



**Response to the consultation by the Department of Health,
Social Services and Public Safety on the 'Modernising
Learning Disabilities Nursing Review Strengthening the
Commitment Northern Ireland Action Plan'**

December 2013.

1. The Equality Commission for Northern Ireland¹ (the Commission), welcomes the opportunity to respond to the consultation by the Department of Health, Social Services and Public Safety (the Department) on the 'Modernising Learning Disabilities Nursing Review Strengthening the Commitment Northern Ireland Action Plan September 2013'.

General Comments and Observations

2. The Commission welcomes the general commitments within the Action Plan to deliver learning disability nursing services for people with learning disabilities of all ages.
3. In particular, the Commission notes that 'Strengthening the Commitment: The Report of the UK Modernising Learning Disabilities Nursing Review' (the Report) which is the basis for this Action Plan reflects the input of the UK Modernising Learning Disabilities Nursing Review Co-production Steering Group which includes representation from people with learning disabilities, people with autism, family, carers as well as nurses who have experience working with people with learning disabilities.
4. We support the service users (including people with learning disabilities) aspiration to be meaningfully involved throughout the whole process of taking forward the recommendations from this report for the development of action plans throughout all of the

¹ The role and functions of the Equality Commission are set out in Annex 1 of this paper.

regions in the UK. Furthermore, the Commission endorses the broad aim set out in the report that people with learning disabilities of all ages have access to nursing services they need.

5. It is important that the Action Plan for Northern Ireland reflects the policy shift outlined in the Report which identifies a number of key aims to develop service modernisation initiatives across all the UK regions, specifically:
 - to promote independence, social inclusion and citizenship for people with learning disabilities;
 - to develop a service ideology which reflects the social model interpretation of disability;
 - to ensure equitable access to healthcare for people with learning disabilities, their families and carers².
6. The above aims correspond well with a number of articles within the UN Convention on the Rights of Persons with Disabilities (CRPD) as well as the Disability Discrimination Act 1995 (as amended), in particular the public sector disability equality duty to encourage participation of disabled people in public life and to promote positive attitudes towards disabled people.
7. Furthermore, actions to deliver all of the above aims will promote equality of opportunity for people with learning disabilities and consideration of their multiple identities including as women, members of ethnic minorities and as younger and older people in line with the Department's Section 74 obligations³.

Specific Comments on the Action Plan

Participation and Involvement

8. The commitment to establish a Northern Ireland Collaborative by December 2013 to support the delivery of actions to include representation from service users is welcome.
9. The Report of the UK Modernising Learning Disabilities Nursing Review clearly identifies service users represented in the UK

² The Scottish Government (April 2012): 'Strengthening the Commitment: The Report of the UK Modernising Learning Disabilities Nursing Review', opening paragraph, page 7. Available at: <http://www.scotland.gov.uk/Publications/2012/04/6465>

³ Equality Commission for Northern Ireland (April 2010): 'Section 75 Guide for Public Authorities'. Available at: <http://www.equalityni.org/archive/pdf/S75GuideforPublicAuthoritiesApril2010.pdf>

Modernising Learning Disabilities Nursing Review Co-production Steering Group as people with learning disabilities, people with Autism, their families and carers. The Department's Action Plan should make clear that people with learning disabilities will be represented in the NI Collaborative in line with the commitment in the Report.

10. The Department has an opportunity in the context of the Action Plan to identify and quantify the number of public life opportunities for people with learning disabilities (and those with multiple disabilities such sensory, physical, mental health issues and hidden disabilities) which will be created as a result of the development of the Northern Ireland Collaborative. Such actions will provide evidence of promoting positive attitudes towards disabled people and encouraging their participation in public life in accordance with the Department's obligations under the Disability Duties⁴.
11. The direct involvement and participation of disabled people in the monitoring and delivery of this Action Plan also meets the requirements of a number of articles within the United Nations Convention on the Rights of Persons with Disabilities (CRPD)⁵. The CRPD is clear that disabled people's voices and experiences, reflecting the aspirations of the individual disabled person and the collective experience of disabled people, are an essential element necessary to inform effective implementation.
12. The first principle set out in **Article 3, General Principles, 3(a)** of the CRPD requires consideration of the need for respect for inherent dignity, individual autonomy, including the freedom to make one's own choices and the independence to enable that choice to be made. Further, **Article 3(c)** calls for the full and effective participation and inclusion in society of disabled people.
13. In terms of understanding the collective experience of disabled people and their situation, **Article 4(3) General Obligations** of the CRPD requires public authorities to **closely consult and actively**

