

The future of learning disabilities nursing in the UK

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Abstract

This article appraises the report *Strengthening the Commitment*, which is a UK-wide review of learning disabilities nursing by the UK's four chief nursing officers. *Strengthening the Commitment* has strategic importance in reviewing progress in the care of people with learning disabilities in the UK. It also has a role in helping to guide future strategies and initiatives addressing the continuing health inequalities experienced by people with learning disabilities throughout the UK.

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THE RELATIONSHIP BETWEEN the UK's learning-disabled population and society has not always been positive. There have been numerous reports of abuse, neglect and cruelty, while periods of officially encouraged segregation remain within the living memory of many people with learning disabilities in the UK (Atherton 2006, Mencap 2007, Department of Health (DH) 2008).

Over the past 40 years policymakers have reformed the way in which services for people with learning disabilities are structured, provided and resourced in the UK, as awareness of the needs and histories of the learning-disabled population has grown. These reforms have been underpinned by legislative documents and policy statements such as *Valuing People: A New Strategy for Learning Disability for the 21st Century* (DH 2001), *Promoting Health, Supporting Inclusion* (Scottish Executive 2002) and *Government Response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities* (DH 2013).

Despite these policy initiatives, the care of people with learning disabilities has been dogged by reports of continuing neglect, abuse and failure to provide genuine equity of care to a vulnerable and often marginalised cohort (Royal College of Nursing (RCN) 2011, DH 2012, Heslop *et al* 2013) with the shocking abuse that was uncovered at Winterbourne View in 2011 (DH 2012), and its consequences on care-delivery, still at the forefront of the nation's memory. As part of the debate on the future resourcing needs of the nursing profession in the UK, the aim of this article is to appraise the report *Strengthening the Commitment* (Scottish Government 2012), a UK-wide review of learning disabilities nursing by the four chief nursing officers. The stated aim of the report is: 'to set the direction of travel for learning disabilities nursing to ensure we can meet current and future demand ... to ensure... the best experience of support and care for people with learning disabilities, their families and carers' (Scottish Government 2012).

The author has chosen to appraise the report because of its strategic importance in improving the care of the growing number of people with learning

disabilities in the UK (Emerson and Hatton 2008), and its high profile role in helping guide future strategies and initiatives addressing the health inequalities that many still experience.

Summary of the report

The report *Strengthening the Commitment* (Scottish Government 2012) identifies that the number of people with learning disabilities within the UK is expected to rise in proportion to the overall population, as a result of improvements in survival rates among premature babies – who are more likely to have a learning disability – and longer life expectancies for people with learning disabilities (Emerson and Hatton 2008). It also identified that, although the numbers of learning disabilities nurses in proportion to the total number of nurses on the Nursing and Midwifery Council (NMC) register are similar throughout the UK (Scotland 2.9%, England 3.3%, Northern Ireland 3.2% and Wales 3.1%) (Scottish Government 2012), the actual numbers of learning disabilities nurses have declined steadily. This trend must be reversed if the specialist knowledge base required for the provision of high quality services for people with learning disabilities is to be maintained and improved (Scottish Government 2012).

The report highlights four key areas in which learning disabilities nursing would benefit from greater scrutiny and input of resources at strategic level, to ensure that the specialism is equipped to meet the present and future needs of people with learning disabilities throughout the UK. These areas are summarised as (Scottish Government 2012):

- ▶ Capacity – assessing the contexts in which learning disabilities nurses are working, and the needs they are addressing, to identify any additional resources they may require.
- ▶ Capability – identifying changes in the skills, knowledge base and competencies of those working within the field of learning disabilities, ensuring that they are trained effectively to meet the changing healthcare needs of the learning-disabled population.
- ▶ Quality – ensuring that systems, policies, structures of training and service provision, and the learning disabilities nursing profession as a whole, are fit for purpose.
- ▶ Leadership – ensuring that strong, effective leadership at all levels of learning disabilities nursing is in place to meet the commitment to strengthening the care of the learning-disabled population.

The report includes 17 recommendations for action (Scottish Government 2012) that, its authors believe, are integral to the successful

realisation of the report's objectives. However, to assess these target areas and recommendations appropriately, it is necessary to understand some of the history relating to the UK's learning-disabled population, the people who care for them and the policies that have shaped services.

Background to the report

At the beginning of the 20th century, the Idiots Act 1886 still applied to the needs and care of people with signs of mental deficiency, without distinguishing between those with mental illness and those we would now call learning-disabled. These people were often found in workhouses, prisons and specialised asylums, with care often being provided by social networks, families or religious organisations (Atherton 2006).

