¹⁸. The Board's key functions include ensuring that recommendations for improvement in health and social care services have been implemented. As such the Board has provided updates on action taken to implement the investigation recommendations.

Between June and September 2012 the investigation team consulted with service users and some organisations representing the views of service users. The review sought the views of people with a learning disability, Mencap and the Patient Client Council, Bamford Monitoring Group.

Health service organisations and member organisations for health professionals were also asked to provide up to date information about any action they have taken to ensure that health information is accessible. Organisations included the Health and Social Care Board, The Belfast and the Northern Health and Social Care Trusts, The Public Health Agency, Pharmaceutical Society of Northern Ireland, the British Medical Association and the British Dental Association.

Focus Groups

The investigation team consulted with people with a learning disability during 7 focus groups held across Northern Ireland. A total of 68 people took part in the focus groups. Participants were asked about their experiences of communication in various health care settings and about their ability to access written health information which they could understand.

¹⁸ The Health and Social Care Board was formed in 2009 to co-ordinate and lead on the actions of the Bamford Review of Mental Health and Learning Disability 2007

The investigation team recognised that measured progress was to be expected in relation to written health information and so the focus groups concentrated mainly on experiences of verbal communication. Appendix 2 provides details of the focus groups.

Progress within Health Care

It is evident that the Department recognises the importance of equality of access to health care for people with a learning disability. Progress is being made in taking forward the Bamford vision, in setting up systems and developing policies to improve equality of access to health and social care for people with a learning disability. It is also evident that the Department recognises that accessibility of health information is a key part of such equality of access; both verbal communication and written information.

Recent policy development has also stressed that receiving information in an accessible format is a right and not a privilege for people with a learning disability. It is also accepted that health care staff should be able to meet the specific communication needs of people with a learning disability and that effective training includes service user involvement.

Bamford Review Progress

Much of the work done has been in response to the Bamford Action Plan which included reference to the formal investigation. The Bamford Action Plan 2012-2015¹⁹ takes forward some actions that were outstanding from the previous Action Plan as well as new areas of work. The theme of making health information accessible to people with a learning disability is maintained in aims such as:

- ensuring that people with a learning disability have equal access to the full range of primary health care services by implementing Direct Enhanced Services across Northern Ireland by March 2015
- involving and employing service users in the commissioning, delivery and evaluation of services
- improving access to advice and information on services and the development of a central point of access for information by March 2015
- ensuring GAIN Guidelines are implemented in hospitals including staff training and easy read material.

¹⁹ Delivering the Bamford Vision; Action Plan 2012-2015; DHSSPS (see page 9, footnote 10).

Progress against the Bamford Action Plan 2009-2011 was evaluated according to the outcomes of the specific actions. Of the 67 learning disability actions contained in the Action Plan the evaluation assessed 81% [54] as having been achieved²⁰. Of course, many of the actions relating to accessibility of information are “ongoing”.

Actions such as the implementation of the “best practice identified in the Equality Commission Report ..” and developing Passport Systems across Northern Ireland to improve communication for people with a learning disability have been assessed as achieved but are ongoing Actions.

The evaluation confirms that a Direct Enhanced Service is up and running in 90% of GP practices. This includes the development of a register of clients with a learning disability and the appointment of health facilitators in each Trust area.²¹ It also states that health care staff are receiving training to raise awareness of the specific needs of people with a learning disability whilst noting that there have been delays in the provision of such training for dental practitioners.

The evaluation acknowledges that further feedback from service users is required to provide a better picture of the effectiveness of communication within GP surgeries and within hospitals.

Although the evaluation indicates that further work is required to improve access to information, there is acknowledgement of the work of the Public Health Agency to improve communication methods and provision of information in accessible formats.

Replies from organisations

Replies received by the Commission from the organisations contacted as part of this review indicate that health care organisations are exploring how they can best meet the communication needs of people with a learning disability and are progressing systems to enable them to do so.

²⁰ Evaluation of the Bamford Action Plan: DHSSPS pages 19-20 (see page 5, footnote 6)

²¹ Ibid; page 79

Specifically, in relation to the recommendations of the formal investigation, the Commission has been advised that the following actions have been taken by health and social care organisations.

