**Carer Involvement in Mental Health Nurse Education: Values, Attitudes and Making a Difference**

ABSTRACT

The active involvement of people with lived experience of mental health (MH) issues and their carers is recognised as good practice internationally. Academic settings are seen to be an ideal, although potentially privileged, environments in which to demonstrate meaningful and authentic involvement. Despite the reported lack of evaluation/evidence relating to the impact of involvement, there continues to be a lack of research in this area with the examination of the carers perspective being even more limited.

This paper presents qualitative findings emerging from the Interpretive Phenomenological Analysis (IPA) of five semi-structured interviews with family carers who contribute to a Bachelor of Nursing (MH) programme. The study explores the perceptions family carers have relating to their involvement in nurse education.

Findings were themed and four central themes identified: having an impact, making a difference, connecting with students and seeing the whole person. Drawing on these themes provides opportunities to understand the motivation and drive carers have to improve health and social care services for carers and for people who use services offering knowledge about how carers perceive and evaluate the impact of their contributions.

Conclusions made relate to the value of involvement and how connecting with students throughout their programme of study builds rapport and meaningful, authentic partnerships. However, strategic planning and continued investment in co-production as well as a deeper understanding of the complex relationship students and carers have is needed.

INTRODUCTION

The active involvement of people with lived experience of MH issues and their carers is recognised as good practice internationally (World Health Organization, 2013). The policy and legislative rhetoric in health and health related professional education internationally indicates that the involvement of people with lived experience and their family carers should by now be embedded (Happell, Byrne, Platania-Phung, Harris, Bradshaw, & Davies, 2014a). Within the United Kingdom (UK), there are clear guidelines for nurse education to be delivered in partnership (Department of Health, 2010; NHS Education for Scotland, 2011, 2012; Nursing and Midwifery Coucil (NMC), 2010). The expectation is that people with experience of health care services and their carers work together with higher education institutions (HEI) to recruit and select students; develop and design health related programmes of study; as well as approve, deliver and evaluate nursing curricula (NMC, 2010).

BACKGROUND

The MH nursing pre-registration programme at authors university have a long history of involvement stemming back from their first co-produced strategy for involvement in the MH nursing curriculum in 2002 (Masters, Forrest, Harley, & Hunter, 2002). More recently universities internationally have formalised and embedded involvement through the development of service user research/academic posts and other co-production initiatives (Happell, *et al* 2014b; Mckeown, Malihi-Shoja, Hogarth, Jones, Holt, Sullivan, & Mather,2012; Rhodes, 2012). These developments are aimed at increasing the level of involvement that people with lived experience have in the education of the health workforce. Through broad, demonstrable engagement with the ideology of co-production, authenticity can be enhanced and will encourage those preparing to work in healthcare to adopt this approach in their daily practice. However, it is perhaps easier to facilitate authentic co-production in an educational setting when compared to practice settings where the power imbalance is more challenging to address (Mckeown *et al.*, 2012).

The Nursing and Midwifery Council (NMC) emphasised the significance of partnership within the standards relating to nurse education. They state that from a general competence perspective all nurses should: “… *work in partnership with other health and social care professionals and agencies, service users their carers and families in all settings*” (NMC, 2010: 21). Specifically, they state that MH nurses must “…*work with service users, carers, other professionals and agencies to shape future services*...” (NMC, 2010: 27).

Conversely, service providers in health settings are reported to continue to hold negative attitudes towards true partnership working (Happell, *et al.,* 2014a). It is these attitudes that are reported to stand in the way of making progress in relation to meaningful, authentic involvement in practice (Warne, McAndrew, King, & Holland, 2007). Educating future nurses in a way that not only models involvement but also provides opportunities for this to be visible and meaningful, could be seen as the catalyst for culture change required in clinical practice (McCaig, McNay, Howatson, McCormack, McIntosh, & Mathers, 2014; Repper & Breeze, 2007). Nevertheless, in academic settings several barriers continue to negatively impact development in this area. In particular internal systems and resource issues within higher education bring challenges to developing and sustaining meaningful involvement (Gutteridge & Dobbins, 2010; Mckeown *et al.*, 2012). Added to these practical barriers are concerns about how representative peoples contributions are, assuring a shared agenda together with a lack of evidence and evaluation of the impact and outcomes of involvement (Happell, et al., 2014a). Despite the barriers, the inclusion of service users and carers in higher education in health and social care has become commonplace, if sporadic and variable (Happell, *et al*., 2014a; Mckeown *et al.*, 2012; Robinson & Webber, 2013).

