

**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**

Summary

June 2013

Introduction

In 2008 the Equality Commission for Northern Ireland published the findings of its formal investigation into the accessibility of health information for people with a learning disability. The investigation report identified a number of barriers to the accessibility of both written and verbal health information for people with a learning disability. It also reported range of good practices in making health information accessible and, based on these practices and expert advice, recommended action to be taken by health services to improve access to vital health information.¹

Removing barriers to effective communication, insofar as possible, will assist people with a learning disability to make their own health choices and to communicate health issues where problems exist. Making health information accessible will enable better understanding of diagnoses. It will assist involvement in discussions around treatment options and understanding of the purpose of treatments. Ultimately, accessible information can contribute to prolonged and more independent lives for people with a learning disability.

This review considers progress made in implementing the recommendations of the formal investigation and assesses whether changes made to date have addressed the identified barriers to effective communication and information provision. A summary of the recommendations is provided in the Appendix.

¹ [http://www.equalityni.org/archive/pdf/FormallInvestDisability\(Full\).pdf](http://www.equalityni.org/archive/pdf/FormallInvestDisability(Full).pdf)

The Review

The review sought information from various sources:

- health service organisations
- organisations representing health care professionals
- people with a learning disability through a series of focus groups across Northern Ireland.
- organisations representing the views of service users such as Mencap and the Patient Client Council, Bamford Monitoring Group.

The review also considered policies and strategies which affect the way in which health services are delivered to people with a learning disability and refers to progress made in taking forward the recommendations of the Bamford Review 2007.

Summary of Main Findings

Health service policies continue to work towards providing mainstream health care in the community for people with a learning disability. The ongoing resettlement of long term hospital residents in the community and strategies, such as the Transforming Your Care² strategy, reinforce the necessity of ensuring that people with a learning disability have access to information about health issues which may affect them and the health services available to them.

Progress is being made in relation to the recommendations of the Bamford Review³. As a consequence some of the recommendations of the Commission's formal investigation are being taken forward through the

² Transforming Your Care: A Review of Health and Social Care in Northern Ireland December 2011
DHSSPS

³ 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>

Bamford Review Action Plans⁴. People with a learning disability are becoming more involved at a strategic level through the Bamford Review structures and feedback regarding service provision is being sought as a matter of course.

Action has been taken to improve access to health services for people with a severe learning disability through improved liaison between health services.

The Direct Enhanced Service has developed the role of health facilitators as liaison between health services on behalf of the individual. This includes ensuring that health care staff are made aware the communication needs of the individual. The Service is to be fully implemented across Northern Ireland by March 2015.

The Guidelines and Audit Implementation Network [GAIN] Guidelines⁵ aim to ensure that the specific communication needs of individuals are met within hospitals settings. The Guidelines provide links to a range of useful communication toolkits. They set out best practice procedures for preparation for the admission of a person with a learning disability for inpatient treatment. This was an area of importance highlighted by the investigation and included in our recommendations.

The Guidelines also highlight the importance of training health care professionals in meeting the communication needs of people with a learning disability at undergraduate and postgraduate level and encourage service user involvement.

Organisations representing people with a learning disability have raised concerns about the effectiveness of the Guidelines in practical terms. It is thought that there is a lack of awareness of the Guidelines amongst both service users and health care staff and that a lack of resources is limiting progress in its implementation. The Guidelines are due to be reviewed in

⁴ Delivering the Bamford Vision the Response of Northern Ireland Executive to The Bamford Review Of Mental Health And Learning Disability : Action Plan 2009-2011 October 2009; and Action Plan 2012-2015 November 2012: DHSSPS

⁵ 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>

2013/14 by the Regulation and Quality Improvement Authority and this will provide an assessment of their effectiveness.

The formal investigation recommended a strategic and standardised approach to the development and provision of accessible written health information. To date this has not been realised although a number of accessible documents have been produced by various health services and organisations in line with the best practice identified in the investigation report.

However, the regional Accessible Formats Steering Group has recently developed an Accessible Formats Policy for health and social care and public safety services organisations to adapt to their own needs. In addition, Health and Social Care Trusts [HSCT] have developed Making Communication Accessible for All guidelines for health and social care staff. The Policy and HSCT guidelines involved service users in their development and should provide a standardised and service-wide approach for making information accessible.

The formal investigation recommended a gradual approach to the development of accessible written information but identified a number of priority documents. One of these priority documents was the appointment letter. The Policy and HSCT guidelines highlight the importance of accessible appointment letters and the guidelines provide a sample easy to read appointment letter for reference. However, there is no indication of when accessible appointment letters will be produced as standard due to software and hardware restrictions.

Health and Social Care Trust Section 75 action plans commit to a central website resource of accessible information being developed by each Trust which should act as a useful source of information for service users and health care professionals alike.⁶ The provision of accessible written information will be monitored through the Learning Disability Service Framework⁷ which requires organisations to provide evidence that accessible information is available.

⁶ For example: Southern Health and Social Care Trust Equality Scheme, Section 75 Action Based Plan Period 1 May 2011 to 30 April 2014

⁷ http://www.dhsspsni.gov.uk/learning_disability_service_framework_-_full_document.pdf

Projects by various departments aim to share best practice and make services accessible for people with a learning disability. For example, Belfast HSCT Speech and Language Therapy Team's Total Communication Event raised awareness of various forms of verbal and non-verbal communication for adults with a learning disability; Northern Ireland Cancer Clinic's initiative provided accessible appointment letters and specific services for women with a learning disability.