Involvement of service users at a strategic level

There is involvement of service users in discussion taking place at strategic level. People with a learning disability are core members of the Bamford Regional Learning Disability subgroup and provide comment on the implementation and progress of the Bamford Review Actions. User groups have a role to play in the auditing of service provision, including the evidence base in relation to the accessible information that is available.

Ensuring Verbal Communication Meets Specific Needs

Training for health professionals

- The GAIN Guidelines “Caring for people with a learning disability in general hospital settings” were launched in June 2010²². One of the priorities of the Guidelines is meeting the specific communication needs and preferences of patients and the document provides links to helpful communication toolkits. They promote, as good practice, service user involvement in the design and delivery of training to health care professionals at both undergraduate and postgraduate level as well as through continuous professional development.
- The Pharmaceutical Society for Northern Ireland [PSNI] has sought service user feedback regarding communication within pharmacy settings and encourages service users to participate in the panel which assesses the content of accredited training courses. The PSNI aims to involve service users in post graduate compulsory training days to provide interactive communication training for pharmacists.

²² GAIN Guidelines; Guidelines and Audit Implementation Network (See page 10, footnote 12)

- Training is being provided for health care staff both in disability awareness and in meeting the communication needs of people with a learning disability. Service users assist with the provision of training to learning disability nurses at Queen’s University Belfast. Mencap involvement has ensured that a service user perspective is provided and parent carers relate their experiences of health care provision.
- The General Medical Council [GMC] has produced credit card size information cards for individuals to give to their doctors. This initiative was launched in May 2012. The card directs General Practitioners to the GMC website where there is a link to a series of interactive training scenarios and information provision on communicating effectively with people with a learning disability. Service users are involved as actors in the training scenarios.²³
- The Low Vision Outreach Service has sought to improve the uptake of eye appointments. This initiative has involved staff training in verbal communication and the provision of accessible written information.
- The Board has funded a “Silent Voices” service to assist people with a learning disability who have no verbal communication to make their views known about resettlement plans. Advocacy services are available for all those being resettled and easy read material about the process.
- Direct Enhanced Services [DES] for adults with a severe learning disability has put in place annual health checks. It has also developed the role of health facilitators who liaise with primary and secondary health care providers on behalf of the person with learning disability and advise of an individual’s specific communication needs. DES is to be implemented fully across Northern Ireland by March 2015. The Board has a responsibility to review progress with DES and this will include a review of written information provided as part of the service.

²³ www.gmc-uk.org/learningdisabilities

- Various measures such as communication folders and passport systems containing details of an individual's specific needs, have been designed to assist communication between people with a learning disability and their General Practitioner or acute senior staff.
- The Speech and Language Therapy Team and the Good Information Group based in Belfast Health and Social Care Trust organised a Total Communication Event in September 2012 where expert advice and best practice was shared on creating communication friendly environments for adults with a learning disability. Total Communication recognises all forms of verbal and non-verbal communication.

Making Written Health Information Accessible

Guidance for health care staff

The Formal Investigation recommended a strategic and standardised approach to the provision of accessible health information.

An Accessible Formats Policy and Practical Guidance for Staff has been developed by the regional Accessible Formats Steering Group. The purpose of this policy is to help health, social care and public safety organisations meet the information and communication needs of all individuals, including those with a learning disability. Consultation on the policy was completed in early 2013.

The policy provides a guideline for health and social care organisations to adopt and to adapt to their organisation's individual needs. It sets out standards for information provision across services and emphasises that service users have a right to expect information to be provided in a way they can understand.

In addition equality leads in the Belfast and the Northern Health and Social Care Trust led on the creation of guidance for health and social care staff. Making Communication Accessible for All is described as a quick reference

resource for health and social care staff to enable them to communicate effectively with people who may have a disability, including people with a learning disability.

A range of disability organisations and health care representatives were involved in the development of the guidelines which are to be reviewed annually as best practice develops.

It is of particular interest to this investigation review that both the policy and the guidelines highlight appointment letters as a priority document for being issued in an accessible way. The Making Communication Accessible for All guidelines provide a sample easy to read letter [Appendix 3]. It is of concern, however, that it may be some time before letters are produced in an easy read format as standard due to the current limitations of hardware and software programmes.