Given the lack of evaluation and evidence related to the impact of involvement in nurse education, the purpose of this study is to add to and enhance understanding of the perceived value and impact of carer involvement in MH nurse education.

Aim: An evaluation of family carers’ perception of their contribution to the learning teaching and assessment of student nurses on the MH Nursing programme.

1. Why do family carers’ become involved in the MH nursing programme?

2. What are family carers’ perceptions of contributing to the pre-registration MH nursing programme?

3. What are family carers’ experiences and perceptions of the impact their contribution has on student nurses.

4. How do family carers’ who contribute to the MH nursing programme evaluate their input?

Literature review

A systematic approach was adopted to search the literature in relation to the topic. Relevant databases: CINAHL and British Educational Index was conducted in July 2016 for the purpose of identifying relevant literature. Inclusion criteria used in the review were: original/primary sources that reported on carers views in relation to involvement in nurse/healthcare education. A range of related terms were included to maximise the identification of literature (Table 1), however none focussed specifically on carer perspectives of involvement in nurse education. Due to the limited sources the review of the literature expanded and included papers that reported on both service user and carer perspectives and studies that were contextualised in other health or social care professional education.

Papers were excluded if they did not focus on the education of health or social care staff/students and if the primary focus was not that of service user and carer perspectives.

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| Carer\*Caregiver\*Family Families  | Involvement Participation Inclusion Co-production | EducationTraining Higher Education | NursingHealth careSocial care |

Table 1: Search terms

While there has been a steady growth of literature that focusses on service user involvement the same cannot be said to research that focuses on carer involvement. No studies that solely reported the carer perspectives of involvement in education were identified although some sources considered both service user and carer perspectives (Mckeown et al., 2012; C. Rhodes, 2012). The detail of the carer perspective was at best limited. Carer perspectives were touched on however they tended not to be the primary focus of the research therefore had limited depth on which to draw related findings. For example, Mckeown et al., (2012) reports on findings from a participatory action research study where the participants included both service users and carers. McKeown et al, note that themes drawn from the analysis did not focus on distinguishing between the views of each. Equally Rhodes et al., (2014) uses a Narrative Enquiry to explore the accounts of service user and carer educators and identifies the individual benefits of involvement but again these do not differentiate between carers and people using services.

In 2007, Repper and Breeze conducted a literature review that concluded there was a lack of clear evaluation of the impact of service user and carer involvement in education and its link to improved outcomes for people receiving MH care. A further review of literature conducted in 2009 by Morgan and Jones with an aim to identify approaches, perceptions and impact of involvement, had similar findings although differed from Repper and Breeze in that it considered outcomes of involvement rather than process (Morgan & Jones, 2009). Similarly this review had limited focus on carers despite the title indicating otherwise. A review was conducted by Happell, *et al*., (2014a), although seven years later than Repper and Breeze, the conclusions relating to lack of evaluation of impact remain.

Speed, Griffiths, Horne, & Keeley, (2012) explored service user, carer and staff perspectives of the barriers to involvement in higher education. This study used focus groups to generate data, two focus groups consisted of family carers. Although the focus group did not set out to explore the participant’s perceptions of involvement it did generate valuable data around the perceived barriers. This study identified the lack of teaching context, preparation and support as impacting on effectiveness although how effectiveness is evaluated was not explored.

The lack of detail relating to carers perspectives of involvement in the literature is in itself significant. Conclusions are difficult to draw from this gap and how to ascertain whether this is due to a general lack of research and reporting on carer involvement or that carer involvement in health education is underdeveloped generally. If it is the latter, then potentially less value is placed on involving family carers in education or that the emphasis in the policy rhetoric guides educators to service user involvement with carer involvement being an afterthought. MH carer networks are more recent and less developed than service user networks and often overshadowed by local and national generic carer organisations, campaigning bodies and networks. The lack of specific exploration of carer perspectives suggests a potential gap in the evidence base (Rhodes, 2012; Speed et al., 2012).

