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Collaboration with service users to develop reusable learning objects: The ROOT to success

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A B S T R A C T

The involvement of service users in the education of health workers is seen as an important component within the curriculum. It is thought to facilitate the students into developing a deeper understanding around the real lives of their patients, and therefore ensuring their care is more person centred. The subject area focused upon was developing students' awareness of the needs of people with a learning disability. Recent incidents in the press have highlighted examples of poor quality care and a lack of understanding by health and social care professionals in regard to their needs. This article highlights a number of key issues which must be considered when involving service users, namely consent, ethical practice and collaboration. This article will describe the participation of service users in the development of reusable learning objects (RLO's) and make recommendations on the optimum way to undertake such an activity. From this process a framework has been developed, described as the ROOT to success. The ROOT element of the structure relates to **R**elationship, **O**rganization, **O**utcome and **T**eam.

Introduction

The Faculty of Health and Social Care at The University of Hull, similar to many education providers of health care, is working to support the development of interprofessional learning using a variety of methods (Connor, 2003; Carpenter et al., 2006 and Quinney et al., 2008). One of the key difficulties in facilitating interprofessional learning can be identifying a subject area that is useful for all groups. During a previous interprofessional online conference within the university, depression was chosen as a relevant subject area for all the professionals involved (Santy et al., 2009). This evaluated positively and a further online conference was organised around learning disability. The topic of learning disability was chosen after a review of the literature (Michael, 2008; Service Users Advisory Group, 2001; Pockney, 2006; Gibbs et al., 2008; Manthorpe et al., 2003). One of the key documents identified was 'Death by Indifference' (MENCAP, 2007) which identified the deficiencies in care given to people with learning disabilities. It was decided that the learning resources for this event would be developed with the aid of relevant service users. The Department of Health (2001, 2009) recognises the importance of service user involvement. People with a learning disability have clearly voiced their views that nothing should be written about them, without their input (Johnson, 2009). So it was important that they were consulted. This article outlines the process of developing RLO's and suggests a framework for the involvement of service users in developing and preparing these resources. A grant was obtained from Yorkshire and Humber Strategic Health Authority to undertake research into online interprofessional learning and to develop RLO's with the involvement of service users. The focus of this paper is not on the outcomes of the research project but on the framework, developed through the process of participating with service users.

The ROOT to success

In developing a framework of involving service users Arnstein's ladder of citizen participation (1969, p. 216) was considered. However, it has been identified that to link participation to a ladder means that it cannot stand alone and needs to be supported by an outside structure (Collins and Ison, 2006). Tritter and McCallum (2005) have recommended the use of a scaffold or a mosaic of connected ideas. The view that the involvement of service users needs to be supported by some outside framework is one, with which we would agree, and have therefore developed the concept of a tree like structure. This is because a tree is something alive and growing and if healthy has a strong network of roots to support it. Hence there is a growing element to any service user participation

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and this involvement should be based on their 'lived experiences'. The network of roots needs to be supported with essential elements and we feel this reflects our view that any such relationship needs to be nurtured and not left to stagnate and remain the same. The ROOT element of the structure relates to **R**elationship, **O**rganization, **O**utcome and **T**eam. Whilst the team forms and develops, it is linked and changed by the project itself.

When working with vulnerable groups the key principles identified were;

Relationships – collaboration, participation, reciprocal, respectful, trust.

Organisation – remuneration, time management, evaluation.

Outcomes – educational, social, effective, knowledge and understanding, gain a different perspective.

Team – interprofessional, developing, inclusive, engage, real, consent.

This paper will explore each element of the ROOT framework and discuss how the principles of working with service users were developed.