Health and Social Care Trusts

The HSC Trusts' audit of health inequalities specifically cite the Commission's formal investigation as a measure of key inequalities and committed to take action to produce a standard appointment letter template for health and social care appointments²⁴.

Commitment was also made to develop the good practice guide and set minimum standards for accessible communication. It highlights the importance of having a strategic approach to this and to sharing best practice across Health and Social Care Trusts.

Health and Social Care Trusts' Section 75 Action Plans commit to increasing the accessibility to information: "the Trust will increase the number of its documents produced in an easy read format and to ensure that this information is readily available in an online easyread library."²⁵

As part of these commitments individual HSC Trusts are developing a library of easy read material which can be accessed on their websites.

²⁴ Health and Social Care Preparing for Health and Social Care Trust's Equality Action Plans, Audit of Inequalities, Section 75 Equality Groups, November 2010 [Belfast HSCT] pages 59-60

²⁵ For example Southern Health and Social Care Trust Equality Scheme, Section 75 Action Based Plan Period 1 May 2011 to 30 April 2014; page 2

Specific Initiatives

The Board has reported that some HSC Trust areas and some services have taken forward accessible information initiatives such as, visually augmented letters of invitation to GP practices and developing a GP toolkit containing health promotion material.

It is to be hoped that successes and best practice will be shared across the organisation.

- The Northern Ireland Cancer Clinic provides a specific service for women with a person centred approach and accessible appointment letters.
- Computer software for making written information accessible for people with a learning disability is used by the Speech and Language Therapy department. [see Total Communication event above].
- The Board has produced a number of written information leaflets in Easyread such as the Board's accessible information policy, its strategy on personal and public involvement, and patient experience satisfaction forms.

British Medical Association

The British Medical Association [BMA] emphasises that its role is to highlight issues, encourage members and to campaign for change to ensure that its members provide a service which is inclusive and responsive to the needs of people with a learning disability.

A BMA report published in 2007 made recommendations to the medical profession, health care organisations, service providers and educators to

break down barriers to access to health care.²⁶ The BMA states that it has actively sought progress at a Governmental level regarding the Direct Enhanced Services for people with a learning disability. It also promoted the General Medical Council's website launch of interactive guidance for working effectively with people with a learning disability amongst BMA members.²⁷

²⁶ Disability equality within health care ;The role of the healthcare professional:British Medical Association
June 2007

²⁷ Ibid page 18

Focus Group Results

Summary

In general participants report that they have experienced good verbal communication in a range of health care environments under the right conditions. It seems that some of the barriers to effective verbal communication identified in the formal investigation remain in certain situations. Participants are aware that time constraints can be a barrier to effective verbal communication and state that when a consultation is rushed they find it more difficult to understand the health information.

A small number of participants, however, feel able to attend General Practitioner [GP] consultations on their own. Most prefer to be accompanied by someone who will assist with understanding and remember what has been said during the consultation.

Participants did report feeling more confident that, time permitting, health care professionals will try to adjust their communication styles to make health information more accessible to them.

The participants reported little difference with regard to written communication. Having access to health information remains important to the participants. However, easy to read information is not generally accessible to them and they do not know where to access such information.

Verbal Communication

The formal investigation reported that participants experienced a number of barriers to effective verbal communication. Particularly, it was reported that certain health care professionals did not speak to them directly when accompanied by carers or relatives. Other reported barriers to good communication may have influenced the way in which health care professionals communicated. Such barriers included time constraints, a lack of awareness of communication needs and a lack of ability to meet

those needs. Further factors affecting good communication highlighted by the investigation included the anxiety caused by long waiting times and unfamiliar environments, health care professionals not utilising other forms of communication and a lack of self confidence on behalf of the person with a learning disability.

- **Direct communication**

During this review it was encouraging that all of the focus groups reported experiencing direct communication with health care professionals and that this applies to experiences of GP appointments, hospital settings and dental appointments.

