People with learning disabilities in rural Scotland: review of policy

Abstract

People with learning disabilities may have additional healthcare needs compared to the general population, and the NHS faces challenges in addressing these needs. Scotland has many remote and rural communities, and residents of these communities can encounter difficulties in accessing healthcare resources. This article considers Scotland's healthcare policy in relation to remote and rural areas, and how effective it is in meeting the needs of people with learning disabilities in these communities.

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SCOTLAND IS A GEOGRAPHICALLY diverse nation of around 5.3 million people, with about 20% of the population living in remote and rural areas (The Scottish Government 2008a, National Records of Scotland 2013). Statistics indicate that approximately 130,000 (2.5%) people in Scotland are likely to have a learning disability (Gates and Wilberforce 2002).

This article analyses and appraises the relevance and effectiveness of *Delivering for Remote and Rural Healthcare: What it Means for You* (The Scottish Government 2008a) in addressing the healthcare needs of people in Scotland's remote and rural communities who have learning disabilities. This document is referred to in this article as The

Policy Document and is based on *Delivering for Remote and Rural Healthcare – The Final Report of the Remote and Rural Workstream* (The Scottish Government 2008b), referred to in this article as The Report.

Literature review of reports and policy documents

The Policy Document is one among many documents relating to Scotland's ongoing healthcare needs that have been published over the past ten years (Table 1), including: *Delivering for Health* (Scottish Executive 2005); *Better Health, Better Care: Action Plan* (The Scottish Government 2007); *The Healthcare Quality Strategy for NHSScotland* (The Scottish Government 2010); *Community Hospitals Strategy Refresh* (The Scottish Government 2012a); *Health Inequalities in Scotland* (Audit Scotland 2012); and *A Route Map to the 2020 Vision for Health and Social Care* (The Scottish Government 2013a). Although an analysis of all the policy documents is beyond the scope of this article, similar themes and recommendations have been identified. However, in regard to how The Policy Document relates to these other documents, Scotland's cabinet secretary for health and wellbeing said that it should be seen as 'the outline of a complementary approach' to delivering health care to the 20% of the population who live in remote and rural areas (The Scottish government 2008a), alongside the action plan *Better Health, Better Care* (The Scottish Government 2007).

Better Health, Better Care (The Scottish Government 2007) has been superseded by *Strategic Narrative: Achieving Sustainable Quality in Scotland's Healthcare. A '20:20' Vision* (The Scottish Government 2012b), which mentions rural healthcare needs once only. NHS Education for Scotland also published the board paper *Supporting Remote and Rural Healthcare* in 2013; however, The Policy Document remains the most up-to-date Scottish Government document relating to the specific healthcare needs of people in rural communities.

A word search was carried out in each of the Scottish Government's policy documents,

and instances in the text of the term 'disabilities' (not specifically learning disabilities) were recorded (Table 1). Few references to people with disabilities and their related additional healthcare needs were found in these documents, despite the fact that about 20% of adults of working age and around 68% of those over 75 years have a long-standing illness, health condition or disability (NHS Health Scotland 2010). The Policy Document did not refer to those in the rural population living with disabilities, either in the context of acknowledging and committing to meeting their additional healthcare needs as part of the wider aim of reducing healthcare inequalities, or in the context of promoting equity of access to healthcare resources for the rural population as a whole. This is particularly salient given the statement: 'Scottish policy is explicitly directed towards social justice and tackling inequalities. However, current public health initiatives and practices in Scotland will not close the gap and are likely to lead to a widening of the health gap for people with learning disabilities.' (NHS Health Scotland 2004).

In the course of reviewing the literature to inform the discussion in this article, only one specific reference to the healthcare needs of people with learning disabilities living in Scotland's remote and rural communities was found, in *Health Needs Assessment Report: People with Learning Disabilities in Scotland* (NHS Health Scotland 2004), and one reference was found to the appointment of two learning disabilities nurses in the Western Isles (The Scottish Government 2002). An internet search for 'learning disabilit* remote rural Scotland' returned brief references to an article

on the sexual health needs of young people with learning disabilities, and to initiatives to improve access to opportunities for learning disabilities nurses to practise closer to home.

The literature review revealed a smaller proportion of the rural population (21%) reported having a long-term condition compared with that in urban areas (23%) (The Scottish Government 2014), and that a need to improve mental health resources in remote and rural communities had been identified (Scottish Association for Mental Health 2012). Communities in the west of Scotland were more likely to have higher levels of deprivation and lower life expectancy, with 12-16% of people in those communities on average likely to be income-deprived (Audit Scotland 2012).

Some differences exist between urban and rural communities in terms of healthcare needs, with higher rates of suicide, alcohol-related disease and accidents related to outdoor activities in rural communities, as well as a higher incidence of community-based palliative care (The Scottish Government 2008b). The Report indicated similarities in the patterns of disease in rural and urban populations, inferring that no departure from national health targets would be required to meet the healthcare needs of the rural population.