The Mental Deficiency Act 1913 introduced a distinction between those with mental illness and those with learning disabilities. It legalised the detention of people with signs of 'mental defect', explicitly including unmarried mothers in receipt of poor-relief, citing four different categories:

- ▶ 'Idiot' – unable to guard themselves against common physical dangers such as fire, water or traffic.
- ▶ 'Imbecile' – could guard against physical dangers but were incapable of managing themselves or their affairs.
- ▶ 'Feeble-minded persons' – needing care or control for protection of self or others.
- ▶ 'Moral imbeciles' – people who, from an early age, displayed 'some permanent mental defect coupled with strong vicious or criminal propensities on which punishment had little or no effect'.

The General Nursing Council subsequently incorporated dedicated sections within the nursing register for those providing care to people with learning disabilities as well as for those who were mentally ill (Mitchell 2003a).

In the early 1900s, Francis Galton's (1883) notion of improving human qualities through selective breeding (eugenics) was influencing policymakers towards segregating and inhibiting procreation among those considered to be 'socially deviant' (Atherton 2003). While other countries were more active in their interventions, the UK followed the recommendation of the *Report of the Mental Deficiency Committee* (Wood 1929) that people with learning disabilities be accommodated in self-sufficient 'colonies' (Atherton 2006). Consequently, the policy of isolating people with 'mental deficiency' was accelerated and 100,000 people were institutionalised in 'collectives'.

Local authorities were given statutory responsibility for providing 'occupation and training' for people in their care, which included contributing to the material upkeep and maintenance of these institutions – a practice that would be considered exploitative according to today's standards. Following the end of the second world war, and the introduction of the NHS in 1947, responsibility for these institutions passed to the NHS (Atherton 2006), with dedicated nursing staff.

The introduction of the European Convention on Human Rights in 1950 and the Mental Health Act 1959 was followed by a number of disturbing reports of poor – even squalid – conditions of care in some of these institutions, for example, the *Report of the Committee of Inquiry into Allegations of Ill-treatment of Patients and Other Irregularities at the Ely Hospital, Cardiff* (DH 1969). Following this, the 1971 white paper *Better Services for the Mentally Handicapped* (Department of Health and Social Security (DHSS) and Welsh Office 1971) recommended that half of those detained within institutions should be re-homed in the community within the following 20 years, and that there should be a greater proportion of local authority residential and day care facilities (Hemming 1982, Atherton 2006).

The *Report of the Committee of Enquiry into Mental Handicap Nursing and Care* (Jay Committee 1979) and *Community Care: Agenda for Action* (Griffiths 1988) continued to highlight abuses in care and to apply pressure on the way in which services for people with learning disabilities were structured and delivered. These reports resulted in the white paper *Caring for People: Community Care in the Next Decade and Beyond* (DH 1989) and the NHS and Community Care Act 1990, in which the dominant role of the nursing and medical professions was replaced by a new social care system based on the notion of 'normalisation' (Barr 1999, Mitchell 2003a, 2003b, Malin and Race 2010), with the intention of providing people with support structures that would enable them, as far as possible, to remain in their own homes (Atherton 2006).

Normalisation was originally defined as: 'making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society' (Nirje 1969). This Scandinavian social care concept sought to challenge the medical model of thinking, with its assumption that people with learning disabilities were, in some way, ill, deficient or lacking, and to encourage society to 'normalise' their differences and treat the learning-disabled population as fellow citizens within society (Culham and Nind 2003).

The term normalisation fell out of favour in the 1980s, owing to a significant misunderstanding of its aim: 'Probably the most common misinterpretation of the normalisation principle is the mistaken belief that it means mentally handicapped people must be expected to, indeed be forced to, act "normal"' (Perrin and Nirje 1985). It was redefined in Europe as 'social role valorisation' (Wolfensberger 1998). In the UK it is perhaps better understood as the social model of disability, and includes strategies used to identify, establish and maintain valued social roles for people, such as those with learning disabilities, whom society often appeared to devalue (Wolfensberger 1998). In its new form, it has underpinned many of the social care structures that remain in the UK, in common with much of Europe and further afield, for people with learning disabilities (Culham and Nind 2003, Scottish Government 2012).

Within the UK, the principles underpinning normalisation are probably best associated with the Five Service Accomplishments (FSAs) outlined in the seminal work of O'Brien and Tyne (1981). These are:

- ▶ Community presence.
- ▶ Competence.
- ▶ Respect.
- ▶ Community participation.
- ▶ Choice.