General Practitioners

Just 2 participants stated that their GP spoke only to the person accompanying them on a regular basis. Although this is unacceptable, it reflects some improvement from the original investigation where 30% of assessment panels reported that their GP talked to their carer and not to them.

Most participants confirmed, however, that they like to have the support of someone accompanying them to a GP consultation. A small number of participants [3] were confident enough to attend consultations on their own.

Some participants were aware that on some occasions their GP would direct the conversation towards the person accompanying them.

For example:

Participants thought that this occurred when the doctor was too constrained by time to properly communicate with them and ensure that they understood. At such times the role of the carer is crucial. This indicates that time constraints remain a barrier to good communication.

One participant complained that their GP regularly speaks to their parent privately prior to their consultation; they thought that this was wrong and that they should be included in all discussions about their health.

Another said that the doctor did speak to them during the appointment but that when it comes to explaining about medications the doctor speaks to the person accompanying him.

Hospital

The majority of participants who had experienced care in the hospital setting, as inpatients, outpatients or when attending A&E, stated that hospital staff, nurses and doctors talked with them directly. One person said that they felt they had been “treated with respect”.

Participants said that being in hospital made them anxious and that taking time to explain what was going to happen helped to calm their anxiety about what to expect.

One person related an experience as an inpatient which made her feel ignored and unimportant. She believes staff were dismissive of her and unhelpful as she says they did not take time to explain to her why she could not do certain things by herself and did not offer to assist her.

Dentist

Experiences of communication at the dentist were also positive with participants stating that dentists talk to them directly. Those participants who are anxious when visiting the dentist state that their dentist is good at calming them down and at explaining what is going to happen.

Pharmacist

Most of the participants confirmed that they go with someone to collect prescriptions. Focus groups were equally divided in their experiences of their pharmacist. Some focus groups stated that their medication was explained to them and some said that medications were explained to the person with them.

Participants do, however, report a generally more positive experience of direct communication with health care professionals. There remain some examples of communication with carers only or at certain times.

- **Self-confidence**

In the original investigation 60% of the assessment panels reported a lack of self confidence as a barrier to good communication within GP settings.

During this review participants stated that they felt confident in communicating with their GP: 57% of the focus groups confirmed that they felt confident enough to ask their GP questions during consultation.

Those participants who stated that they feel confident during GP consultations said that the GP talked directly to them, used simple language and, in a few cases, would use diagrams to assist with helping them understand.

Familiarity with their GP was also a factor for participants in feeling confident. Most focus groups [86%] stated that they would like to see their own GP when they attended surgery but said that they may have to wait a long time for an appointment with their familiar GP.

Participants, who did not feel confident during their GP consultation, said that they did not always understand what their GP was saying and that this made them afraid to ask questions. They thought that at times their GP talked too fast and did not have enough time to properly explain.

- **Time issues**

The focus groups referred to the short duration of appointments as a barrier to good communication. Participants noticed that the health care professional did not communicate as effectively when they are rushed and this reflects the findings of the original investigation.

A rushed consultation may mean that there is no time to meet the communication needs of the individual which may result in the individual being denied the opportunity to discuss their health issue properly. In extreme cases health issues may be overlooked.

One participant who has a life threatening illness found this to be particularly stressful and worrying. She explained that she attends hospital regularly for scans and that she relies on her GP and carers to explain the

results. However, she said that there is often a longer delay than expected before the results of her scan are available and that she becomes anxious when she has an appointment for a further scan without having had the results of the previous one. Ideally she would like more information about her scan results from her Consultant and to have this information prior to her next scan.

- **Attitude/ Language used/ Other forms of communication**

Participants have said that they have experienced health care professionals adjusting the way in which they communicate and that this has assisted them to understand and has helped them feel confident enough to ask questions.

The adjustments made appear to be in relation to language used as only a small number of participants [3] stated that the health care professional has used any other form of communication to assist with understanding. In these cases communication was assisted through pictures or diagrams.

One participant in particular had found a great improvement and, in practical terms, this has meant that he is able to attend GP appointments on his own. He said that his GP uses language that he can understand and takes time to explain and ensure that he has understood.

Another participant stated that her GP took time to read through and explain a leaflet on a particular treatment which she required. The information in the leaflet was not available in a format which she could easily read. She found this helped her to understand the treatment and its importance.