RESEARCH DESIGN

The approach taken for this study is phenomenological in nature as this qualitative methodology provides opportunities to examine the lived experience from the individual’s perspective (Bryman, 2016). This approach acknowledges that the participants will hold individual understanding of the concepts, values and meaning drawn from the experience (Pringle, Hendry, & McLafferty, 2011). IPA was chosen as it values the researcher perspective and encourages exploration of the researcher’s views to be explored throughout (Dowling, 2007; Heinonen, 2015; Smith, Flowers, & Larkin, 2009). Reflexivity is central to the analysis process and was used to document, explore and narrate the process recognising the researcher perspective (Jeanes & Huzzard, 2014). Reflexivity is the way in which the researcher can expose and examine the influence or potential impact they have on the research process.

IPA is an approach to qualitative research design that offers insight into how an individual in a particular set of circumstances makes sense of the phenomena (Maltby, Williams, McGarry, & Day, 2010; Smith & Osborn, 2004). IPA offers a stepped and detailed analysis of individual lived experiences which has resulted in increased use of IPA in health related research (Pringle *et al*., 2011; Wagstaff & Williams, 2014).

Due to the small number of participants in this study the individual focus is of specific value as it allows for detailed examination of complex individual human experiences that has not to date been explored (Smith *et al.*, 2009). IPA requires rich data that offers individuals to freely describe, explore and draw meaning from the given phenomena (Brocki & Wearden, 2006) and is usually, but not limited to the spoken word. Individual semi-structured, recorded interviews are used in this study as they have been shown to be an effective way to gather detailed, reflective and personal data required for IPA (Grossoehme, 2014; Smith *et al*., 2009). Semi-structured interviews allow for flexibility while also ensuring some quality and consistency, avoiding a drift away from the phenomena being explored (Gillham, 2013).

Interviews lasted between 40 - 55 minutes and participants were encouraged to give as much detail as they cared to. Open ended questions were developed from the research aim and questions to allow for a natural flow of dialog (Silverman, 2013). The language used in the interview was accessible avoiding abbreviations and offered prompts when needed, encouraging participants to use their own words which is valued in IPA (Grossoehme, 2014).

Sample

The sampling strategy was purposeful, criterion based. The target group was small and known to the researcher through work and teaching in the nursing programme. The inclusion and exclusion criterion (Table 2) supports the identification of individuals who share common experiences and therefore increased the homogeneity of the participants.

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| Inclusion criteriaFamily carers who currently contribute to the MH nursing curriculum.Family carers who have contributed to the current 2011 MH nursing curriculum. |
| Exclusion criteria Other partners who are not family carers who contribute to the current or previous programmes. |

Table 2: Inclusion and Exclusion Criteria

Six carers expressed an interest in being involved in the study; one withdrew from the process prior to the interview being conducted. All five remaining participants were interviewed and their contributions used in the analysis process.

All participants were female and had contributed to nurse education through; interviewing and selecting students for the programme, teaching and learning activities, module and programme development and student assessment. All participants had contributed to the programme for more than one year ranging from 1 – 7 years.

Ethical considerations

Ethical approval was gained through the author’s institutions ethics committee and participants were invited to take part and given information about the aims and research questions related to the study. The potential participants were given the interview questions before the interview and free to withdraw from the study at any point. Invitation to participate were sent by an independent team member to ensure participants felt able to decline. Signed consent was obtained.

Confidentiality was maintained throughout, all documentation, recordings and data generated by the interview process was made anonymous and stored according to the university’s ethical code.

Analysis

The five transcribed interviews were analysed using an IPA process. The IPA process is described as moving from *“…the particular to the shared…”* or from the descriptive to the interpretive (Smith, *et al,* 2009: 79).

Each transcript was examined line by line to identify the concepts, perceptions and meaning-making of each participant. Smith *et al.,* (2009) describe a set of 6 steps for the analysis of data described in Table 3. As the researcher was known to the participant a reflective diary was maintained throughout the data gathering and analysis process, this helped the researcher to explore the thoughts and feelings of being an active participant in the research.

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| Step 1 | Reading and re-reading |
| Step 2 | Initial noting |
| Step 3 | Developing emergent themes |
| Step 4 | Searching for connections across the emergent themes |
| Step 5 | Moving to the next case |
| Step 6 | Looking at the patterns across cases |

Table 3: Stages of IPA adapted from Smith *et al* 2009

Analysis in IPA is completed case by case, steps 1 – 4 are competed for each transcript and the final steps encourage the researcher to reflect on the similarities and differences in each and those that are shared while keeping the individual voice and variations at the core (Smith et al., 2009).

