

CONSULTATION QUESTIONS

Progress and Challenges

Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/ carers?

Yes No

The Royal College of Nursing (RCN), Scotland is pleased to have the opportunity to comment on *'The same as you?' 2000-2012: Consultation Report*. RCN Scotland represents around 39,000 nurses, nursing students and health care assistants, as both a trade union and professional body, including a significant number of learning disability nurses. We have been working with our members and contacts within the RCN's UK-wide learning disability nursing forum to engage constructively in this consultation, focusing particularly on the importance of ensuring a sustainable workforce of learning disability nurses who are able to deliver on the key aims of 'The same as you' and the follow-up Strategy.

RCN Scotland supports the need for a review of 'The same as you' and commends the Scottish Government for its continued commitment to improving services and safeguarding a high quality of life for people with learning disabilities. We recognise many of the issues that this consultation raises—notably the growing prevalence and complexity of need and an increasingly older population—and hope that the subsequent Strategy and action plan contains the necessary steps to comprehensively tackle these issues. Central to this is ensuring that there are enough registered learning disability specialist nurses to face the challenges posed by the changing demographic in Scotland in an era of financial austerity and cutbacks to the nursing workforce, just at a time when it is expected that the need for their services will continue to increase.

RCN Scotland fully agrees with the review that the move from a medical to a social-based model has been positive and has welcomed the closure of all the long-stay learning disability hospitals in Scotland. We are also supportive of the acknowledgement that in the wake of these changes a much greater emphasis must be placed on support that builds people's capacity to lead independent, healthy lives. In our view learning disability nurses are vital to meeting this challenge and have a pivotal role to play in improving health outcomes for those with learning disabilities.

We support the review findings that being healthy underpins all other activities. We are pleased that the review recognises that people with learning disabilities continue to face barriers relating to healthy living and hope that the resulting Strategy and action plan contains necessary recommendations to ensure that health services and health promotion messages are accessible to all.

Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?*

Over the last ten years much progress has been made in terms of ensuring that people with learning disabilities are able to live independently—often within their own tenancies—in the community. The Royal College of Nursing has produced a number of films that capture the experience of people with learning disabilities and the progress that has been made over the last decade (http://www.rcn.org.uk/development/practice/social_inclusion/learning_disabilities/voices).

Crucially, closer partnerships have been forged between social services and health professionals working with people with learning disabilities and it is evident that the needs of people with learning disabilities are appearing higher on the national agenda. RCN Scotland recognises the work that has been done to promote equality, diversity, public awareness and the rights of people with learning disabilities, and person-centred approaches to care. Our members have seen an increase in social integration, including increased employment opportunities, and a wider choice of agencies providing services for people with learning disabilities. We are also supportive of the progress that has been made in developing the evidence-base for practice and in improving the skills of the workforce to support people whose behaviour is perceived as challenging—but we are mindful that there remains a great deal more to be done.

We acknowledge the contribution of NES Education for Scotland (NES) which has worked to commission a training programme in Positive Behaviour for learning disability nurses and others. We also acknowledge the NES work-based educational resource to enhance workers' knowledge and skills in supporting people with a learning disability, and their families and carers.

RCN Scotland has fought hard to ensure that the Scottish Government is aware of the vital and irreplaceable services provided by learning disability nurses. Since an alarming low of 50 student nurses in training in 2008/9 the number rose to 60 in 2009/10 with an increase to 90 students in 2012/13. We are supportive of the increase in places for learning disability nursing students in Scotland, and in the planning being undertaken by NHS Boards to increase staffing for learning disability services, but are very clear that this is not enough to address the increasing number of people with complex needs outlined in the review. A continued rise in the number of places for learning disability nursing students is essential in order to meet the needs of the growing number of people who have a learning disability and the growing complexity of these needs.

Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

RCN Scotland is clear that the need for much greater investment in learning disability nursing is the most pressing issue that must be addressed by the review of 'The same as you'. In the absence of a sustainable, highly trained and specialised workforce to meet the needs of people with learning disabilities the Scottish Government will risk the delivery of its policy recommendations.

As outlined in the report of the UK Modernising Learning Disabilities Nursing Review, 'Strengthening the Commitment,' (<http://www.scotland.gov.uk/Resource/0039/00391946.pdf>) the learning disability nursing workforce is smaller and more widely distributed across the health and social care sector than ever before. This has resulted in a lack of focus and direction for learning disability nursing, fragmentation of the learning disability nursing community and—potentially—a loss of core nursing and specialist learning disability nursing skills to the system at a time when demand is likely to increase.

