

# **Presentation by Emeritus Professor Roy McConkey OBE, PhD., Ulster University, The Muckamore Abbey Hospital Inquiry, March 2023**

## **Overview of the presentation**

The points I will cover in my presentation are:

- In the interests of full disclosure to the Panel, I declare that during my career in learning disability, I have advocated the need for local, personalized, community-based supports and services that promote the quality of life of people with a learning disability (see Annex 1).
- The foundation for the Equal Lives Review goes back to the 1990s with accumulating evidence for the failings of hospital-based assessment and treatment services and the need for resettlement of long-stay patients.
- The Bamford Review was the most comprehensive analysis ever undertaken in Northern Ireland of present and future learning disability services across the life span. The review was arguably more participative of people with a learning disability and of their family carers than similar reviews undertaken in these islands. A remarkable consensus emerged across users and providers as to the necessary improvements to present provision.
- Specific recommendations were made about completing the resettlement process of long-stay residents and the provision of assessment and treatment facilities in community settings with the intention (albeit not made explicit) of closing learning disability hospitals.
- The implementation of the recommendations did not start until 2009 after the Northern Ireland Executive formally accepted the 'broad thrust' of the recommendations. The Department of Health on behalf of the Executive, led an inter-departmental process to prepare three-yearly action plans; initially 2009 to 2012 and 2012 to 2015. In the main these were aspirational and often covered actions that the Departments had already in hand. This process went into abeyance in 2016 with no further plans published.
- The initial plans made reference to the delays in completing resettlement with scant reference to relocating assessment and treatment services to community settings. A review in 2016 by RQIA of learning disability community services highlighted continued shortcomings in the provision of suitable accommodation and supports for people with challenging behaviour and/or mental health problems with variation in the models of provision across the five HSC Trusts.
- An independent review of the resettlement programme undertaken in 2021/22 noted that these shortcomings were still apparent and reaffirmed that DoH should develop a strategic policy for learning disability services. The HSCB/PHA had already undertaken a consultation with a wide range of stakeholders which led to the production of a 'We Matter: Learning Disability Service Model'. The final draft of a regional framework was formally presented to officials at the DoH in early October 2021, but to date this has not resulted in the issuing of the long awaited updated strategic framework.

## **Useful resources**

An overview of the Bamford Review is given here:

<https://www.health-ni.gov.uk/articles/bamford-review-mental-health-and-learning-disability>

The Equal Lives Report from the Bamford Review is available here:

<https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/Equal%20Lives%20Report.pdf>

Here is the link to the Action Plan for its implementation produced by the NI Executive for 2009 to 2011 (with a section devoted Learning Disability).

<http://www.niassembly.gov.uk/globalassets/documents/employment-and-learning/inquiries/post-sen/government--academic-papers/delivering-the-bamford-vision---action-plan-2009---2011.pdf>

A review by RQIA into community services for adults with a learning disability gives details of the models of care that are provided in Northern Ireland some 10 years after the publication of Equal Lives and their shortcomings.

<https://www.rqia.org.uk/RQIA/files/4a/4a883fbc-92a7-4fda-97b0-ac2e664e5d8d.pdf>

In October 2021 the Health and Social Care Board (HSCB) commissioned two experienced senior leaders in health and social care to undertake an independent review of the learning disability resettlement programme in Northern Ireland, with a particular focus on the resettlement from Muckamore Abbey. Their wide ranging report provides a historical overview of the process, comparisons with other jurisdictions in these islands as well making recommendations for service improvements, notably the need for a strategic framework. Their report was published in September 2022.

<https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-ind-review-ld-resttlement-july-2022.PDF>

## **The Origins of the Bamford Equal Lives Review**

The basis of the review has its origins at least a decade before its inception; most notably in the policy statement produced in 1996 by the Eastern Health and Social Services Board on a proposed Model for Community Based Services. A major focus was the resettlement of existing long-term residents from Muckamore Abbey Hospital but also addressing the delayed discharge of more recently admitted patients for 'assessment and treatment'. With a doctoral student (now Professor Laurence Taggart at Ulster University), I and the Hospital's medical director (Dr Caroline Marriott), co-directed a research project in which all admissions and discharges were recorded and analysed over a two-year period. Four findings stood out. First, there was a revolving door of the same people being re-admitted mainly from congregated living settings such as nursing or residential homes. Second many of the 'patients' had mild or borderline learning disabilities. Third, medication was by far the most commonly prescribed treatment provided. Fourth, there was little outreach or inreach between the Hospital and community services.

