



ORIGINAL ARTICLE

An investigation into the public health roles of community learning disability nurses

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Accessible summary

- People with learning disabilities find it difficult to get their health checked and to get information about their health.
- Community learning disability nurses play an important role in supporting people with learning disabilities to stay healthy.
- Community learning disability nurses support people with learning disabilities to get their health checked and to get information about their health.

Summary

International studies have shown poor uptake of public health initiatives by people with learning disabilities. In addition, studies have shown that people with learning disabilities experience poor access to public health services. The contribution of community learning disability nurses in meeting the public health needs of people with learning disabilities has evolved differently across the UK resulting in conflicting understanding of this role. This paper reports on a study that explored and explained the contribution of community learning disability nurses in the implementation of public health policies for people with learning disabilities. The study demonstrates that community learning disability nurses are involved in health surveillance, health promotion, health facilitation, health prevention and protection, health education, and healthcare delivery.

Keywords Community learning disability nurse, health action planning, health facilitation, public health policy, public health role

Introduction

This paper reports on an investigation into the public health roles of community learning disability nurses. The paper describes and explains the extent of community learning disability nurses' public health roles. The paper is the first of two papers reporting on responses to one question of nine of stage 3 of a 3-stage sequential multiple methods study into how community learning disability nurses enact their public health roles in implementing public health policy for

people with learning disabilities in the UK. This paper is the first of two papers reporting the findings of stage 3 of the study. Stage one of the study explored how public health policy was reflected and articulated in community learning disability nurses' job descriptions and or person specifications using documentary analysis. Stage two involved learning disability nurse consultants and sought to describe and hypothesise how community learning disability nurses interpreted and enacted their public health roles using grounded theory. Stage 3 of the study involved a broader

group of community learning disability nurses and sought to explain moderators of how community learning disability nurses enacted their public health roles in implementing public health policy for people with learning disabilities in the context of role theory using an online survey.

Background

Jukes (1994) has traced the origins of the learning disability nurse's involvement with public health for people with learning disabilities to the 1960s. In the 1980s, several attempts were made to identify and clarify the contribution of community learning disability nurses to health promotion (Elliot-Cannon 1981). The Griffiths Report (Griffiths 1988) and the NHS and Community Care Act (DH 1990) emphasised the 'health' contribution of community learning disability nursing. More recently, the Department of Health has clearly emphasised the public health role of the learning disability nurse in England (DH 2001, 2007). However, there is a lack of clarity in how this role is supposed to be carried out in practice. Consequently, defining a public health role of the CLDN has been difficult (Mobbs *et al.* 2002). It is therefore not surprising that this role has evolved differently across the UK (Mobbs *et al.* 2002), and that primary care and social care services have a conflicting understanding of the role and contribution of community learning disability nurses to the delivery of public health policy to people with learning disabilities (McGarry & Arthur 2001).

The involvement of community learning disability nurses with public health implementation is important because international studies have shown poor uptake of public health initiatives in the population of people with learning disabilities (Beange & Bauman 1990; Beange *et al.* 1995; Jacobson *et al.* 1989; Jones & Kerr 1997; Kerr *et al.* 1996; Stein & Allen 1999; Sullivan *et al.* 2003; Wood & Douglas 2007). Other studies have shown that people with learning disabilities have reduced access to health screening and health promotion services (Kerr *et al.* 1996; Whitfield *et al.* 1996). Lennox *et al.* (2000) have noted the need for effective health advocacy from relevant health professionals. A limited number of studies that scrutinised access to health promotion activities by people with learning disabilities, exist (Messent *et al.* 1999; Beart *et al.*, 2001). Thomas & Kerr (2011) have concluded that delivering effective public health initiatives for people with learning disabilities is challenging. Felce *et al.* (2008) have suggested that in the absence of people with learning disabilities' ability to self refer for health care, it was logical that provision of health services for this population be proactive rather than reactive. Existing studies in the UK, Australia and New Zealand have demonstrated that preventative interventions such as health screening are effective in identifying the health needs of people with learning disabilities (Baxter *et al.* 2006; Beange *et al.* 1995; Cooper *et al.* 2006; Emerson & Glover

2010; Emerson *et al.* 2011; Martin *et al.* 1997; Webb & Rogers 1999). Lennox *et al.* (2000) have argued that the opportunistic approach to preventative health for people with learning disabilities was not adequate to meet the healthcare needs of this population. Although in the UK the introduction of the Quality Outcomes Framework (QOF) in 2004 (NHS Employers 2003) and the later introduction of Directed Enhanced Services (DES) in England [*Scottish enhanced services programme* (SESP) in Scotland], which placed the responsibility of preventative health service provision for people with learning disabilities on GPs, there has been a longstanding debate as to whether this role belongs to primary care or to the community team for people with learning disabilities (Curtice & Long 2002; Matthews & Hegarty 1997). What was not clear from these studies, and which needed investigating was the role played by community learning disability nurses in preventative interventions for people with learning disabilities.