As the age profile of Scotland's nursing workforce grows older—more than 75% of nurses within the small speciality of learning disability are over the age of 40—and the bulk of staff begin to retire, the number of registered learning disability nurses will substantially decrease. However, recent increases in the number of student learning disability nurses are wholly inadequate, as the unmet needs of people with learning disabilities continues to increase.

If this growing problem is to be tackled, the Scottish Government must address the lack of availability of places for student learning disability nurses and work systematically to map out learning disabilities service provision by the NHS, social care and the independent sector to identify the gaps. Services must have enough

appropriately skilled nurses so that people with learning disabilities are provided with the services they need. It is vital to ensure a sufficient number of registered nurses are in place to care for people across all health and social care settings in Scotland, including the growing third sector, recognising the changing balance between the NHS, health and social care. This is particularly relevant for people with learning disabilities where services may be delivered by a variety of different agencies, and demand from non-NHS employers may only be predicted to increase.

RCN Scotland is therefore keen to highlight the need for greater investment in three areas: (1) training and retention of learning disability nurses. There needs to be a focus on the strategic development and delivery plan of the next phase of learning disabilities nursing pre-registration education. Such a focus must address the potential loss of specialist learning disability nursing skills, which are an essential element to ensuring high-quality care; (2) increasing the capacity of Scotland's non-registered nursing workforce, which should be prioritised to ensure all the necessary safeguards for this vulnerable group of people; (3) supporting practitioners and practice education facilitators to develop local practice delivery elements of programmes for people working within the specialised field of learning disability nursing. The continuing education of the nursing workforce through appropriate training is vital to ensure that skills, knowledge and competencies are extended to reflect the changing needs of people with learning disabilities.

A focus on ensuring a robust and sustainable workforce for people with learning disabilities will serve to address some of the main outstanding policy areas of 'The same as you.' Crucially, there remains an unacceptable number of individuals with learning disabilities and additional support needs that remain in smaller-scale hospital settings. Additionally, there is a requirement for the service needs of people with Autistic Spectrum Disorders to be more adequately addressed both in terms of service provision and the policy framework.

RCN Scotland would also like to highlight the vital importance of monitoring the quality of care being received by people with learning disabilities both within their own homes and within a care home setting. Our members feel that the present framework in place to assure quality of care is inadequate and would welcome more robust structures to ensure that the needs of people with learning disabilities are being met.

Good Practice – Organisations

Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

The RCN's commitment during 2012/13 and beyond is to influence those who plan and deliver services to ensure that they have a nursing workforce fit for the future needs of people who have a learning disability, their families and their carers. The care and support needs, including access to vital services, of people who have learning disabilities are of high importance to the RCN and our members, particularly those working within this speciality. Nursing care is central to this agenda and we are keen to share with you some of our activities and achievements:

- Recently, the RCN acted as a key partner to the development of the UK Modernising Learning Disabilities Nursing Review, 'Strengthening the Commitment', which sets out recommendations across a wide range of areas that reflect the complexity and importance of modern learning disability

nursing.

- In 2011 the RCN set out its nursing priorities in its position paper 'Learning from the past- setting out the future,' which focuses on workforce, education and leadership (http://www.rcn.org.uk/data/assets/pdf_file/0007/359359/003871.pdf). This paper acted as the catalyst for the strong collaboration between all four UK health departments towards 'Strengthening the Commitment'.
- As mentioned in our answer to question two, earlier this year at RCN Congress we launched a high profile film around the value of learning disability nursing. We captured the needs of service users and also the qualities, motivations and strengths of learning disability nurses from around the UK.
- We have worked collaboratively with other organisations—including the National Institute for Health and Clinical Excellence (NICE) and other Royal Colleges—to set out clear guidance around autism. (See <http://nursingstandard.rcnpublishing.co.uk/supplements/autism-online-resource-centre> for further information).
- Our members provide clinical expertise and guidance to inform RCN policies and consultations while continuing to work tirelessly to deliver on the recommendations of 'The Same as you,' 'Towards an Autism Strategy for Scotland' and on overarching strategies such as 'Equally Well' and 'Getting it right for every child.' For example, members working in NHS Ayrshire and Arran have worked to ensure the placement of learning disability registers within GP practices; the recruitment of an acute/ primary care liaison nurse for learning disability; the development of a learning disability resource pack; the maintenance of enhanced health checks for people with a learning disability; and closer collaboration with social services. They have also initiated group work regarding health improvement and Health Needs Assessments for people with learning disabilities and worked to improve the accessibility of health information for people with a learning disability.