Relationships

Relationships within a project environment are important in order to ensure effective collaboration. It was important to the project team and particularly those involved in meeting the 'Speak Up' group and actors that there was a true collaboration. Speak Up groups are self advocacy groups which encourage people with learning disabilities to speak up for themselves and therefore contribute to challenging the structure of society (Monach and Spriggs, 1994). It has been identified that accessing vulnerable groups in order to gain some understanding of their needs and views is very difficult, but crucial to improving their care (Marsham, 2009). There has been a lot of discussion within the literature around different levels of participation (Whittaker and Taylor, 2004; Flanagan, 1999; Gutteridge and Dobbins, 2010; Forrest et al., 2000; Hickey and Kipping, 1998). An example of this is 'A Ladder of Citizen Participation' (Arnstein, 1969, p. 216). It is argued that many collaborations are in fact just a 'tokenistic way of saying that service users are being involved (Arnstein, 1969, p. 4, Hart, 1992). One of the aims during the process of writing and filming was to establish a relationship between the project team and the service users. The 'Speak Up' group drove the agenda around the story and therefore were the focus of the script. This, according to Arnstein (1969) would link with the delegation of power and citizen control. A story board was developed with the use of pictures and discussion so that the group could confirm that this was what they had said and wanted to include in the story.

There are criticisms of Arnstein's (1969) work and whether this is transferable into health care. Tritter and McCallum (2005) indicated that the need identified within Arnstein's model to share power is not necessarily helpful. They highlight that power sharing may not be the goal for some service users and that they can benefit just from the act of participation. The question is: Does there need to be a 'hierarchical approach' to the involvement of citizens? (Tritter and McCallum, 2005, p. 158). Within this project the team would say no, as the 'essential role of service users was to frame problems', through sharing their lived experiences.

When dealing with vulnerable groups the issue of consent must be considered, this was a key area of concern for the project team. The Speak Up group and actors were all briefed as to what their role would be and were informed that participation was voluntary and that they could decide to withdraw from the project at any time. This was communicated using an accessible form of information sheet to illustrate the point. The actors were also debriefed after the filming to ensure that they understood that the events filmed were not real. This was particularly important, as the story included some scenes which could be considered to be quite distressing. They were given the opportunity to talk about their experiences, which they appeared to enjoy. During the preparation for their roles and during filming, the actors were accompanied by either a supporter or carer. This was again another safeguard for their rights and views, although both actors were living independently. There was also a need to debrief the drama students, as they had found it particularly difficult to ignore a person's cries for help in a scene depicting a fall in a public place.

Good working relationships were essential in the project and it was important to confirm that these were built on trust, effective communication, and ensuring that consent issues were thoroughly discussed and addressed. The organization of the meetings and the filming was crucial to ensure that everyone knew his or her role.

Organisation

There are, of course, challenges to any development of this type. One of these was the length of time it took to do the filming, but we had to give an opportunity for the actors to rest and also review what they were going to say and do. Communication was a key factor, it was important to communicate in a way that all participants could understand and it was therefore necessary to take advice from the learning disability lecturer about how best to do this. The group had developed the story with support from their group leader and learning disability lecturer. The lecturer was the link to the project team. Two members of the team met with the actors and their carers to discuss the story and develop a script. Finding and working with user groups requires a significant amount of organisation. The needs of the user group and carers must be paramount when organising any meetings or activities. This involves meeting them at times and places convenient for the group rather than the project team.

The cost of such a project should be considered; this mainly consisted of filming, transport, and hospitality and Information Technology (IT) costs, associated with development of the virtual town to accommodate the story.

Another important factor is one of remuneration, as with anyone who participates in the teaching of students at The University of Hull there is a need to provide appropriate payment, whilst not jeopardising any employment or benefit arrangements. If vulnerable people are to be involved in this type of project as full partners then they must receive appropriate expenses. This involved travel expenses, hospitality and a payment of an agreed fee to the acting group for their time.

Outcomes

The key areas which the 'Speak Up' group wanted to address related to poor communication, their anxiety about what they should do in the event of an emergency and the lack of willingness of the general public to help a person with a learning disability who was distressed. The group identified that people were hesitant to talk to them and tended to avoid contact as much as possible. This was included within the script when people in a shopping centre were shown ignoring the actor's pleas for help, after his partner had fallen and broken her arm. As well as in the hospital when the female actor was put into a single room and left alone for long periods of time without any support. The couple's key worker was also identified as being 'bossy' and not really listening to their views and not considering their needs in relation to written communication from the GP and practice nurse. All these incidents led to miscommunication between those who were there to care and the couple themselves which resulted in a great deal of distress.