Methods

Ethics approval was obtained before the commencement of the study. A 9-item online questionnaire survey was developed and pilot tested. The questionnaire focused on a participant's employer, participants' job descriptions, participants' public health roles and participants' perceptions of their employer's priorities regarding public health policy implementation for people with learning disabilities. The questionnaire was developed as a rating scale (DeVellis 2003). SurveyMonkey was used as a platform for the administration of the questionnaire.

The participants were grouped into the UK National Health Service pay bands. The pay band was the key unit of data categorisation that was common across all three stages of the study (Parahoo 2006). This allowed comparability and triangulation of data (Parahoo 2006). Only 1 of the four countries provided data categorised by pay band. Consequently, it was impossible to use the quota sampling method, and nonproportional quota sampling was used. In keeping with the questions, which needed to be answered, nonproportional quota sampling was appropriate because it was flexible enough to allow the recruitment of statistically sufficient participants for each of the four pay bands of community learning disability nurses. In addition, this approach was appropriate because the study intended to compare the results of the subgroups in terms of their public health roles. The sampling method was focused on the representativeness rather than the variability of the sample (Punch 2003; band 5: $n = 19$; band 6: $n = 67$; band 7: $n = 59$; band 8: $n = 26$; see Table 1). Nonproportional quota sampling was used to target each subgroup of the nursing pay bands of participants separately. Without using nonproportional quota sampling, it would have been impossible to have adequate representation (Morrow *et al.* 2007).

Table 1 Participants

	England (%)	Northern Ireland (%)	Scotland (%)	Wales (%)
Total number of participants	120 (70.2)	8 (4.7)	24 (14)	19 (11.1)
Male	33 (19.3)	3 (1.8)	13 (7.6)	10 (5.8)
Female	87 (50.9)	5 (2.9)	11 (6.4)	9 (5.3)
Age				
30<	24 (14)	0	4 (2.3)	3 (1.8)
31–49	55 (32.2)	6 (3.5)	15 (8.8)	13 (7.6)
>50	41 (24)	2 (1.2)	5 (2.9)	3 (1.8)
Band				
5 (<i>n</i> = 19)	15 (8.8)	0	0	4 (2.3)
6 (<i>n</i> = 67)	32 (18.7)	7 (4.1)	17 (9.9)	11 (6.4)
7 (<i>n</i> = 59)	49 (28.7)	1 (0.6)	6 (3.5)	3 (1.8)
8 (<i>n</i> = 26)	24 (14)	0	1 (0.6)	1 (0.6)

Participants were included in this study if the prerequisite professional qualification of their role was NMC registration as a learning disabilities nurse. Secondly, the participants were employed as part of community-based multi-disciplinary team providing health services to people with learning disabilities in a variety of settings. Participants were excluded if they were required to provide services in one specific location. In addition, participants were included if they carried a caseload and were excluded if their role did not require them to carry a caseload. Furthermore, participants were only included if they were able to admit and discharge people with learning disabilities into and from their caseload.

Participants were recruited through local and national professional organisations for learning disability nurses from across the four countries of the UK. Four Internet sites (one for each pay band), each containing a copy of a previously pilot-tested survey questionnaire, were created on SurveyMonkey. An e-mail containing information about the study, consent, confidentiality and a link to each of the four sites was sent to all potential participants. During the period of data collection, the website was checked several times a day to ensure that it was functioning correctly and also to monitor the progress of the responses. Data were collected until the achievement of minimum targets for the subgroups and the overall sample size. The descriptive statistics presented here were analysed using Survey Monkey (2010).

Results

Of the band 5 participants who participated in this study, the most common public health activity was health promotion, with 95.2% of the respondents reporting that they participated in this role. Health surveillance was the least public health role band 5 community learning disability

nurses engaged with 57.1% of the participants reporting some level of involvement and participation (see Fig. 1).

Of the band 6 participants who took part in this study, 100% of the respondents reported that they participated in health promotion and in facilitating access to health services. Health surveillance and healthcare delivery were the least reported public health roles band 6 community learning disability nurses engaged in, with 73.7% of the participants reporting some level of involvement and participation in both roles (see Fig. 2).

Of the band 7 participants who participated in this study, the most common public health activity was facilitating access to health, with 96% of the respondents reporting that they participated in this role in some way (see Fig. 3). At 60%, health surveillance was the least public health role band 7 community learning disability nurses engaged in.

Of the band 8 participants who participated in this study, the most common public health activity was facilitating access to health, with 94.4% of the respondents reporting that they participated in this role in some way. Health surveillance was the least reported public health role band 8 community learning disability nurses engaged in, with 44.4% of the participants reporting some level of involvement and participation (see Fig. 4).