Through the application of the FSAs, steady progress was made in reforming care of the learning-disabled population in the UK. By the 1990s, many people had been discharged from long-stay institutions successfully and were living independently or in supported accommodation in their local communities. On April 30 2009, the last NHS long-stay hospital for people with learning disabilities closed (DH 2001, Culham and Nind 2003, Mencap 2009). However, the FSAs appear to have had two significant unintended effects, for people with learning disabilities and for their specialist healthcare workers.

First, normalisation's assumption that all members of society will enjoy 'equality' of access to mainstream healthcare services presupposes the ability or insight of the individual to identify his or her need to access a healthcare professional regarding a problem or concern, and the ability or confidence to then seek appropriate help or advice (Barr 1999). There is a compelling evidence base supporting the view that such assumptions are unsound, that people with learning disabilities are disadvantaged significantly in this regard (Clark and While 2008, Atkinson *et al* 2013), and that effective healthcare provision should be based on the notion of 'equity', as opposed to 'equality', of access, where those with greater difficulty in

accessing healthcare are given greater assistance to achieve parity of access (DH 2001, Braveman and Gruskin 2003, World Health Organization 2013). Current healthcare policy throughout the UK aims to ensure that people with learning disabilities can access mainstream healthcare provision equipped to meet their needs. However, this can be achieved only with the intervention and support of specialist learning disability health services. Indeed, the Health Equalities Framework (HEF) has been introduced as an outcomes-based tool to aid improvements in healthcare outcomes not only for the learning-disabled population but also for other cohorts in UK society (Atkinson *et al* 2013).

Second, the Jay Committee's (1979) recommendations, following the *Report of the Committee on Nursing* (DHSS 1972), set in motion a policy shift that resulted in resources for people with learning disabilities focusing more on education, and specialist healthcare resources being reduced in favour of generic mainstream health services (DH 2001, Malin and Race 2010). The gradual closure of long-stay institutions, with their association with the medical model of disability, and the dissipation of the specialist knowledge they garnered, amounted to a drive towards normalisation that led to a loss of nursing and medical expertise in caring for this vulnerable group. It also created new challenges – both in identities and in roles for those working with people with learning disabilities (Mitchell 2003b, Clark 2006, Turnbull 2007) – and in the effective provision of care for the learning-disabled population (Chaplin and Flynn 2000, Mencap 2007, Gaskell and Nightingale 2010).

The *Report of the Committee on Nursing* (DHSS 1972) and *Report of the Committee of Enquiry into Mental Handicap Nursing and Care* (Jay Committee 1979) also made the contentious recommendation that nurses working within the field of learning disabilities should be registered through social services instead of the nursing register, with training based on the Certificate in Social Services as approved by the Central Council for Education and Training in Social Work. Although the recommendation was rejected, it has nevertheless received exposure in subsequent decades whenever poor quality care of people with learning disabilities has come to light. The enduring debate concerning the manner in which learning disabilities nursing relates to the wider healthcare field, and to nursing itself (Shaw 2000, Mitchell 2003a, Vere-Jones 2007, Scottish Government 2012, Smith 2013), has resulted in numerous responses from leading learning disabilities nurses. These responses have refuted the notion that the learning disabilities nursing

specialism is no longer necessary, and attempted to define the specialism's ongoing role throughout the UK within an evolving healthcare environment (Turnbull 2007, Rich 2011, RCN 2011, Scottish Government 2012, Marsden 2013).

It is also worth noting the gradual shift in recent times towards joint working between health and social care in the UK, which has seen changes in the way services for vulnerable groups – including those with learning disabilities – are structured and provided. The exact manner and form of this shift is still being determined. However, there is greater emphasis on joint working between health and social care professionals, not only within learning disabilities nursing but also across the wider spectrum of medicine and nursing, and this has resulted in a greater mixing of ideas, roles and perspectives within the two models of care (DH 2006, Samuel 2011, Scottish Government 2011, Health and Social Care Board 2014).

Evidence underpinning the report

As a policy-influencing document, *Strengthening the Commitment* (Scottish Government 2012) has a duty to use the best available evidence to provide a solid foundation for its statements and to inform its recommendations. Indeed, its authors affirm that 'there is still scope to further develop robust evidence' (Scottish Government 2012).

The evidence base informing learning disabilities nursing care has been, and continues to be, limited in its scope and depth (Northway and Jenkins 2003, Thomas 2013). The reasons for this are varied, and linked in part to the entirely appropriate safeguards in place to protect the interests of those unable to give informed consent to participate in research projects. However, another challenge is that of finding new ways of gathering and analysing sufficient appropriate and meaningful data from the learning-disabled population in the UK. This population is a small and disparate group with diverse conditions and healthcare needs, and hence it is difficult, for example, to ensure sample sizes are large enough to achieve statistical significance in groups of people with specific conditions or healthcare needs.