Good Practice - Individuals

Q.5 What have you done, as an individual, to make positive changes within your local area?

This question is not applicable to RCN Scotland.

Future Priorities - Healthcare

Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?

Further to RCN Scotland's response to question three, which emphasised the importance of a sustainable, high-quality workforce of learning disability nurses to meet the rising demands of those with learning disabilities, we take this opportunity to highlight the areas in which increased investment in learning disability nursing will reap dividends in terms of ensuring people with learning disabilities are provided with better and more appropriate healthcare.

(1) *Improved implementation of the role of acute liaison nurses through elevated*

numbers and increasing the awareness of this particular role in health care services is pivotal in ensuring equality of access to health services.

- (2) *Colleagues working in hospitals, in the community and other services such as prison healthcare must have access to the specialist skills of learning disability nurses* in order to improve the services provided to service users. Social care organisations must have more awareness and improved training on the health needs of individuals with learning disabilities, including the most recurrent health issues and the implications these can have. As outlined in the review, many people with learning disabilities—in particular those people coming out of prison—do not have access to the services that they require. The inclusion of the expertise of learning disability nurses within health and social care teams would vastly improve professional knowledge and deliver on the holistic, person-centred approach at the centre of 'The same as you'. With changing demographics meaning a potential increase in individuals with complex health needs this will become more and more important.
- (3) *Learning disability nurses in both the NHS and the independent sector require ongoing support and development to maintain their skills*, thereby ensuring that people with learning disabilities have access to well trained and up-to-date nursing staff, and, as a result, better and more appropriate healthcare. Given that a growing number of learning disability nurses are moving from the NHS to work in the independent sector the RCN has been working to support nurses and healthcare assistance in this area and we encourage the government to ensure that this important sector is not overlooked.
- (4) *Awareness of the role of the learning disability nurse must be strengthened so that both people with learning disabilities and their families and health and social care professionals are clearer regarding the way in which the health needs of people with learning disabilities can be met*. This would serve to avoid unnecessary hospital admissions and would allow learning disability nurses to have more of a role in supporting timely access to services, as well as contributing to preventative and anticipatory care—addressing general health needs, not just learning disability needs. As identified in the review, people with learning disabilities are more likely to have health problems than other people. Although there has been improved healthcare within primary and acute settings, including uptake in health screening, and despite legislation that explicitly sets out a legal framework for the delivery of equal treatment, the general health needs of people with learning disabilities are often ignored and health improvement and promotion messages and services can remain largely inaccessible. It is vital to ensure that efforts are re-doubled to change this by implementing learning disability nurse skills to help people navigate the health system and support other health professionals to modify delivery care models to best suit service user circumstances. Although it was originally envisaged that social care teams would take on this role—hence the reduction of pre-registration training for learning disability nurses—the reality has been that the health needs of people with learning disabilities are hugely complex (including high rates of mental health issues, long term conditions management, etc) and more specialised services are required.
- (5) *Nurses should engage actively in planning, designing, monitoring and delivering services* to ensure service accessibility to people with learning disabilities, as outlined in 'Strengthening the Commitment'. Access to general health and health improvement services has been highlighted in the review as one of the key barriers to people with learning disabilities. Including learning disability nurses in the discussions relating to these services will undoubtedly ensure that services are of a more appropriate and higher standard.
- (6) *There must be closer joint working between health and social care*, not only at the points of discharge from hospital care but also throughout a person's lifespan. Although some progress has been made in terms of the partnerships

forged between social services and health professionals a closer alliance would be beneficial. The subsequent learning disability Strategy and action plan must be fully aligned with the government's plans relating to integration of health and social care.

RCN Scotland encourages the Scottish Government to move forward in the areas outlined above in order to address the evidence that has highlighted the higher levels of unmet need and ineffective treatment received by people with learning disabilities (See, for example, Disability Rights Commission 2006 and 2007, Mencap 2007, Michael 2008).

Future Priorities - Education

Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?

RCN Scotland has no particular comments for this question.

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

Although the review recognises the excellent progress that has been made to improve independent living for people with learning disabilities, RCN Scotland is mindful that there is still work to be done. In particular, social inclusion and the variation in packages of support remain large challenges. Our members have highlighted that a smooth transition from children's to adult services remains difficult given the competing priorities between the different services.