Focus groups reported that to date they have not seen much improvement in the provision of accessible written health information. Such information is not readily available to them but most confirmed that having this information was important to them and that they like to have information to take away from appointments to refer to at a later date.

Measured progress in this area was expected. The formal investigation recognised that such changes are subject to resource constraints.

Focus groups did report, however, that they had been consulted by their local Health and Social Care Trust regarding the development of accessible information although they were unaware of the outcome of these consultations.

One focus group has collaborated with their local Health and Social Care Trust to produce accessible health information about its local accident and emergency department and to enhance a health project for women. Funding was received from their local Health and Social Care Trust and the University of Ulster. They are keen to produce more as the information provided as part of the project has been shown to have had a positive impact and has raised awareness of particular health issues.

Action is also being taken to raise awareness of the need to make information accessible amongst health care staff. For example,

- undergraduate nurses are provided with practical experience training involving service users
- the Bamford Review Action Plans have identified the need for specialist training for dental professionals

- the General Medical Council has provided an online communication training tool for doctors.
- the Pharmaceutical Society of Northern Ireland is involving service users in a review of its accredited training courses and in provision of interactive training to postgraduates.

Such training is obviously ongoing but is not mandatory for all health care staff. It was noted from the focus group sessions that training offered by one of the focus groups to their local Health and Social Trust ceased due to poor attendance by staff.

Discussions with focus groups do indicate a greater awareness amongst health care staff and willingness to communicate effectively with people with a learning disability. They reported that good communication assisted understanding, calmed anxious individuals down, raised self confidence, and in some instances enabled independence.

Some participants who had attended hospital reported being “treated with respect” and thought that hospital staff had been advised of their specific communication needs. In most cases the participants were more confident that the health care professional will adjust their communication style and speak directly to them.

Some participants did report experiences of poor verbal communication in various health care settings. In such instances health care professionals failed to adjust their communication style and to address the individual. It was noted that time constraints in particular remain a barrier to effective communication, particularly in the GP surgery.

Those who had poor experiences reported a lack of understanding, feeling ignored or unimportant, and confusion or raised anxiety about their health issue.

Conclusion

Health service policy aims of inclusion and access to mainstream services must be supported by good and effective communication provision strategies if they are to be successful. People with a learning disability have the right to receive health information in a format they are able to understand.

The commitments made by the Department and the Northern Ireland Executive through the Bamford Review Action Plans to improve equality of access to health care also address the issue of making health information accessible through a number of measures.

The provision of training for health care staff in meeting the specific communication needs of people with a learning disability is ongoing and includes undergraduate and post graduate training. Although the main focus at present for such training includes the nursing and dental professions there is scope for it to be spread further across other health care professions. The value of involving people with learning disability in the development and delivery of training has been recognised.

The reported experiences of focus group participants do seem to indicate that the steps taken to date to raise awareness amongst health care staff of the need to adjust verbal communication styles, and the willingness of health care staff to do so, has had some impact. This is encouraging and reinforces the Commission's view that such training should be mandatory.

Liaison between health services also appears to be improving through the Direct Enhanced Services, through the Communication Folders and the Passport Systems which assist various services prepare to meet individual communication needs.

Within hospital settings the GAIN Guidelines aim to ensure that health information is accessible and that verbal and non verbal communication needs are met. Concerns have been raised about practical application of the Guidelines and the planned review of the Guidelines will provide an indication of the effectiveness of the Guidelines in practice. The formal investigation had recommended that hospitals have a Patient Liaison

nurse. A review of the role of a specific liaison person within hospital settings, as set out in the Guidelines, will therefore be of particular interest.

This review has found that barriers to effective communication remain but that they are much more evident when there are time constraints, particularly at GP surgeries. It therefore remains an investigation recommendation that where possible, people with a learning disability should be allocated longer appointment times as a reasonable adjustment at GP surgeries. Anxiety remained a barrier to good communication for some participants but where this was caused by long waiting times they suggested that their anxiety could be reduced if they were advised of delays on arrival at surgery.

It is also encouraging that steps are being taken to standardise the approach to making information accessible across the health services, at an organisational level and at local HSC Trust level. Individual HSC Trusts are developing an online resource of accessible information which has the potential to improve access to health information for people with a learning disability. It is important that this resource is widely publicised, that best practice and generic information is shared across the Trust areas. Such a resource, if it includes information about healthy choices, health issues and health services could be invaluable to service users and health care staff alike.

There has been much activity by health services in the 5 years since the formal investigation which has provided the foundation for improving the accessibility of health information for people with a learning disability. It will take further time for the overall benefits of policies and strategies to be seen. Progress is being monitored through the Bamford Review Action Plans, through the Learning Disability Services Framework and through the review of strategies such as the GAIN Guidelines. Systems have been set up to ensure that people with a learning disability have the opportunity to voice their opinion about the services provided. It remains important that health information is accessible and it is encouraging that the health service has committed through a number of measurable strategies to do this.

Appendix

Summary of formal investigation recommendations

The 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 to all. It was recognised that some individuals are likely to continue to rely on others for support when communicating; however, the Commission believed that making 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 it was recommended:

- Establishing robust medical records about people with a learning disability on General Practice register Health Records.
- Improving collaboration between General Practices and Local Community Learning Disability Team to facilitate better access for people with a learning disability within primary care settings.
- 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.

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)