Indeed, greater use could have been made of the existing evidence-base in supporting the valid points being made in *Strengthening the Commitment* (Scottish Government 2012). Furthermore, the reference list is too small, given the importance of the points being made, and many of those points were made without providing supporting references in the text to substantiate or explain their

background or context. However, despite this deficit there is no doubt that the existing evidence base for the needs of people with learning disabilities and the role played by specialist nurses provide a robust foundation on which *Strengthening the Commitment* was based. The report presents compelling and insightful case studies of examples of best practice, of innovative and life-enhancing strategies, and of the many ways in which learning disabilities nurses make significant differences to the lives of patients, families and carers (Scottish Government 2012). The report makes it clear that it is not intended to be a 'top-down' pronouncement but rather a roadmap of the way forward that highlights, through example and encouragement, the excellent and groundbreaking work already being done by learning disabilities nurses. This recognition is, in itself, reflected in the fact that almost half of the recommendations recognise the participation of nurses 'on the ground' as being vital in implementing the recommendations (Scottish Government 2012).

Although the use of available evidence might have been more robust, the report highlighted the changing needs and demographics of the learning-disabled population in the UK, alongside excellent examples of best practice to inform strategies to address current deficits in meeting those needs. This information is then used to recommend strategies that will inform decision makers throughout the UK in planning for the future provision of specialist care of the learning-disabled population. The aim is to ensure that specialist healthcare practitioners, equipped with the necessary skills and resources, will always be available to support people with learning disabilities to enjoy the best health they can within a healthcare system committed to the ideals of a social model of healthcare provision.

Assessing the strength of the report

The process of evaluating research findings and government policies, to implement best-practice, evidence-based patient care effectively, is complicated and multifactorial. It involves collaboration at local, regional and national levels between health boards, the various royal colleges, and supervisory as well as regulatory bodies such as the National Institute for Health and Care Excellence and the Scottish Intercollegiate Guidelines Network.

To this already significant challenge can be added the various, and sometimes contradictory, findings and opinions published by professional journals (Haynes and Haines 1998). Much care and insight is required by the reader to

assess the findings of small-scale preliminary studies, case reports and opinions, which have not been subjected to the stringent research requirements imposed on more formal clinical research (McKibbin 1998). Within learning disabilities studies, this is a concern, given the increased challenges in achieving statistical significance when investigating the specialist needs of a comparatively small and disparate cohort (approximately 2.5%) of the general population (Gates and Wilberforce 2002).

Given the different and, at times divergent, research approaches that inform evidence-based practice in health care, it has been necessary to formulate a range of information gathering and assessment tools and methodologies to enable the researcher to filter and assess objectively the strengths and limitations of journal and research articles written to inform evidence-based practice. Numerous appraisal tools have been developed by academic research establishments, such as the Critical Appraisal Skills Programme based in Oxford (www.casp-uk.net/), with the aim of helping healthcare practitioners develop core skills in critically evaluating scientific evidence to ensure that healthcare-related policies and decisions are made and implemented on the basis of the best information available.

Of the tools currently available, the policy appraisal framework outlined in *Principles to Inform Decision Making: What Do I Need to Know?* (RCN 2008), is the most appropriate to aid discussion of the *Strengthening the Commitment* report, which is establishing its place as a source of significant influence for government and health department policies concerned with the future care of learning-disabled people in the UK. A summary of the author's main observations is shown in Table 1, using the principles of quality, accountability, equality and partnership, provided by the RCN (2008).

Evaluating the success of the report

The 17 core recommendations of *Strengthening the Commitment* aim to identify strategic targets for the care of people with learning disabilities, and to ensure that the most effective resources are in place to realise them (Scottish Government 2012). However, given that government policies do not always achieve their intended outcomes (Greer 2004), and legislation must be thought through before it is implemented, the manner in which these targets are taken forward will determine whether *Strengthening the Commitment* will be remembered as a formative policy document. A strong foundation for the future of learning disabilities nursing would

assist in developing an excellent knowledge and skills base to support the needs of people with learning disabilities for decades to come.

Government, healthcare workers, the learning disabled-population and their families and carers had a positive initial response to *Strengthening the Commitment* (Scottish Government 2012). Formal responses through healthcare policy programmes are being developed and appraised.