⁴ Equality Commission for Northern Ireland (March 2007): A Guide for Public Authorities – 'promoting positive attitudes towards disabled people and encouraging their participation in public life.' Available at: <http://www.equalityni.org/archive/pdf/ECNIDisPlan.pdf>

⁵ For further information on the UN Convention see: <http://www.equalityni.org/archive/pdf/UNCRPDOptionalProtocolPE.pdf>

involve disabled people, including disabled children⁶ through their representative organisations in the development and implementation of legislation and policies to implement the CPRD and in decision making processes related to them. Furthermore, the CPRD requires that civil society and **disabled people in particular, are involved and participate fully in the monitoring processes (Article 33(3) National implementation and monitoring).**

14. The Department should also consider what further actions are needed to involve disabled people at a local level, including the identification of service user groups already established by the five Health and Social Care Trusts and independent service user forums established within the disability community and voluntary sector.

Strengthening the Profession – Research and Evidence

15. The Commission welcomes the proposed action to identify and implement methods whereby learning disability nurses will have the opportunity to receive and learn from service user feedback in order to improve and develop practice.
16. The above measure reflects the Commission's recommendations following a formal investigation into the accessibility of health information for people with a learning disability⁷ which concluded that people with learning disabilities faced a number of barriers when accessing the health service including 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 and lack of relevant written information provided in an accessible format⁸.

Strengthening Capability – Training and Awareness

17. The investigation recommended that the health service involves service users in the development of accessible written information

⁶ Equality Commission for Northern Ireland (2008): 'Let's talk, Let's Listen – Guidance for Public Authorities on Consulting and Involving Children and Young People' is available at: [http://www.equalityni.org/archive/LetsTalkLetsListen\(Final\).pdf](http://www.equalityni.org/archive/LetsTalkLetsListen(Final).pdf)

⁷ Equality Commission for Northern Ireland (June 2008): 'Formal Investigation the Accessibility of Health Information in Northern Ireland for People with a Learning Disability'. Available at: [www.equalityni.org/archive/tempdocs/LiteratureRev\(F\)I.doc](http://www.equalityni.org/archive/tempdocs/LiteratureRev(F)I.doc)

⁸ Ibid. See findings at pages 7, 8 and 9.

and also in the provision of awareness training for health care professionals⁹.

18. Over half [57%] of the members of the focus groups participating in our recent review of the 2008 investigation¹⁰ had some involvement with their local Health and Social Care Trust, either with regard to written information or with communication training.
19. This involvement included:
 - communication training for health care staff and health care undergraduates;
 - assisting with the development of accessible written information;
 - participation in consultations and providing feedback about written health information.
20. However, while significant progress has been made against our recommendations the review concluded that, in some cases, there was not enough interest among Health and Social Care Trust Staff to continue the training. A number of focus groups who had been consulted by their local Trust would have liked to have heard further about what action was being taken to make services and information provision more accessible¹¹.
21. While the review acknowledges that undergraduate training for nurses has been developed to include practical training sessions with people with learning disabilities as evidenced by this Action Plan, it concluded that one of the key recommendations from the original investigation, that communication training be mandatory and even accredited, has not yet been addressed. The Commission urges that the Department take action to implement this recommendation.
22. The formal investigation also recommended that there should a Patient Liaison Nurse in each main hospital to prepare hospitals for the admission of people with a learning disability and to support

⁹ Ibid, see recommendations, pages 10, 11 and 12.

¹⁰ Equality Commission for Northern Ireland (June 2013): 'Review of the Formal Investigation into the Accessibility of Health Information for People with a Learning Disability in Northern Ireland'. Available at:
http://www.equalityni.org/archive/word/Disability_Investigation_paper_full_ross_harknessep13.docx

reasonable adjustments to be made. The review found that although the Patient Liaison Nurse role has been piloted, no such nurses had been recruited. The Commission recommends that the Department address this issue in the Action Plan.