The EHSSB proposal included the development of small-scale housing units (group homes) and the formation of community teams who would support persons with challenging behaviours and/or mental health problems. However these proposals faced determined opposition from the consultant psychiatrists and Trust officials who seemed eager to preserve the status quo.

There were broader issues that our research from 1997 onwards had also identified. For example:

- Compared to other parts of these islands, NI has the highest proportion of people with a learning disability in receipt of services. Social deprivation may be a contributing factor.
- NI also has a growing population of people with a learning disability, because these individuals are living longer, and children are being born with more severe disabilities than would have been possible in the past, due to improvements in medical care.
- Investment in services, certainly in the recent past, has not kept pace with changing needs and aspirations of family carers and service users. Compared to Great Britain and the Republic of Ireland,

NI services were underfunded as they were reliant on funding from central government unlike GB where local authorities also have access to income from Council taxes.

- There is a marked shortage of supported accommodation for people who can no longer live with their families, with 50% fewer places available compared to the Republic of Ireland or GB. Moreover much of the current provision was modelled on nursing and residential homes for the elderly. It was provided mainly by the private sector with funding from social security payments which absolved health and social services from investing in other more personalized accommodation and support models.
- Family carers have had to continue caring long beyond what can be reasonably expected. More than one third of the carers in Northern Ireland were single-parent carers aged 65 years and over.

To my knowledge, the inclusion of learning disability into the Department's original intention to undertake a review of mental health in Northern Ireland was championed by a direct rule Minister, Des Browne MP, a former Scottish advocate who had worked mainly in children law. Previously the Department had completed an internal review of learning disability services (in 1995) which had been criticized mainly for its failure to produce an implementation plan for its recommendations which included the resettlement of patients from learning disability hospitals.

Concerns were expressed that the needs of persons with a learning disability would not be adequately addressed by a Mental Health Review as their needs were largely distinct from those of persons requiring or availing of mental health services. However these concerns were assuaged once the Review progressed.

Learning disability is a life-long condition and a range of services is required to meet the needs of persons as they move from early childhood through to old-age. There is not one model of a learning disability service as such but rather a variety of models that address the needs of persons at different ages, with differing levels of severity of their disability and the outcomes they seek to produce for the person in terms of health, education, employment, accommodation and social relationships.

### **The Bamford Review of Mental Health and Learning Disability**

The choice of David Bamford, Professor of Social Work at Ulster University was an inspired choice of chair. Professor Roy McClelland, a consultant psychiatrist was deputy chair who later became chair on David's untimely death, after whom the review was renamed. Its terms of reference were: "To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986" and "to make recommendations regarding future policy, strategy, service priorities and legislation, to reflect the needs of users and carers".

Much of the work of the Review was carried forward through 10 expert Working Committees reporting back to the Steering Committee on specific issues. These commenced in 2002 and 11 separate reports were completed by 2007. These were:

- A Strategic Framework for Adult Mental Health Services (June 2005)
- Equal Lives Learning Disability Report (September 2005).
- Alcohol and Substance Misuse Report (December 2005)
- Mental Health Promotion Report (May 2006)
- Autistic Spectrum Disorders (ASD) Report (May 2006)
- A Vision of a Comprehensive Child and Adolescent Mental Health Service (July 2006)
- Forensic Services Report (October 2006)
- Human Rights and Equality of Opportunity Report (October 2006)
- Living fuller lives: Dementia and Mental Health Issues in Older Age (June 2007)
- A Comprehensive Legal Framework for Mental Health and Learning Disability (August 2007)

- Promoting Social Inclusion (August 2007)

Given the Inquiry's focus on Muckamore Abbey Hospital and the limited time available for this presentation, I have chosen to focus on the Learning Disability Working Committee and their Equal Lives report in which I was directly involved.

### **The Equal Lives Review of Learning Disability Services**

David Bamford invited Siobhan Bogues (an experienced social worker but employed by ARC NI (an NGO), to lead the learning disability arm of the review. She was another inspired choice who assembled a range of professionals from different disciplines and service agencies to serve on the Learning Disability Working Group but also a person with a learning disability and two-family carers. In addition an advisory 'Equal Lives Group' was established of people with a learning disability who use services and also a Carer's Advisory group from across Northern Ireland (see pages 161 to 163 of the Equal Lives Report for their membership).