Significant work has already been commissioned and published in response to

the report's recommendations. This includes the launch of a revised pre-registration training structure for nursing students (NHS Education for Scotland 2013) and an outcomes-based *Health Equalities Framework* (Atkinson *et al* 2013) in March 2013. Designed by learning disabilities nurse-consultants in England and based on the five determinants of health inequalities, the *Health Equalities Framework* was developed for use across the healthcare spectrum in auditing and tackling

TABLE 1

Evaluation of Strengthening the Commitment using the Principles framework

Principle	Relevance to learning disabilities and learning disabilities nursing
Quality – safety, dignity, efficiency, effectiveness, sustainability.	<ul style="list-style-type: none"> ▶ Highlights the continuing need for providing safe and effective care for people with LD. ▶ Outlines strategies to identify the training and resourcing needs of RNLDs and ensure that the workforce is fit for purpose and evidence-based in its approach. ▶ Highlights shortfalls in care identified by people with LD, their families and carers, and outlines steps to address those issues. ▶ Highlights the need for all nurses to have an effective core working knowledge of the basic healthcare needs of people with LD.
Accountability – transparency, leadership, confidentiality, trust, responsibility.	<ul style="list-style-type: none"> ▶ Highlights the vital role of effective and informed leadership of healthcare structures that care for people with LD, and the need for RNLDs to take on senior leadership roles within these structures. ▶ Presents 17 S.M.A.R.T (specific, measurable, achievable, realistic and time-bound) (Doran 1981, Tunmore and Thomas 2000) recommendations for action.
Equality – accessibility, universality, diversity, advocacy, equity.	<ul style="list-style-type: none"> ▶ Highlights the values base for LD nursing: a commitment to person-centred care, inclusion, choice, the right to participate as an equal citizen within society and valuing the whole person. ▶ Highlights the continuing need to provide equity of care for people with LD. ▶ Demonstrates the skills that RNLDs possess not only for people with LD but also across the population range; highlights the need for strategic workforce planning that uses RNLDs' specialist skills more widely. ▶ Highlights the need to reverse the decline in numbers of RNLDs. ▶ Summarises the role of the RNLD in promoting effective holistic health care for people with LD. ▶ Summarises the diverse range of contexts in which RNLDs may be found, and highlights the challenges faced by some in positions without a context for using their skills effectively or developing them further. ▶ Highlights the need to identify new, advanced roles for RNLDs as part of a modernisation of nursing, and recognises the restricted opportunities for further training within the LD training branch. Recognises the need for RNLDs to be better represented in strategic leadership positions within healthcare services. ▶ Highlights that the evidence base for the specialist care needs of people with LD should be strengthened and broadened; highlights the role of the RNLD in this.
Partnership – consultation and negotiation, collaborative decision making, representation, legitimacy, involvement.	<ul style="list-style-type: none"> ▶ Highlights the need for all disciplines and professions who provide care for people with LD to demonstrate holistic and effective partnership working and to work proactively with people with LD to meet their needs. ▶ Structured around the four key themes of the <i>Modernising Nursing Careers</i> policy document (Scottish Executive 2006), evidencing a collaborative approach, and synthesised thinking. ▶ Highlights the need for improved partnership working to help recruit and train sufficient RNLDs.

LD = learning disabilities, RNLD = registered nurse learning disabilities.

(Adapted from Royal College of Nursing 2008)

health inequalities experienced by all patients and not solely those with learning disabilities (Thomas 2013).

Strengthening the Commitment therefore demonstrates in the clearest way possible the contribution that learning disabilities nurses, properly empowered, can make to UK society, and also that their expertise is not limited to the often marginalised populations they serve (Scottish Government 2012).

Conclusion

Returning, then, to the stated aim and purpose of *Strengthening the Commitment*, its findings and its consequent recommendations, in light of the well-documented healthcare challenges encountered by people with learning disabilities, and the growing interest from other nations in revisiting their structure of care for this population, it is clear that the decision to retain learning disabilities nursing within the nursing register is a correct and logical one.

If the progress that has been made in the 18 months following the publication of

Strengthening the Commitment is maintained and consolidated through consistent and committed action and the clear support of Health Departments throughout the UK, it is likely that the effects of this report will exceed the expectations of its authors. However, more significantly, it also has the potential to reinforce the roles and capabilities of learning disabilities nurses as champions not only of the health and social care needs of people with learning disabilities but also, in a symbolic way, the healthcare aspirations of individuals across society, as we learn what it means to live up to the visions of people like Nirje (1969) and O'Brien and Tyne (1981) in realising a truly social model of disability within a holistic society. Perhaps, then, the shocking abuses that people with learning disabilities – and other vulnerable groups within our society, for that matter – have experienced at places like Winterbourne View will then begin to be truly consigned to the history books as we make sure as a nation that we do ‘learn lessons’ from these appalling events and ensure such abuses never occur again **NS**

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