23. Recent research examining the evidence relating to health inequalities experienced by people with learning disabilities noted that although the accessibility of written health information had improved, further progress was required with respect to the availability of 'easy read' formats and improved staff training¹².
24. The Department will be aware of the obligation of public authorities arising from the Disability Duties to provide awareness training for staff of disability issues as well as awareness of disability discrimination law¹³. The Department may wish to consider revising the plan to include provision for regular training to maintain knowledge of disability equality awareness and on-going changes to disability equality legislation.
25. The above-mentioned research also drew attention to the conclusions of a comprehensive review of UK and international evidence, 'Health Inequalities and People with Learning Disabilities', which concluded that existing patterns of care are insufficient, inequitable and likely to be in contravention of legal requirements under the Disability Discrimination Act and the CRPD¹⁴.

Other Information Sources

26. The Commission acknowledges the wide range of information and data sources used to inform the UK wide report which constitutes the basis for the current Action Plan as well as the link to other key policies such as the Bamford Review and Transforming Your Care. The Commission recommends that the Department consider a number of additional sources of information to shape and inform the development of the Action Plan including:

¹² Black, Dr Lesley-Ann (November 2013): 'Health inequalities and people with a learning disability', Northern Ireland Assembly Research and Information Service Research Paper 134/13, paragraph 2, page 15. Available at:

<http://www.niassembly.gov.uk/Documents/RalSe/Publications/2013/health/13413.pdf>

¹³ Equality Commission for Northern Ireland (March 2007): 'A Guide for Public Authorities – 'promoting positive attitudes towards disabled people and encouraging their participation in public life'', paragraphs 5.9 – 5.12, pages 52 and 53.

¹⁴ Ibid. The main findings of the research are summarised at paragraph 4 and subsequent bullet points at page 10.

- Good practice examples from the Commission's Disability Discrimination Act 1995 (DDA) Codes of Practice¹⁵;
- The guide to the disability duties¹⁶;
- Information obtained by the Department in the development of their disability action plans, Section 75 action plans and employment equality action plans;
- Evidence from people with learning disabilities obtained through previous and current public consultations, disability sector reference/ focus/steering groups such as the Bamford Monitoring Group; Patient client Council and local health trust user forums;
- Independent research and in-house research, for example in relation to previous work on audit of inequalities for Section 75 action plans and disability action plans;
- Training and educational materials which address the multiple identities of people with learning disabilities such as children, women, and ethnic minorities¹⁷.

Strengthening Quality – Quality improvement and outcomes

27. The Action Plan should identify more clearly how the actions within the Plan will be achieved, identifying appropriate structures and realistic measurable achievable outcomes. The Department should revise the Action Plan to set specific performance indicators against each of the actions. Performance indicators should ensure that action measures become less about 'outputs' and more 'outcome' focused. Further actions should be added to the plan identifying what monitoring arrangements are in place to assess progress and effectiveness of the delivery of the proposed actions.
28. With respect to the above point we note the commitment that the Northern Ireland Collaborative will link with the Regional Key Performance Indicators (KPIs) project to consider the introduction of relevant KPIs within settings where learning disability nurses work. If the KPI's have a direct relationship with the Action Plan it would

¹⁵All Codes of Practice related to DDA can be accessed via the Commission's website through the following link:

<http://www.equalityni.org/search/search.asp?cx=013850830204714881413%3A88nbkseifea&cof=FO RID%3A11 &ie=UTF-8&num=10&q=disability+codes+of+practice&sa=Search#1125>

¹⁶ The Commission's 'Guide to the Disability Duties' (2007) is available at:

<http://www.equalityni.org/archive/pdf/ECNIDisPlan.pdf>

¹⁷ Paragraph (p) of the Preamble to the CRPD highlights that disabled people are the subject of multiple or aggravated forms of discrimination on the basis of other status they may hold.

be beneficial for them to be included and referenced within the Plan to demonstrate clearly how actions are being taken forward.