There were also some examples provided of where hospitals have been provided with information about an individual's specific communication needs when participants have had planned visits to hospital.

Two participants who had experience of planned visits to hospital settings appreciated that hospital staff were aware of their specific communication needs when they arrived. As a result the health care professionals were prepared and able to communicate effectively with the participants.

Participants did identify barriers to understanding in situations where the health care professional spoke too fast or did not use simple language. They also thought that the accessibility of the health information could be enhanced if the health care professional used additional forms of communication, such as pictures or diagrams.

One focus group raised a concern that they sometimes have tests done at their GP surgery but they do not know what these tests are for. They would like someone to explain the purpose of the tests.

Further suggestions made by several participants indicated that they understood what was said during the consultation, but that they would later forget. They suggested that having something to take away from the consultation in writing would assist them.

A small number of participants were concerned that they were not given information following x rays or scans. They said that they were not shown the x-ray or scan nor were the results explained to them and they would have liked to have had this information.

- **Waiting times as barriers to the accessibility of health information**

The formal investigation reported that long waiting times contributed to participants' anxiety, particularly when attending hospital, and that this affected their ability to communicate well. It was thought that communicating and keeping people informed during their wait helped to reduce their anxiety.

In this review focus groups did not highlight waiting times at hospital as causing them any anxiety and thus a potential barrier to good communication. Anxiety about the situation of attending the hospital was a factor, but this was reported as anxiety about their health or a lack of familiarity with their environment. In such instances participants who had experienced hospitals said that being communicated with them and letting them know what was going to happen helped to ease their anxiety.

Waiting times, however, were highlighted as a problem in GP surgeries. 71% of focus groups thought that they spent too long waiting for their

consultation with their doctor. Some participants said that they get annoyed when they see other people going in to their appointment before them when they have arrived earlier. One participant who suffers from epilepsy said that her GP surgery provides a separate waiting room for her to wait in and that she is taken quickly and that this assists her greatly in preventing raising levels of anxiety.

Waiting times when attending the dentist were not generally thought to cause anxiety or annoyance even though they could also be lengthy. Participants said that dentals surgeries were good at letting them know if they will have to wait for some time and why. They were content because they had been given this information

In summary, addressing the barriers of time constraints may assist with some of the reported barriers to effective and accessible communication. Participants thought that the ability or willingness of the health care professional to adjust language used and ensure their understanding was largely dependent on time available.

It remains a recommendation that longer GP appointment times are required for people with a learning disability.

It is recognised that there will, however, always be individuals whose communication needs will require more time than can properly met in the busy environment of a GP surgery or an Accident and Emergency department. However, there is also some evidence that health care professionals could do more to meet the specific communication needs of the individual. The health care professional should attempt to meet these needs as far as possible by adjusting language used and being prepared to use other forms of communication where necessary.

Written Information

Access to information about health issues and health services is crucial to improving the health of people with a learning disability. Information empowers individuals to make informed choices about their health and the services they receive.

As mentioned previously this review has focussed mainly on verbal communication because it is thought that making written information accessible to people with a learning disability requires more time and resources. The experiences of the focus group participants appear to confirm that written health information is no more accessible to people with a learning disability than it was in 2008.

The majority [71%] of the focus groups said that there is no easy to read information available in their local GP surgery. These groups said that they would like to have accessible material to look at. They said that although leaflets were on display none met their needs.

One focus group had conducted its own survey of their local GP surgeries. They had found no health information leaflets which they could understand. The ones which were available contained too many words, did not use simple language and the pictures displayed on them did not relate to the subject matter of the leaflet.

One person had lifted a leaflet about Alzheimer's Disease. He said that, although he was unaware of the subject matter when he took the leaflet, he would have liked to have been able to understand it as he has close family members with the condition and was anxious about them.

The general consensus was that participants would like to have health information accessible to them in a format they can understand but they did not know how to obtain such information.

In 2008 the formal investigation recommended that hospital appointment letters should be tailored to suit the needs of people with a learning disability, containing larger font and a simple and clear message. It was thought that providing information about what to expect during the visit to the hospital would help to reduce anxiety. Focus groups confirmed that appointment letters remain unchanged and that they do not include any other easy read information about what they are to expect when in hospital.