The review commenced in 2002 and details of how their evidence was assembled are given in pages 3 to 5 of the Report. This included the setting up of six Task Groups with various stakeholders to examine issues identified as being particularly significant in relation to improving the lives of people with a learning disability; taking account of existing models of service and identifying new models of service provision. The topics addressed were:

- Support for Children and Young People and Their Families
- Accommodation and Support
- Day Opportunities
- Ageing
- Mental Health
- Physical Health

In all, 12 public meetings were held for carers and service users across NI; a free phone line was established to provide an opportunity for people to share their views in a confidential manner and 12 conferences and seminars were held on particular issues attended by over 400 people so that new developments in services nationally and internationally could be presented and recommendations for local service models identified.

The Equal Lives Report was published in 2005; one of the first to be published from the Bamford Review. The report identified five key values to underpin service provision<sup>1</sup>, proposed 12 objectives for re-modelling supports and services to people with a learning disability and their family carers, and made 74 recommendations for actions needed to remodel and extend learning disability services across the life span from early childhood to old age.

David Bamford's preface to the report succinctly summarised its conclusion in terms of a new over-arching service model for learning disability services.

*The Equal Lives Review has concluded that progress needs to be accelerated on establishing a new service model, which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. The model of the future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else. (page ii).*

The report did not underestimate the challenges to be faced:

*... "there is a need for major co-ordinated developments in support and services and a continuing change in attitudes over at least the next 15 years". (page 6)*

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<sup>1</sup> The values were: Citizenship, Social Inclusion, Empowerment, Working Together, Individual support

## **Pertinent finding from the Equal Lives Review**

Again in the interests of time, I have chosen to highlight the recommendations that are especially pertinent for the Inquiry in two respects. First the need for new service models in relation to person-centred housing and support rather than in congregated and segregated provision which dominated in Northern Ireland at the time of the Review and to an extent still does<sup>2</sup>. Second, developing community-based assessment and treatment services rather than the over-reliance of hospital based provision that should also reduce the risk of delayed discharges which created 'new' long-stay residents for whom the hospital became their home.

With respect to resettlement, the recommendations for the new model of service were:

**Recommendation 27:** By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011.

**Recommendation 28:** With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability. Hospitals will not provide this service from 1st January 2008. (Page 65)

**Recommendation 29:** With immediate effect, all new housing with support provision for people with a learning disability should be for no more than 5 individuals with a learning disability - preferably less - within the same household.

**Recommendation 30:** By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than 5 people.

The model of service to replace hospital-based assessment and treatment services, such as those provided at Muckamore Abbey Hospital was described in two recommendations.

**Recommendation 46:** By the end of the Review period people with high levels of adaptive functioning/mild learning disability who require therapeutic intervention as a result of mental health problems should be able to access mainstream mental health services. Support from dedicated learning disability services should be available if required.

**Recommendation 47:** "Community based assessment and treatment services should be developed on an incremental basis to provide assessment and treatment of men and women with a learning disability who have specific mental health needs and/or challenging behaviours. The community-based assessment and treatment services will encompass behaviour support expertise that will provide outreach to individuals, families and community services and short-term intensive treatment to those within a residential facility which may be approved to treat people under mental health legislation" (p.82)

These recommendations were informed by international best practice and mirror the arrangements that were already being implemented in Great Britain. The heightened risk of abuse of residents in congregated settings was well established from the scandals that hastened the closure of long stay hospitals in England and Wales.

In addition, the review was mindful of the need to effect change in service systems across the region as well as at a local level and devoted a chapter (#12) with recommendations as to how this might be done.

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<sup>2</sup> In 2021, there were 21 specialist LD nursing homes in NI offering a total of 606 places; there were a total of 48 residential care homes (15 statutory and 33 independent) offering a total of 546 places (123 statutory residential care places and 423 independent residential care places); and there are 149 accommodation based supported living schemes for people with learning disabilities offering a total of 1334 places across Northern Ireland by both statutory and non-statutory providers.

## **Changes to learning disability services during the Equal Lives Review**

The Equal Lives Review affirmed the new models of services that service providers – especially those in the voluntary (not-for-profit) sector, Housing Associations and certain HSC Trusts – had instigated and continued to develop during and beyond the Review period.