Strength of evidence informing The Policy Document

Throughout The Report that underpinned The Policy Document, 46 references were made to

TABLE 1

Instances of the use of the term 'disabilities' in Scottish Government policy documents	
Document	Number of instances
Delivering for Health (Scottish Executive 2005)	2
Better Health, Better Care: Action Plan (The Scottish Government 2007)	11
Delivering for Remote and Rural Healthcare: What it Means for You (The Scottish Government 2008a) ['The Policy Document']	0
Delivering for Remote and Rural Healthcare – The Final Report of the Remote and Rural Workstream (The Scottish Government 2008b) ['The Report']	1*
The Healthcare Quality Strategy for NHSScotland (The Scottish Government 2010)	1*
Community Hospitals Strategy Refresh (The Scottish Government 2012a)	2
Health Inequalities in Scotland (Audit Scotland 2012)	0
A Route Map to the 2020 Vision for Health and Social Care (The Scottish Government 2013a)	0
Supporting Remote and Rural Healthcare (NHS Education for Scotland 2013)	0
(* Reference occurred in the equality and diversity impact statement or commitment to equality)	

other reports or evidence informing The Report and its recommendations. This evidence appeared valid and contextual. However, The Report does not contain supporting evidence on healthcare provision for people with disabilities. Emerson *et al*'s (2011) article on the health inequalities of people with learning disabilities in the UK (a more specific topic) cites 272 such references. Other evidence (NHS Health Scotland 2004) emphasises the difficulties of people with learning disabilities in accessing appropriate health care in Scotland's remote and rural communities. There appears to be a lack of synergy, or 'joining the dots', between these reports and policy documents, to reduce shortcomings in timely access to appropriate healthcare resources for those with disabilities, and ultimately increase effective use of resources, with potential savings for the Scottish Government (Audit Scotland 2012).

Summary of The Policy Document and The Report

The Policy Document was published as a booklet with six core commitments – better community care, better hospital care, better healthcare teams, better use of technology, better buildings and better emergency response – which were informed by The Report. The Report's 61 commitments, including numerous sub-sections, identify the steps necessary to implement the Scottish Government's remote and rural healthcare policy. However, there is a lack of reference to the needs of people with learning disabilities, or with any disability, in Scotland's remote and rural communities.

Healthcare challenges for people with learning disabilities

Learning disabilities result from a complex range of environmental, lifestyle and genetic factors that may be experienced to varying degrees (Watson 2002). The healthcare needs of people with learning disabilities are similarly varied. However, evidence has consistently shown that the healthcare needs of these individuals are different and additional to those usually encountered in the general population (van Schrojenstein Lantman-De Valk *et al* 2000, NHS Health Scotland 2004, Cooper *et al* 2004, Clark and While 2008, Emerson *et al* 2011). A significant proportion of people with learning disabilities experience difficulties in having their healthcare needs met (van Schrojenstein Lantman-De Valk 2005, Department of Health (DH) 2007, Clark and While 2008, Emerson *et al* 2011). As a consequence of these difficulties,

these individuals have a disproportionately increased mortality rate and their causes of death diverge from the population norm (Mencap 2007, Heslop *et al* 2014). The leading causes of death in the general population are lung, prostate and breast cancers, followed by ischaemic heart disease and cerebrovascular diseases (NHS Health Scotland 2004, Cooper *et al* 2004). The leading causes of death in people with learning disabilities are respiratory disease, congenital cardiovascular diseases, and oesophageal, stomach and gall bladder cancers, and these individuals have above-average leukaemia and epilepsy mortality rates (Janicki *et al* 1999, Durvasula *et al* 2002, NHS Health Scotland 2004, Cooper *et al* 2004, Gustavson *et al* 2005, Clark and While 2008).

Mortality statistics for people with learning disabilities may be masked by the volume of statistics for the general population, therefore there is an increased risk that insufficient resources will be made available to support the healthcare needs of people with learning disabilities, resulting in unmet health needs, impaired access to healthcare resources and increased mortality. Paradoxically, resources such as the Health Equalities Framework, introduced by learning disabilities nurses as an outcomes-based tool to assist improvements in healthcare outcomes for their patients, may be used to improve healthcare outcomes for all cohorts of society (Thomas 2013, Atkinson *et al* 2013).

The evidence base cited by the working group lacks reference to the additional healthcare needs of people with disabilities in general, so it is perhaps unsurprising that the guidelines do not address the specific healthcare needs of people with learning disabilities, in particular, or consider the relevant issues affecting people with disabilities.

This appears to be an oversight, given the Scottish Government's long-standing commitment to social justice and tackling inequalities, most recently demonstrated in *Strengthening the Commitment. The Report of the UK Modernising Learning Disabilities Nursing Review* (The Scottish Government 2012c) – on which this author has previously commented (Clapham 2014) – and in *The Keys to Life: Improving Quality of Life for People with Learning Disabilities* (The Scottish Government 2013b).

The UK's national and devolved government policies in relation to the care of people with learning disabilities are best understood through their application of the five essential service accomplishments: community presence,

competence, respect, community participation and choice (O'Brien and Tyne 1981). These arose from a misunderstanding of the 'normalisation' social care concept introduced in Scandinavia in the late 1960s (Nirje 1969). Normalisation was defined as making available to people with learning disabilities 'patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society' (Nirje 1969). There followed a 'mistaken belief' that people with learning disabilities 'must be expected to, indeed be forced to, act "normal"…' (Perrin and Nirje 1985). The concept of normalisation was redefined to clarify this misunderstanding (Perrin and Nirje 1985).