FINDINGS

Four central themes emerged through the data analysis process (See Table 4): *Having an Impact; Making a Difference; Connecting with Students;* and *Seeing the Whole Person.* Participants had many reasons for deciding to become involved in nurse education, some were personal and some altruistic in nature. However, the common goal was to make a difference both for carers and for people who use MH services. All carers interviewed experienced involvement in both recruitment and selection of student nurses onto the programme and face to face teaching. Four of the five carers had also been involved in assessing students work. The findings unsurprisingly indicate a different description of impact depending on the type of involvement being discussed.

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| **Core theme** | **Subthemes** |
| **Having an impact** | Showing emotionsStory tellingTraumatic Difficult to talk aboutPersonal Achievement |
| **Making a difference** | Raising awarenessShaping practiceImproving things in the futureBringing a different perspective |
| **Connecting with students** | Challenging attitudesChanging perceptionsGetting the message acrossEngagement/lack of engagement |
| **Seeing the whole person** | As a personMore than just an illnessIdentity Understanding the person |

Table 4: Themes and examples of sub themes

The themes identified are not hierarchical and are described as they emerged from the analysis.

Theme 1: Having an impact

Participants spoke of the value of storytelling and sharing their experiences with students to express their experiences in a genuine and honest way. The strength of personal story-telling helped to highlight the challenges that they faced in the caring role, relationships with those they were caring for and the experiences of connecting with nurses:

*“…it is the anecdotes that kind of makes the story and I think that you probably remember that better”*

*“I hope that they will take it away and think… I can change that!”*

Some participants wanted to change the way carers are viewed:

*“…if you have changed their perception [of carers] at the beginning everything they do while doing that course will be done in that way.*”

For most, storytelling allowed for the expression of a range of emotions connected with their experiences of caring. Showing of emotions while sharing their experiences seemed to link with the sense of having an impact and the reality of the caring role on the student group:

*“…they should be horrified that I think this is normal.”*

*“I think it is really important that we do show the extremes of what it is like and not just gloss over because you are embarrassed”*

*“…I think that by showing my emotions and my feelings and by them sharing them, they will remember.”*

Participants described the reactions of students as a way to gauge the impact of their teaching. Most outlined how they evaluated the impact the stories and experiences shared had on the student group by picking up on non-verbal cues and the questions and comments from students:

*“…you can see their facial expressions change.”*

*“…the thoughtful students really responded.”*

*“…some have been shocked by some of the things that I have had to tell them…”*

It was clear from the participants perspective that having an impact on the group was a significant part of how they evaluated their contribution. Carers placed a value on open, honest descriptions of the reality of caring. This reality was key to creating engagement with the group and having an impact. Most noted that this came through a personal determination to make an impact on the student indicating the meaning placed on student reaction as a form of feedback.

The participants described different experiences when they considered the impact on themselves. When speaking about their caring roles most described both positive and negative personal impact. The participants describe a labour in sharing stories and talking about caring that at times was traumatic.

 *“It can get you down, it can be difficult…I would have a rant and would be fine”*

However, most described the difficulties being outweighed by the potential for making a difference for other carers and people who use MH services.

*“…so for me, it is a positive thing, but it is draining.”*

*“…you are re-visiting the negative all the time – but that is the message you need to get over to the students.”*

Theme 2: Making a difference

Carers spoke of changing things for the better. This was in relation to the experiences of other family carers and the experience of those they care for. There was a perception that influencing student nurses views and attitudes at an early point in their education would ultimately influence their practice.

*“…that is the hope, that students will take this into their practice.”*

*“I wanted to maybe change things so that people didn’t experience the negative stuff that we experienced with MH services.”*

*“…it is important to get the right attitude into someone before they start”*

*“…so they also have to put their emotions not just their brain into it* [nursing]*”*

Carers considered their contribution gave a different perspective from others involved. Most spoke about this in relation to contributing to the recruitment of students and student assessment:

*“I think that when you hear perspective students speaking you can pick up on things that professionals, professional teachers might not.”*

*“…we can each see a different thing”*

*“…although they are looking for different things the end role is going to be the same….a good quality of student”*

Participants described making a difference that appeared to be related to the reason they became involved in education. For those who wanted to increase the awareness of a particular condition, for example dementia, the way they described making a difference was related to promoting understanding of the condition and how it affects people and issues that presents carers. For others the focus was to make things better for the person they care for, for example to improve communication, to highlight effective ways of working or to give the service user a voice.