Discussion

Figures 1–4 and Table 2 illustrate the public health roles in which participants in the study were involved. These findings demonstrate changes in how community learning disability nurses enact their roles, with an increasing public health role. A previous study identified education, health promotion and health screening as key areas of public health involvement by community learning disability nurses (Barr 2006). In that study, 81.08% of participants were involved with health education, 70.27% with health promotion and 35.13% with health screening. This is comparable with 81.4%, 93% and 58.8%, respectively, in the present study. No significant change was noted in the level of involvement by community learning disability nurses with health education, but there was a significant increase in community learning disability nurses'

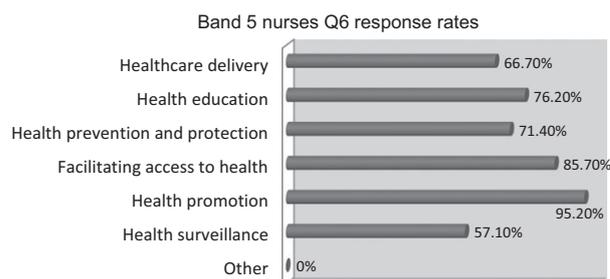


Figure 1 Band 5 community learning disability nurses' involvement with public health.

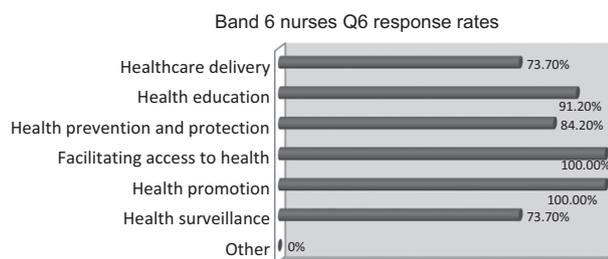


Figure 2 Band 6 community learning disability nurses' involvement with public health.

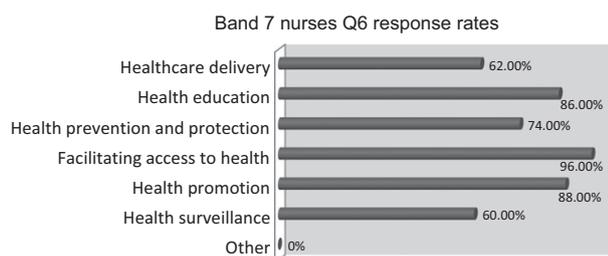


Figure 3 Band 7 community learning disability nurses' involvement with public health.

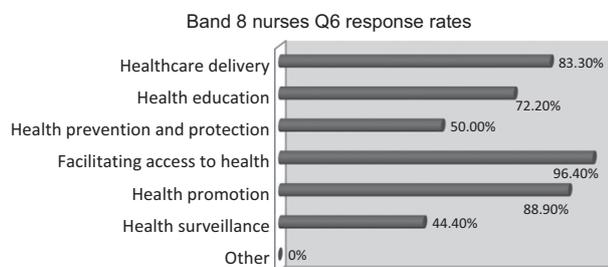


Figure 4 Band 8 community learning disability nurses' involvement with public health.

involvement in health promotion and health screening activities. What is also significant in the current study was the proportion of participants who reported involvement with health prevention and protection (50.0%) and facilitating access to health (94.4%).

Previous studies have noted changes to the role of community learning disability nurses, including increasing involvement with public health in England (Boarder 2002; Mobbs *et al.* 2002). Barr (2006), Barr *et al.* (1999) and McConkey *et al.* (2002) have also noted the increasing involvement of community learning disability nurses with health promotion and health screening in Northern Ireland. However, what is not clear from these studies are the drivers for this change in the public health roles of community learning disability nurses. What has been noted during this study is the influence of recent policy initiatives such as health facilitation and health action planning (DH

Table 2 Public health involvement summary of response rates

Area of public health	Involvement response rates (%)				
	Band 5	Band 6	Band 7	Band 8	Total
Healthcare delivery	66.7	73.7	62.0	83.3	71.3
Health education	76.2	91.2	86.0	72.2	81.4
Health prevention and protection	71.4	84.2	74.0	50.0	69.9
Facilitating access to health	85.7	100.0	96.0	94.4	94.0
Health promotion	95.2	100.0	88.0	88.9	93.0
Health surveillance	57.1	73.7	60.0	44.4	58.8

2001). What has also been observed during this study is that the moderators of how community learning disability nurses enact their public health roles are complex.