Focus groups reported that letters issued from dental surgeries and GP surgeries were good because of the large font used and the simple message.

A focus group raised the issue of forms signed following a visit to the dentist. One member of the group had asked for information about what they were signing and the receptionist had explained the purpose of the form. The rest of the group said that they did not know what they were signing.

One participant was keen that the focus should remain on verbal communication and on changing the attitudes of health care professionals rather than on the provision of accessible written health information for the time being.

However, the Commission firmly believes that the provision of health information in accessible formats should not be viewed as an “extra” but that it should be provided as a matter of course. Doing so would assist people with a learning disability to make informed choices about their health and about the health services they receive.

Involvement in Training and developing accessible information

The original investigation recommended that the health service involves service users in the development of accessible written information and also in the provision of awareness training for health care professionals.

Half [57%] of the focus groups participating in this review have had some involvement with their local Health and Social Care Trust, either with regard to written information or with communication training.

This involvement has included:

- Communication training for health care staff
- Communication training for health care undergraduates
- Assisting with the development of accessible written information
- Taking part in consultations and providing feedback about written health information.

One of the focus groups is assisting the University of Ulster nurse training course by making themselves available for practical communication training sessions. This provides the nursing students with the opportunity to interact with people with a learning disability and to develop and practise their skills. Previously the students would have practised these skills on each other and so this new method is an improvement which can only benefit the health care professional and the service user.

Some focus groups had very positive experiences of providing assistance to the HSC Trusts and have felt that health care professionals are willing to make improvements in the way in which they made health information accessible for people with a learning disability.

Unfortunately one focus group which had been approached by their local Trust to assist with training health care professionals found that, having delivered a couple of training sessions, there was not enough interest from staff to continue with the training.

Some of the focus groups, who had been consulted by their HSC Trust with regard to written health information, said that they would have liked to have heard further from the Trust about action taken or written information that has been developed.

One focus group approached their local HSC Trust to develop more accessible leaflets for the local Accident and Emergency Department. This group has also received funding from the HSC Trust and the University of Ulster to deliver a health programme which included an accessible leaflet for women "How are my boobs today?". They have reported that such initiatives have already had an impact on the lives of women taking part having assisted one woman detect a lump in her breast and receive treatment. The group is seeking funding to expand their programme to include a men's health programme.

Conclusion

This review has highlighted that the Department, and indeed the Northern Ireland Executive, has committed to improving equality of access to health care through implementation of the Bamford Review Action Plans. It is recognised that equality includes access to information about health as an essential starting point to enable individuals make informed choices about their health. There is also recognition that action must be taken to equip health care practitioners with the skills needed to meet the communication needs of the people with a learning disability they come into contact with.

To date the Department and various health and social care organisations have developed a number of policies and strategies which aim to improve equality of access to health care and to ensure that health information is accessible. Some policies have not yet been implemented and it will take some time before the results of their operation will be evident. However, action has been taken to identify baselines against which to measure future performance. Tools such as the Learning Disability Service Framework will, in future, act as a good measure of performance against standards.

Although the Commission's formal investigation is not referred to in the most recent Bamford Review Action Plan a number of the recommendations of the investigation remain as ongoing actions to be achieved; for example, the involvement of service users at a strategic level and training of health care professionals in the skills required to satisfy communication needs. The formal investigation is referred to in other documents, such as the learning Disability Service Framework and HSC Trust's Section 75 Action Plans, and so remains an influence in changes to improve accessibility of health information.

Written Health Information

This review confirms that, to date, progress in relation to making written health information accessible for people with a learning disability as standard has been gradual. This is understandable due to the resources

required to make a noticeable change in this area. Work is being carried out, however, which may mean noticeable improvement in future.

A standardised approach to the provision of accessible health information across health and social care services is being developed. The Accessible Information Policy and the Making Information Accessible for All guidelines provide organisations with the standards and best practice required. The policy and guidelines were developed through consultation with various disability groups, including people with a learning disability, and reflect the best practice identified in the formal investigation.

