



Learning from the experience of working with consumers in educational developments

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Summary *Aim.* The aim of this paper is to report the experience of working with local parents as collaborators in an educationally focussed research study. This work subsequently led to the development of a new module aimed at professionals providing parenting support. The ensuing discussion centres on the involvement of healthcare consumers in the development of educational programmes.

Methods. Focus group interviews were held with local parents to identify their various experiences of parenting support services. In addition the interviews were used as a means of recruiting local parent volunteers willing to join the research advisory group. This group had the task of guiding both the research and development of the educational programme.

Findings. Involvement of the parents introduced fresh insights to both the understanding of the content of parent education module and the necessary ingredients needed for effective consumer involvement.

Conclusion. Lecturers have gained first hand experience of working collaboratively with parents in carrying out a research study and curriculum development. Three key issues emerged from this experience. These included the identification of who the consumer is, the approaches and skills required by professionals and lastly the importance of resources to support this commitment.

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Introduction

The aim of this paper is to report an experience of working with consumers as collaborators. Our purpose is to draw attention to the issues pertinent to involving healthcare consumers in educational de-

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velopments for professionals, as well as illustrate the added value lay perspectives can bring to education. The paper is divided into three parts: firstly consideration will be given to the background and context of consumer involvement. Secondly, a parenting research study will be used to illustrate the experience of consumer involvement and the influence on subsequent module development. Finally there will be a discussion of key issues relevant to educationalists.

Terminology

When reviewing published health care literature there appears to be an array of terminology ('Users', 'Consumers', 'Clients' or 'Patients') used to describe public involvement or participation (Allen, 2000). Lloyd et al. (2001) and Telford et al. (2002) comment on this confusion from both a client and professional perspective, emphasizing that the key issue of concern is the partnership created rather than role labels. Within this paper the term 'consumer' is used to mean individuals who receive health care and therefore have a vested interest in the level and quality of care received.

Background

The ultimate goal of health care practice is to improve the health and well being of the recipients of those practices. This being equally applicable to those with responsibility for educating future practitioners' as it is for those whose daily practice involves patient/client contact. Such goals have acted as levers for the increasing demand that practice shows clear relevance to the needs of various consumers (Department of Health [DoH], 2000a) and practitioners are urged to accommodate consumer involvement in health care developments and research (National Consumer Council [NCC], 2002). Action, which aims to improve local understanding of service provision, by strengthening local ownership, public confidence and access to services.

The origins of consumer involvement within British health care can be tracked back to the late Victorian period when charitable organisations began community development type activities (Smithies and Webster, 1998). By the mid-20th century demands grew for new strategies to tackle health problems in Developing Nations, generating the impetus for 'Health For All by the year 2000', an internationally recognised strategy endorsing the importance of lay involvement in public health

and community development methods (WHO, 1991). Lying at the heart of 'community development' is consumer involvement in-action, where local community members are encouraged to become 'active participants' in healthcare as opposed to 'passive recipients' of care (Smithies and Webster, 1998).

Evidence of how local populations can positively contribute to health programme planning and training can be found in work supported by the WHO and UNICEF (Rifkin, 1996). Although Ndekha et al. (2003) warn that the success of these programmes depends largely on how community participation is approached and whether the complexities of participation are fully understood. Despite such complexities action by international agencies has raised global consciousness and influenced the political moves for consumer involvement in healthcare not only in the developing world (Rifkin, 1990), but also within modern developed states (McKee and Figueras, 1996; McKee and Fulop, 2000; Lloyd et al., 2001). Certainly within British policy there has been a clear and resounding message about the need for greater public involvement in health care decision-making (DoH, 2000a, 2001a, 2002a), research (Consumers in NHS Research [CNHSR], 2000)¹ and nurse education (English National Board [ENB], 1996). A drive grown from the need to develop public services which are more relevant and accessible to local communities (DoH, 2001b) as well as the need for increased transparency in the activities of public bodies (DoH, 2002b).