In order to deliver on these challenges it is essential that people with learning disabilities of all ages have access to the expert learning disability nursing they need, want and deserve. Learning disability nurses support people in all aspects of their lives, not just their health needs, and have a key role in addressing and improving access to health promotion, social integration, employment opportunities, higher education and providing support to families with the provision of care. Indeed, one of the identified barriers to socialising and feeling a part of the community within the review includes a 'lack of support staff'. Strategic investment in developing the learning disabilities workforce would address this and ensure person-centred and strengths-based approaches are further developed.

Additionally, there is a growing evidence base around psychological therapies and their benefits for people with learning disabilities which, supported by learning disability nursing staff, could vastly improve opportunities for independent living.

Future Priorities – Employment

Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?

RCN Scotland considers the priorities that it focused on in its responses to questions six and eight to have relevance to improving employment opportunities

for people with learning disabilities. Learning disability nurses have a crucial role in ensuring that people with learning disabilities are supported in the employment opportunities that they choose.

Future Priorities

**Q.10 What other future priorities do we need to focus on?
(Please list these in order of importance with the most important first)**

1. We are very clear that the **priorities for future action that will form the basis of new recommendations must include reference to the learning disability workforce**, without which the rest of the recommendations are at risk. The previous reductions in training places plus current inadequate levels of learning disabilities student nurses will continue to directly impact on numbers of newly registered learning disabilities nurses entering employment. It is therefore vital to implement processes of proactive forward planning to take account of other significant factors—such as the changing age demographic of people with learning disabilities, the maturing workforce, the improvements in neonatal care, and people living longer with more complex long term conditions—all of which influence the demand for learning disabilities nurses in the future. The Scottish Government's main concern in this respect should be to ensure that there is a sufficient number of highly trained, registered learning disability nurses to meet the rising need for their services. In order to do this, as a priority, the government must address the:

- a) reduction in the number of universities across Scotland providing learning disability nursing courses;
- b) increasing, but still inadequate, number of places available for student learning disability nurses;
- c) requirement to continually modernise the learning disability workforce to meet current and future needs;
- d) need to ensure clear career pathways and development frameworks for learning disability nurses to promote strong leadership and appropriate supervision for other learning disability nurses; and
- e) extensive competition within the labour market for skilled learning disabilities staff, from both NHS and non-NHS providers.

2. The development of the new Strategy, and the review and assessment of services for people with learning disabilities must be viewed through the lens of integration. Whilst we are still awaiting final proposals from the Scottish Government for the governance structures and legislation to better support collaborative working, we are concerned to ensure that services for people with learning disabilities across the full age spectrum are integral to plans to redesign services that deliver improved outcomes. An ongoing focus on integration for older people and early years alone risks fragmenting existing good work to ensure an holistic approach to service support for those people with a learning disability and their carers. We would hope that the Scottish Government will use a future Strategy on learning disability to send a clear message of the need to ensure that services for those with learning disabilities are at the heart of local integration plans, however services are configured. The RCN has recently published a document, 'Principles for delivering the integration of care' (http://www.rcn.org.uk/data/assets/pdf_file/0016/442132/RCN_in_Scotland_in_tegration_principles.pdf), that we hope will support local partnerships, as well as the Scottish Government and CoSLA, in developing a truly joined-up approach

to future care services, whatever the particular needs of an individual.

3. RCN Scotland is pleased that the review of 'The Same as you' recognises the important need to plan for the increasing number of young people with complex needs and for the needs of older people with increased health needs, including dementia. Our members are keen to emphasise the emerging population with mild learning disabilities, self harm issues and social problems and are concerned that those with Autistic Spectrum Disorder are fully represented. We hope that the new Strategy and action plan will take into the account these changing realities and we look forward to having the opportunity to provide our comments.
4. Given the complex health needs of people with learning disabilities we are keen to emphasise, as a priority, the importance of accessible general health services and health promotion. Learning disability nursing staff must have a key role in signposting these services. Links with technology, sport and exercise should also be further developed.
5. RCN Scotland recognises the research that has been commissioned following the 'The Same as you' recommendation on the number of people with learning disabilities in prison or in secure accommodation and arrangements for assessing and providing them with care. However, much more work needs to be done to understand the actual figures, and to address the needs of people with learning disabilities both in prison and secure accommodation and upon release. Those working in social settings must have access to the specialist skills of learning disability nurses in order to improve these services, particularly in light of recent changes to incorporate prison healthcare within the NHS.

If you wish to discuss RCN Scotland's response in more detail please contact Chloe Swift chloe.swift@rcn.org.