The current emphasis for accessible written information is on health services. Individual HSC Trusts, however, are developing a website resource of accessible information which will, hopefully, cover a range of health promotion materials and information about health issues. These websites are under construction but they could be an invaluable source of information for people with a learning disability, user groups, carers and health care professionals. It is also important that there should be a standardised approach to the information available on websites across the Trust areas, that the resource is well advertised and that it is accessible for people with a learning disability.

The formal investigation suggested that accessible information be available on the internet as an additional source. However, the recommendations also highlighted that accessible material should be available to people with a learning disability in the same way that it is available to the general public. Ideally accessible information should be on display alongside other information available at surgeries and hospitals. When information is available on HSC Trust websites then it is not inconceivable that these can be downloaded and made generally available as hard copies.

It is also evident that the opinions of people with a learning disability are being sought in the development process of accessible information policies and guidance documents. It is to be hoped that this will continue as best practice. The Board involves service users who contribute feedback about health services; individual HSC Trusts work with various local user groups

who input into decisions which will affect them. Organisations should ensure that they update the focus groups about subsequent action taken as a direct result of their input.

Both Mencap and the Patient Client Council have identified access to information as a problem for people with a learning disability. This includes information about health services and advice about health issues. The Patient Client Council believe that it should be the norm for all information to be produced in a clear and easy to understand format which would benefit all service users, not only people with a learning disability. They have been campaigning for the development of a website as a central resource of easy to read health information.

Although it is desirable that health information is provided in such a way, health information requires more than clear and simple language to be accessible to people with a learning disability. The Accessible Information Policy and Making Information Accessible for All guidelines provide information about how to make information accessible specifically to people with a learning disability. Involvement of services users in the process of developing accessible written information remains important and it is noted that Belfast Trust's Disability Action Plan identifies the need for a Regional Easy Read Forum.

Work is yet to be done regarding the formal investigation's recommendations for accessible appointment letters and information about medicines. Software and hardware restrictions mean that it may be some time before any change is made to improve this type of information as standard. The sample easy to read appointment letter provided by the Making Information Accessible for All guidelines may be adapted in the meantime.

Verbal Communication

Focus groups have reported that, in general, health care professionals speak directly to them and, in some cases, will try to meet their communication needs. This reflects an improvement from the results of the investigation and indicates a raised awareness of the communication

needs of people with a learning disability and willingness to meet these needs. It is also encouraging that some participants who had visited hospital reported that they have benefitted from the improvements in liaison between health services and advanced notification of preferred methods of communication. In situations where there is no familiarity with the individual, being informed of specific communication needs and preferences is essential.

It is, of course, important that health care professionals speak directly to the person with a learning disability. It is equally important that in doing so the individual's specific communication needs are met. Familiarity with the individual will help but, in any situation, it is obviously easier to do this if the health care professional has the information and the tools required to meet communication needs. The Direct Enhanced Service, GAIN Guidelines, communication folders, and passport systems provide such tools and are designed to ensure that communication needs are identified and met

The formal investigation recommended that there should be a Patient Liaison Nurse in each main hospital to prepare hospitals for the admission of people with a learning disability and to support reasonable adjustments to be made. Although, the Patient Liaison Nurse role has been piloted it appears that such Patient Liaison Nurses have not been recruited. GAIN Guidelines reflect the investigation's recommendation where it is described as best practice to identify a link person or "champion" to act as main support and carer for the individual in hospital.

The GAIN Guidelines have been in place since June 2010; however, learning disability organisations have identified the Guidelines, including passport systems and communication folders, as good in theory but a work in progress as reports have been made of problems in their practical application.

An evaluation of the Guidelines is to take place in 2013/14 and hopefully, any areas for improvement identified can be addressed. The Bamford Action Plan 2012-2015 aims to train staff and to produce Easyread

information and to further develop links between hospital and community services.

Undergraduate training for nurses has been developed to include practical sessions with people with a learning disability. The pharmaceutical profession is considering similar training experiences for its undergraduates. Training for dental practitioners has been highlighted as an outstanding action of the Bamford Review Action Plan and is included in the 2012-2015 Action Plan. The benefits of this training may not be seen immediately but should be evident in future.