One aspect of normalisation that is often found in policy documents is the notion that all members of society, including those with disabilities, should enjoy equality of access to mainstream healthcare resources. This notion of equality in health care, whether it relates to access to healthcare buildings or treatment, or to outcomes, presumes that the individual has the ability or insight to identify their need to see a healthcare professional regarding a problem or concern, and the ability or confidence to then seek appropriate help or advice (Barr 1999). For people with learning disabilities, such assumptions are unsound; evidence indicates that these individuals are significantly disadvantaged in this regard (Cooper *et al* 2004, Clark and While 2008, Atkinson *et al* 2013).

Effective healthcare provision should be based on the notion of equity, rather than equality of access, where those with greater difficulty in accessing services are given greater assistance to achieve parity of access, treatment and healthcare outcomes (DH 2001, Braveman and Gruskin 2003, World Health Organization 2013). *The Health Needs Assessment Report: People with Learning Disabilities in Scotland* (NHS Health Scotland 2004) states: 'Areas of priority for development in rural and remote areas include health surveillance and services to enable access to health services and mental health care. The development of service models to meet the needs of people with problem behaviours, forensic and offending needs, and profound learning and multiple physical disabilities requires attention.'

Current plans to integrate health and social care in the UK (Health and Social Care Act 2012, Public Bodies (Joint Working) (Scotland) Act 2014) are relevant to meeting the healthcare needs of people with learning disabilities. However, plans for integration are still being developed in Scotland and it is too soon to determine how effective such integration may prove in delivering community-based care for individuals who experience difficulties in accessing healthcare resources.

Discussion

The Policy Document aims to 'enhance the accessibility of a wide range of services in order to deliver further improvements to the health of people living in remote and rural areas… This is not another strategy, but the outline of a complementary approach, one that recognises the distinct challenges inherent in delivering first-class health services to the one in five Scots who live in our remote and rural areas' (The Scottish Government 2008a). There is much to be commended in The Policy Document and The Report, including evidence of a commitment to:

▸ Find creative ways to enhance the quality of healthcare provision for remote and rural communities, and to instil a 'can-do' approach to the challenge of providing truly local care in geographically diverse regions in Scotland.
▸ Provide person-centred community-based care.
▸ Make the physical resources of the NHS infrastructure 'fit-for-purpose' through the development of buildings and vehicles that will meet the healthcare needs of the communities they serve.
▸ Identify ways of overcoming the challenges that healthcare workers in rural areas encounter in maintaining their skills to the standard required to care for their patients, using innovative educational approaches.

However, The Policy Document and The Report do not address the additional healthcare challenges faced by people with disabilities, or by people in the rural population with learning disabilities and their carers. The Policy Document and The Report make frequent reference to 'accessibility for all', yet appear not to have considered the challenges that these individuals may face in achieving access to health care.

There is a need for increased awareness of the needs of people with learning disabilities, and other disabilities, in remote and rural communities, and awareness of the ways in which these individuals live. Based on the author's professional knowledge of the healthcare needs of people with learning disabilities, these individuals are likely to experience difficulties relating to mental health and isolation, unmet healthcare needs, unwanted behaviours and carer burnout. However, it is difficult to determine the actual needs of people with learning disabilities in rural areas of Scotland without supporting evidence.

Further research would be valuable to determine the number of people with learning disabilities living in Scotland's remote and rural communities, the extent to which their healthcare needs are adversely affected by the limitations of their location, and to inform policymakers on their needs (NHS Health Scotland 2004, Inclusion Scotland 2008).

The author suggests the high-profile commitment to people with learning disabilities in Scotland referred to in *Strengthening the Commitment* (The Scottish Government 2012c) could be extended to address the deficits in care for people with learning disabilities living in remote and rural communities in Scotland and throughout the UK.

A starting point would be a commitment to acknowledge the needs of those with disabilities in all UK healthcare policies, along with a resolution to address deficiencies in healthcare provision experienced by these individuals. Given the challenges to accessing health care for those with disabilities in remote and rural communities, there is still a long way to go to realise The Scottish Government's (2013a) vision for health care in Scotland, which is safe, effective and person-centred care that supports people to live as long as possible at home or in a homely setting.

Conclusion

The Policy Document and The Report contain much to commend them in addressing some of the healthcare challenges in remote and rural communities (The Scottish Government 2008a, 2008b). However, neither considers the additional healthcare challenges faced by people with disabilities, including people with learning disabilities and their carers, nor the challenges these individuals may have in accessing health care in remote and rural communities – despite the fact that mainstream healthcare policy acknowledges the additional healthcare needs of people with learning disabilities. Steps should be taken to improve awareness of the needs of those with learning disabilities and other disabilities in remote and rural communities as a priority, and to address deficiencies in healthcare provision that those with disabilities have experienced **NS**

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