Theme 3: Connecting with students

Participants valued connecting with students and having an opportunity to speak to them about their experiences of caring. Some spoke of connecting with students on a personal level. For those, this was a way to challenge some of the potentially negative views of carers:

*“…it is positive for the student to actually hear from someone who has been through it.”*

“*I think a general attitude to carers and the feeling that we have a lot to contribute rather than being an obstacle”*

*“…the more people [students] that are aware of what it is like to be in that situation [being a carer] the better ‘cause sometimes you are completely ignored by people. [staff]”*

Some participants described being approached by students out with the class room in practice to express how much of an impact the teaching session had on them. Carers valued this recognition and validation of the contribution they made. This also occurred when carers were involved in teaching student groups later in the educational programme. Two participants spoke of how students they interviewed approached them in class in subsequent years.

When exploring the connection with students participants described two extremes, those students who connected positively with them:

*“It comes over when they ask questions you realise that they actually are interested…”*

*“I did enjoy talking to both classes that I have spoken to. I felt they really did listen.”*

*“…you can just tell a lot from the facial expressions and then the questions.”*

However there were also descriptions of students who appeared to be disconnected. This was described as not making eye contact or using a mobile phone while in class. When this occurred, carers felt de-valued and frustrated and considered it as an indication of disinterest or negative attitudes towards the value of carer contribution in education.

*“Horrendous, mobiles should be off and away...Oh I got cross at that”*

*“…chatting up the back, that is really upsetting”*

However, some did not describe negative engagement with students and one noted similar behaviours but did not see this as negative but as a way of dealing with or processing difficult or challenging content:

*“there are quite a few students who have personal experience and that makes it difficult.”*

*“…looking disinterested or doodling and then ask a really good question”*

Theme 4: Seeing the whole person

All participants spoke of the need to campaign and stand up for the rights of people receiving MH care. For some, the primary reason for becoming involved in education is to improve the care:

*“…if you can alert professionals or future professional to what actually goes on then hopefully things can be improved for other people.”*

*“…it was a kind of a burning passion to you know, bang the drum for carer and people with dementia and try to get the system improved.”*

While for others it was about ensuring that staff see the person in the way their family sees them with the history, skills, knowledge and experiences they have had throughout their live and importantly before they were affected by MH issues.

 *“…it’s about him having a daughter, a sister, a mother…”*

*“…you have no benchmark against which to say he is improving…”*

The perceptions of participants indicated that they felt staff providing care viewed the person in relation to the condition that affected them, connecting with the person in the context of their condition, symptoms and past MH history rather than an individual.

*“…help [staff] understand that it is more than just and illness, it is more than just what they are seeing at that moment in time and that person doesn’t exist in a bubble.”*

Due to this there was a perception that the carer is the connection between the person before the illness and the person as they are seen by MH care professionals.

DISCUSSION

There are different reasons for family carers to become involved in education. The participants in this study demonstrate a drive and determination to bring about change and to support the education of student nurses. This is clear when consideration is given to the personal impact this has on some participants. The common aspects described by people who commit time and energy to educating student nurses include but are not exclusive to the greater good. This altruism is evident in the narratives from the interviews and focusses around two key desires; to make things better for the people they care for and to make things better for other carers. Unfortunately, this appears to stem from negative experiences that carers have had when being in contact with health care services as indicated in the quote: *“…you are re-visiting the negative all the time – but that is the message you need to get over to the students.”* Consideration needs to be given to the benefits of revisiting negative experiences from both the student and carer perspective. In education settings this could however, provide an opportunity for carers and students to work collaboratively to explore ways to change practice, creating a more positive outcome while demonstrating co-production in action.

The reasons for becoming involved is in some ways similar to the perspectives of people who use MH services particularly in relation to changing and improving practice (Happell, *et al.*, 2014a). Although in contrast to personal health benefits, empowerment or to “give something back” which appear to be described more by people with lived experience of MH services (Mckeown *et al.,* 2012). On reflection, opportunity is also a factor, involvement is only possible if institutions invest and embrace the value of involvement.