29. Without the inclusion of KPIs it is difficult to determine whether the action measures within the Plan are appropriate and outcome focussed. The Commission is of the view that none of the action measures in the plan has appropriate outcome focused, quantifiable performance indicators or targets.
30. Research by the Northern Ireland Assembly Commission has highlighted that despite the development of two Bamford-related Action Plans and a Service Framework for Learning Disability, progress to reduce the health inequalities faced by people with a learning disability, whilst commendable, has been slow. The research concluded that the reason for the lack of progress was because it appeared that details of actions have been vague and targets have not always been met¹⁸.
31. The Bamford Action Plan 2009-12, included actions in response to our recommendations in the 'Formal Investigation into the Accessibility of Health Information for People with a Learning Disability in Northern Ireland'. The Bamford Action Plan 2012-2015 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 material¹⁹.

¹⁸ Black, Dr Lesley-Ann (November 2013): Op cit. Key Points, bullet point 8, page 3.

¹⁹ Equality Commission for Northern Ireland (June 2013). Op cit., first paragraph, page 16.

32. Progress against the Bamford Action Plan 2009-2011 was evaluated with regard to the outcomes of specific actions. Of the 67 learning disability actions contained in the Action Plan the evaluation concluded that 81% [54] had been achieved²⁰. Many of the actions relating to accessibility of information are “ongoing”²¹.

Allocation of Resources

33. The Bamford 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.

34. This Action Plan needs to be given a clear allocation of resources if the actions outlined are to be fulfilled within their stated time frame. We have noted that a number of the measures correspond well to our recommendations, for example with respect to service user involvement and training and awareness measures for learning disability nurses. However, without the allocation of appropriate resources there is a significant risk that outcomes will not be realised.

35. We hope that the Department considers the issues highlighted in this response, to ensure the actions committed to in the Plan deliver real outcomes for service users and provide support to learning disability nurses to deliver an effective service. In summary, the Commission recommends that the Department:

- clarifies that the principle of service user involvement within the NI Collaborative responsible for the delivery, implementation, monitoring and review of the plan will include representation from people with learning disabilities. This commitment would be line with UK wide actions already adopted in the UK wide Review Report;
- considers further actions to deliver training to nurses to promote further awareness of the issues facing people with learning disabilities, including provision of disability equality awareness training and awareness of disability equality legislation;

²⁰ DHSSPS (Dec 2011): ‘Evaluation of the Bamford Action Plan’, pages 19-20. Available at: www.dhsspsni.gov.uk/bamford-evaluation-action-plan2009-2011.pdf

²¹ Equality Commission for Northern Ireland (June 2013): Op.Cit. paragraph 2, page 5.

- considers further specific actions with respect to our recommendations to address the historical barriers facing people with learning disabilities in accessing health care services such as written materials in accessible formats, and the communication requirements of people with learning disabilities when interacting directly with nursing staff and health care professionals generally;
- considers revising the actions within the Plan to quantify more clearly specific outcomes including measurable, realistic, and achievable targets;
- clearly set out key performance indicators to demonstrate how actions within the plan will be progressed;
- demonstrates a clear commitment to the allocation of resources to deliver tangible outcomes.

Annex 1: The Equality Commission for Northern Ireland

1. The Equality Commission for Northern Ireland (the Commission) is an independent public body established under the Northern Ireland Act 1998. The Commission is responsible for implementing the legislation on fair employment, sex discrimination and equal pay, race relations, sexual orientation, disability and age.
2. The Commission's remit also includes overseeing the statutory duties on public authorities to promote equality of opportunity and good relations under Section 75 of the Northern Ireland Act 1998 (Section 75) and to promote positive attitudes towards disabled people and encourage participation by disabled people in public life under the Disability Discrimination Act 1995.
3. The Commission's general duties include:
 - working towards the elimination of discrimination;
 - promoting equality of opportunity and encouraging good practice;
 - promoting positive / affirmative action
 - promoting good relations between people of different racial groups;
 - overseeing the implementation and effectiveness of the statutory duty on relevant public authorities;
 - keeping the legislation under review;
 - promoting good relations between people of different religious belief and / or political opinion.

The Equality Commission, together with the Northern Ireland Human Rights Commission, has been designated under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as the Independent Mechanism tasked with promoting, protecting and monitoring implementation of CRPD in Northern Ireland.