However one significant development was contrary to the Equal Lives vision and recommendations. During the Review, the Eastern Health and Social Services Board and the Western Health and Social Services outlined their intentions to rebuild and extend the assessment and treatment facilities at Muckamore Abbey Hospital and at Gransha Hospital in Derry. Despite the strong reservations expressed by the Review members and their subsequent recommendations, these capital improvements went ahead with strong support from the medical profession, HSC Trusts and the HSC Boards with funding provided by the Department. One consequence was to divert revenue funding from community services and increased the propensity for delayed discharges which did indeed happen.

## **The follow on to the Equal Lives Report**

There was no immediate follow on the Equal Lives Report. The other reports that related chiefly to the mental health aspects of the review were not completed until 2007. With the return of devolved government, the response came from the Northern Ireland Executive who formally “accepted the broad thrust of the Review’s recommendations” and issued a response - *Delivering the Bamford Vision* – for public consultation. This led to the publication by the Executive in October 2009 of the Bamford Action Plan 2009 –2011. (This was four years after the Equal Lives Review was submitted in 2005).

The first Action Plan devoted a section to Learning Disability and consisted of 46 pages. Among the actions proposed was a 25% reduction in the number of long-stay patients in learning disability hospitals (baseline 2007/08); by 2013 anyone who has a learning disability is promptly and suitably treated in the community and no-one remains unnecessarily in hospital, and by March 2011, to develop a plan for a community LD Forensic Service. A review of progress in 2015 identified that these targets were not met.

The second action plan (2012 to 2015) was much shorter and included only two pages specific to learning disability. However it noted that there were around 200 long stay patients in learning disability hospitals who no longer require hospital treatment and who could be resettled into the community. The intention in the coming three years was to seek alternative care arrangements for as many of these people as possible to achieve the long-term objective of completing the resettlement programme by 2015. This did not happen.

On 15 February 2016, the Department of Health, Social Services and Public Safety (DHSSPS) launched an evaluation of the Bamford Action Plan 2012-2015 to determine “what impact these actions have made on the lives of people with mental health problems or a learning disability”. A report on the consultation has yet to be disseminated and no further Action Plans for the implementation of recommendations from the Bamford Review have been published by the Department.

## **Service Frameworks**

More broadly, in this period the Department of Health had embarked on a programme of developing Safety and Quality Standards service frameworks as part of a standards driven system for improving health and social care planning, commissioning and delivery<sup>3</sup>. Initially the service frameworks covered cardiovascular health, respiratory health and cancer prevention, treatment and care but learning disability and mental health standards were later developed from 2013 onwards and the Learning Disability Framework was published in 2015.

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<sup>3</sup> <https://www.health-ni.gov.uk/topics/safety-and-quality-standards/safety-and-quality-standards-service-frameworks>

The common aim was to ensure that health and social care services are 1) Safe - minimises risk and harm to service users and staff; 2) Effective –informed by an evidence base; commissioned and delivered in an efficient manner; accessible and equitable and 3) Person centred –gives due regard to the preferences and aspirations of those who use services, their family and carers and respects the culture of their communities. The HSC Board and the PHA were jointly responsible for the implementation and monitoring of the service frameworks.

The Standards largely translated recommendations from Equal Lives into statements describing the model of service that users could expect to receive along with performance indicators for each standard. These covered the life span of users and the differing services they may require. Two standards related to accommodation and assessment and treatment services.

**Standard 26:** All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services, as appropriate, based on assessed need. (A Performance Indicator was: Percentage of people labelled as challenging who are not living in a congregate setting described as a challenging behaviour or specialist assessment/treatment service.)

**Standard 28:** HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed. (Performance indicators included: Percentage of people in receipt of public funding living in households of 5 people or less with a learning disability. Percentage of people leaving learning disability hospital within one week after treatment has been completed.)

The Department’s website contains no recent reports on the implementation of the Standards nor are any details available on the key performance indicators associated with them. It is unclear the extent of funding was made available to encourage the implementation of the Standards or of the capacity of HSC Board (now defunct) and the PHA to undertake their monitoring role of the Standards overall and in learning disability in particular.