A significant finding of this study is that negative experiences influenced carers drive to become involved. This shows that there continues to be issues with the attitudes that health and social care staff hold in relation to family carers. From a carers perspective, this also shows that carers believe that these negative attitudes can be challenged and changed through their involvement in education, particularly early in students’ careers. This view is in line with the policy rhetoric in health and in education but is assumed rather than evidenced.

Some literature indicates that there are fundamental issues with involvement due to how representative an individual’s views are for the purpose of professional education (Anghel & Ramon, 2009). None of the carers interviewed considered their experience and or contribution as representative of all carers but rather a personal narrative or perspective to enhance learning and change practice for the better.

Participants described how they evaluated the impact of their involvement by using the verbal responses and visual non-verbal cues from the students during the teaching session or activity. This clearly subjective evaluation of impact in the moment provides only limited evidence on which to draw any conclusions. However, all participants valued connecting with the students through on-going involvement through their programme. Developing a rapport or connection was seen to be supported by building on the initial contact like the interview and selection process, followed by teaching in subsequent years. This was further enhanced by involvement in module delivery and assessment in the final year. The notion of connection concurs with other research where findings suggest that impact could be enhanced through a planned and strategic approach to involvement (Rhodes, *et al.*, 2014) providing further opportunities for essential evaluation of involvement (Happell, *et al.*, 2014a).

The experience of being involved in the education of student nurses was on the whole a positive experience for all the carers interviewed. However, worthy of note was the personal and emotional impact this involvement triggered for both the carers and the students. Interestingly, O’Donnell and Gormley (2013) note that increased exposure to negative service user experience in education could be troublesome particularly for vulnerable students and recommend that further research and ongoing review is needed.

The perceptions of carers in relation to the level of engagement the students had in the class room was important in demonstrating their values, attitudes and respect. When this was not demonstrated, some carers felt devalued and frustrated which could impact on future involvement and limit the educational experience. The way in which people respond to emotional narratives in educational settings is complex and may be a result of long held values, attitudes and personal/professional experiences rather than disinterest (Anghel & Ramon, 2009). Further examination of the complex interaction with students, carers and lecturers for that matter, is needed to establish why people respond in the way they do and how this knowledge can enhance the impact of involvement.

Due to the limited research specifically around carer involvement in nurse education and the potential value it has to bring about changes in attitudes and values, emphasis needs to be placed on sharing good practice. As involvement remains central to MH strategies (NHS England 2016; Scottish Government 2017), collaboration and wider research across the UK and internationally is needed to inform and develop comprehensive, enriched nursing curricula in relation to the involvement of people receiving care that is considerate of the impact on all those involved.

Limitations

The small number of participants is in line with the nature of this individual perspective and the findings are not intended to be generalised. The findings and interpretation are limited to the context of the participants and their experience in the moment.

The different aspects of involvement, in particular teaching that focusses around personal experiences of carers and the more task focussed recruitment and assessment aspects are not a natural fit to explore perceived impact and meaning and perhaps could be examined separately to draw out more specific detail.

CONCLUSION

Research interest on the impact of carer involvement in nurse education is at best tokenistic despite the policy and professional requirements. This study contributes to the emerging knowledge and understanding of what encourages carers to become involved and what carers perceive as the possible outcomes of this involvement. The participants in this study indicated that their involvement in the education of future MH nurses often stemmed from negative experiences of health care. Their continued involvement is perceived to improve experiences of carers and help provide nurses with context within which to view the people they care for that is not framed by a diagnosis.

In order for involvement to have impact it needs to be strategically planned across a programme of learning to maximise the rapport and connection students have with carers while offering opportunities for further evaluation. Preparation is required to ensure that the exploration of difficult experiences do not impact negatively on carers and students. Rather, they should provide a springboard for co-production and creative dialog to bring about change. There is a clear policy rhetoric internationally for the inclusion of people who use services and their carers in the education of health and social care professionals. Collaborative, international research and sharing of good practice along with further, longitudinal research studies into the impact of carer involvement throughout and beyond nurse education would provide the required evidence base to formulate frameworks that support inclusive curricula.

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