It is not clear if the medical profession has identified a need for such communication training at undergraduate level. The General Medical Council's interactive web based training has, however, provided relevant information for doctors and could be a useful training tool for this profession.

The formal investigation had recommended that communication training is made mandatory and even accredited. This remains a recommendation. People with a learning disability are entitled to expect to receive health information in a way which they can understand. There was evidence of poor uptake in one Trust area of training offered by one of the focus groups and it is not clear whether time constraints or attitudes created barriers to participating in this training. Focus groups' experiences indicated a willingness amongst most health care professionals to make communication accessible. It is important that awareness is raised on how to meet specific communication needs.

It is evident from this review that time constraints remain a major barrier to effective communication between health care professionals and people with a learning disability. Participants noticed a difference in communication style which they felt affected their ability to understand the health information being given. The formal investigation had recommended that longer appointment times be allocated as a reasonable adjustment for people with a learning disability attending GP appointments. This remains the case. As Bamford Review Action Plans include the development of a

register of clients with a learning disability in each GP surgery this could make it easier for surgeries to identify patients who may benefit from a double appointment. The Learning Disability Service Framework also sets longer appointment times as a service standard.

Anxiety and agitation caused by long waiting times was identified as barrier to effective communication in the formal investigation. This was not the case during this review. However, participants did report that they are content to wait for long periods without becoming anxious or agitated if they are informed on arrival that they will be waiting beyond their expected appointment time. Providing this information is a simple and effective way of addressing this issue.

This review has taken place 5 years after the publication of the formal investigation. There has been much activity in relation to providing the foundation for improving the accessibility of health information for people with a learning disability. It will take some time to see the benefits of policies and strategies which aim to make health information accessible to people with a learning disability, some of which are not yet implemented. Documents such as the Learning Disability Service Framework and the Bamford Review Action Plan provide a basis for monitoring and measuring progress made in this area, However, as recognised by the Bamford Review, qualitative feedback from service users and user organisations is required to monitor whether they are actually improving access to health information for people with a learning disability. The Commission will continue to monitor progress made in relation to the recommendations made in its formal investigation.

Appendices

Appendix 1

Specific actions contained in the Learning Disability Service Framework 2013-2016 which reflect the recommendations of the formal investigation

- Supporting communication needs in such a way as to assist service users' involvement in making choices and decisions about their health and social care needs
- Ensuring that organisations have strategies and policies in place which support the involvement of people with a learning disability in service planning and delivery of those services.
- Regional training plans for HSC staff to raise awareness of communication needs of people with a learning disability and how to meet those needs, including how to establish functional communication systems for those who do not use speech as their main form of communication.
- HSC organisations to provide evidence that they are making information about services available to people with a learning disability accessible to them.
- Each person with a learning disability will have access to a named person who can assist them in understanding what services are available.
- Reasonable adjustments will be made to support people with learning disability to access mainstream services. Such as longer appointment times, appropriate waiting facilities and fast tracking arrangements e.g. in A&E departments. GAIN guidelines are to be implemented in acute hospital settings.
- GPs are to have in place a system whereby they can identify people with a learning disability on their register and a designated link person with the CLDT.
- Health improvement actions plans are to be implemented to ensure that people with a learning disability receive effective screening and regular health checks.

Appendix 2

Focus Groups

Strule Buzz Group	Omagh
The Working Party	Dungannon
Killadeas	Lisnaskea
TILLI Group	Bangor
The Skyway Club	Belfast
The User Council	Ballymoney
The Advocacy Group	Portadown

Gender	Number of people
male	28
female	40
total	67

Appendix 3 : Making Communication Accessible for All Appointment Letter

This letter is for Anne Wallace



FRI
Friday

Friday

Feb
24

24th February

2012

2012



12.00 noon

Where we will be meeting

**Dermatology
Belfast City Hospital
Lisburn Road
Belfast
BT6 0JE**

for your skin appointment

For more information please contact Doctor David Murphy



028 90 569687



david.murphy@belfasttrust.hscni.net

Created at www.surreyhealthaction.org

Dermatology Unit, Belfast City Hospital