This study has shown that on average the most common public health role of community learning disability nurses was facilitating access to services (94%; see Table 2). Previous studies identified this role (Abbott 2007; Bollard 2002; Marshall & Moore 2003). However, none of these studies quantified community learning disability nurses' involvement with health facilitation. One explanation for this the high rate of involvement observed in the current study may be the impact of policy changes noted by previous studies (Barr 2006; Boarder 2002; Mobbs *et al.* 2002). Another explanation could be that the roles of community learning disability nurses are becoming more facilitatory as a result of recent policy initiatives. It is clear from these findings that community learning disability nurses are increasingly expected to be involved in implementing public health initiatives for people with learning disabilities. Significant changes in role expectations were noted in the liaison and facilitation roles in implementing public health policies for people with learning disabilities. This observation indicates that there has been a significant shift from the lack of visibility reported in previous studies (Barr 2004; Boarder 2002; Hames & Carlson 2006; Mobbs *et al.* 2002; Stewart & Todd 2001). It is, however, important to note that the context in which these roles evolved is undergoing fundamental change, and particularly in England, with the proposed transfer of the 'public health' function of the NHS to local authorities. At the same time, the re-organisation of the English NHS is seeing learning disability nursing roles being transferred to acute NHS trusts, specialist mental health and learning disability NHS organisations, local authorities and social enterprises. All these changes are likely to impact on how community learning disability nurses participate in the implementation of public health policies for people with learning disabilities.

In the study by Barr (2006), health screening (35.13%) was the least reported area of public health involvement by community learning disability nurses in Northern Ireland.

In this study, at 58.8%, health surveillance was the least public health role in which community learning disability nurses who participated in this present study were involved. In stage 2 of the overall study, participants cited demographic ignorance as one of the most important moderators of how community learning disability nurses enacted their public health roles (Mafuba 2013). It was not clear why community learning disability nurses were least likely to be involved with health screening/health surveillance than any other area of their public health roles. One explanation could be that health screening is part of the GP contract, and community learning disability nurses' involvement in this area is only through collaboration with GPs who might not see these activities as a priority (NHS Employers 2003). Another explanation could be that UK health has been target driven in the recent past (Bevan 2006). This may have resulted in people with learning disabilities being part of the national statistics.

The *National skills framework – Dimension HWB1* clearly outlines public health role expectations for each community learning disability nursing band (DH 2004). For example, band 5 community learning disability nurses are expected to predominantly engage in health promotion activities, while band 8 nurses are expected to engage in more preventive work. The findings in this current study demonstrate a disconnect between the expectations in the *National skills framework* and the public health roles of community learning disability nurses in practice. What is perhaps of significant concern is the limited levels of engagement by band 8 nurses with health surveillance (44.4%), health prevention and health protection (50.0%). These findings are consistent with a study by Abbott (2007), which noted little involvement by nurse consultants in these roles. These results raise important questions about the contribution of band 8 community learning disability nurses in meeting the public health needs of people with learning disabilities. The reasons for this are unclear, but they are likely to be complex. What is, however, clear is the need for an in-depth evaluation of the contribution of band 8 community learning disability nurses in meeting the public health needs of people with learning disabilities. This is important because band 8 community learning disability nurses are in positions of leadership. Lack of role clarity on their part is likely to impact on public health role enactment by the nurses they manage.

Limitations of the study

All nonlongitudinal studies are limited in that they provide a temporal snapshot in constantly and rapidly changing policy and practice landscapes. Therefore, the findings of this study need to be understood and interpreted in the context of public health services for people with learning disabilities in the UK between 2008 and 2012. The sampling

method used in this study was focused on achieving representativeness rather than variability. This limits the generalisability of the findings beyond community learning disability nursing practice. In addition, although the sample size was sufficient for internal validity, a larger sample size would be required for wider external validity.

Conclusion

The current structure of the National Health Services is complex and presents significant challenges for the implementation of public health policies for people with learning disabilities by community learning disability nurses. There is a need for the National Health Services and other organisations to be aware and be more responsive to the public health needs of people with learning disabilities. The impact of the recent restructuring of the public health systems in Northern Ireland and England and especially the shift of responsibility of agency leadership for the delivery of public health services to local authorities in England will remain unclear for some considerable time. What is also likely to remain unclear is how community learning disability nurses will contribute to the delivery of public health services for people with learning disabilities in the light of these re-organisations. This study has highlighted the importance of the public health roles of community learning disability nurses in meeting the public health needs of people with learning disabilities. For the new system to succeed in meeting the public health needs of people with learning disabilities, the public health skills of community learning disability nurses need to be harnessed.

It is recommended that a national survey to obtain comparable data from a randomised sample be undertaken. Findings from the survey need to inform national guidance on the public health contributions of community learning disability nurses to the delivery of public health policies for people with learning disabilities. This is important to clarify their 'upstream' roles necessary in promoting the health and well-being of people with learning disabilities. The survey could contribute to the evidence base for current and future roles of community learning disability nurses. This will further clarify the national workforce needs and enhance the work already undertaken by the Learning Disabilities Nursing Task and Finish Group (Gates 2011).

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