### **Further reviews of progress**

In 2016 the RQIA undertook a review of the community services for people with a learning disability across the five HSC Trusts. Some improvements were commended in relation to models of service to support adult persons in other aspects of their lives such as employment. However, the RQIA review identified continuing shortcomings. They noted: “it is unlikely that the target of all long stay patients being resettled in the community will be achieved by June 2017; the admission of people with a mild learning disability to mainstream mental health services remains very low; the behaviour support teams set up by the five Trusts did not provide an evidence base for the different models of service configuration they have put in place and four Trusts could not provide evidence for the effectiveness and outcomes of their challenging behaviour support services”.

In October 2021 the Health and Social Care Board (HSCB) commissioned two experienced senior leaders in health and social care to undertake an independent review of the learning disability resettlement programme in Northern Ireland, with a particular focus on the resettlement from Muckamore Abbey Hospital which the Equal Lives review has proposed should be completed by 2011 but was still incomplete ten years later. They concluded that “the HSC Board was not good enough in terms of performance management of the resettlement programme which amounted to little more than performance monitoring”. Moreover they considered that the current plans of the Belfast HSC Trusts “failed to progress beyond the preliminary stages. The lack of either effective programme or project management meant there was no over-arching, costed plan”.

The HSCB/PHA had also commissioned a consultation with a wide range of stakeholders which led to the production of ‘We Matter: Learning Disability Service Model’. The aim was provide the framework for a

regionally consistent, whole system approach to Learning Disability Services in Northern Ireland “to ensure that adults with a learning disability in Northern Ireland receive the right care, at the right time in the right place ... along with a costed implementation plan” The final draft was formally presented to officials at the Department of Health in early October 2021, but to date this has not resulted in the issuing of the long awaited, updated strategic framework.

## **Conclusions**

The Equal Lives Learning Disability Review was a model of co-production with all the major stakeholders participating. In particular the views of persons with learning disability were obtained to an extent that had never been done before in Northern Ireland but which subsequently has increasingly become common practice.

The report outlined a range of service models that addressed the needs and aspirations of children, youth, adults and older persons with a learning disability and which drew on international best practice. In particular individualized, small scale accommodation housing and support options would replace the congregated models commonly used in Northern Ireland with no one living in hospital settings. Moreover community-based assessment and treatment services delivered by multi-disciplinary teams would reduce the need for admissions to learning disability hospitals such as Muckamore Abbey Hospital.

The implementation of the recommendations did result in the development of new models of provision although these were not uniformly implemented by HSC Trusts nor did they lead to the required transformation in longer-established services. The reasons for the failures of implementation remain speculative but the risk is that they will be repeated unless lessons are learnt.



## **Annex 1**

### **Roy McConkey**

After graduating with a Bachelor's degree in psychology at Queen's University Belfast in 1970, I undertook Doctoral studies at the newly opened, Hester Adrian Research Centre at the University of Manchester devoted to psychological and social research into 'mental handicap'. From 1973, I co-led a four-year, Department of Health funded project that aimed to promote parental involvement in their child's preschool development. In 1977 I took up a research position with St Michaels' House, Dublin a large voluntary organisation providing services across the city to children and adults with learning disability. In 1988 I moved to the Scottish Borders to a similar position with the Brothers of Charity but with a focus solely on adult persons. There I was involved in the resettlement of residents from long-stay institutions. I returned to Northern Ireland in 1997, to take up a joint appointment between Ulster University and the then, Eastern Health and Social Services Board with a focus on developing a community-based model for services for people with a learning Disability. Hence my professional career has been rooted in service improvement and innovations. During this time, I had also undertaken similar consultancies with various UN agencies such as UNESCO, UNICEF and WHO as well as for International NGOs such as Leonard Cheshire International and Special Olympics.

I was a member of the Equal Lives Working Group for the Bamford Review and two of its sub-committees. With colleagues at the University we completed a scoping review of the international literature for the Equal Lives Working Group. In addition we had published a series of studies undertaken in Northern Ireland that were cited in the Equal Lives Report.

At the invitation of the Minister for Health, I was subsequently a member of the 'Board of Experts for Mental Health and Learning Disability' from 2007 to 2009 to advise on the implementation of the Bamford Review. I also served on the Project Team appointed by the Department of Health to produce the Service Framework for Learning Disability. I was an independent reviewer to the RQIA review of community services to adults with a learning disability in 2016.