The rationale for consumer involvement

Commonly, improved accessibility of information and consumer empowerment, are cited as reasons for moving ahead with consumer involvement (Hickey and Kipping, 1998; CNHSR, 2000). In expanding these laudable goals Boote et al. (2002) encourage reasoning within theoretical, ethical and political dimensions. Theoretically, consumers are experts in subjective experiences of illness and as such can balance the clinicians' expertise in disease and support a more holistic view of health. Added to this it would be unethical to deny patients the right to comment on and represent the illness experience, given their own expertise, particularly when it affects daily functioning. Finally the political dimension is equally compelling if accepting consumers as citizens who have the right to challenge traditional decision-making systems through

¹ Consumers in NHS Research is now known as INVOLVE.

civic action. This latter dimension is evident within the NCC's work, which includes development of a training programme for patients wishing to be advocates and represent consumer views to health service decision-makers (National Consumer Council, 2004). Within the conduct of research too, practitioners are urged to use methodologies that give service users a true voice. An ambition that will only be realised if consumers are included in the decision making and action required for programme design, delivery and evaluation and not simply by the completion of surveys driven by provider-led agendas (Edwards, 2000).

The above perspectives tend to point towards positive reasoning for lay participation on the basis that it gives more power to those traditionally denied it. Cynics may contend this position, arguing that in reality little power is actually transferred to consumers and what really results is a dilution of responsibility where professionals get 'off the hook'. In a similar vein White (2000) argues that it is the professionals who realize benefits, since involving local people can be a means of diffusing professional conflict, which in-turn strengthens the professional power base and maintains professional/lay distance. Currently however these various positions at least for consumer involvement in health research (Boote et al., 2002) and nurse education (Wood and Wilson Barnett, 1999) remain relatively academic since little evaluative work has been done to demonstrate the effectiveness of such strategies.

Involvement in education

The subject of consumer involvement has within nurse education typically gained attention from the mental health field (Edwards, 1995; Rudman, 1996; Wood and Wilson Barnett, 1999; Forrest et al., 2000; Le Var, 2002) as a result of specific government attention on this area (DoH, 1994) and perhaps the obvious ethical reasoning for involving these patients in decisions about their care. A similar move is now also being seen within cancer care (Flanagan, 1999; Daykin et al., 2002), with the introduction of the NHS Cancer Plan (DoH, 2000b). Features common to both these fields include a concern about the lack of organisational systems and practical help available to those planning to involve consumers. Whilst some advice is available (ENB, 1996), others advocate the need for specialist training (Flanagan, 1999; Forrest et al., 2000) as without such tangible support the involvement of consumers is unlikely to extend beyond organisational

speaking and spin. Training addressing the topics of partnership working and shared decision-making is recommended for both consumers and educationalists, in view of the need for cooperative working between these potential diverse groups. Interestingly this recommendation mirrors pleas from a Zimbabwean community development programme that also called for providers and consumers to engage in mutual learning processes, claiming it to be an essential ingredient for achieving community participation (Ndekha et al., 2003).

Levels of involvement

To conquer challenges posed by aspirations of partnerships, consumer involvement can usefully be envisaged as operating along a participation continuum, anchored by two different approaches to consumer involvement. Namely, consumerist and democratisation approaches (Hickey and Kipping, 1998). The consumerist approach is typified by information sharing and consultation activities where at best consumers are enabled to make independent choices through acquisition of information. By contrast the democratisation approach recognises those using services as citizens, who not only comment on service outputs but who can also decide the content. Here Hickey and Kipping (1998) explain there is a notable redistribution of power supporting partnerships and in some instances user control over service decision-making. Additionally with regards to research CNHSR provide a list of descriptors identifying levels of involvement. A comparison of Hickey and Kipping's (1998) continuum and the CNHSR descriptors are illustrated in Table 1.

As an alternative Boote et al. (2002) illustrate how consumers may be classified according to (a) their vested interest and (b) the numbers involved which can range from an individual to whole populations. These classifications are less concerned with the nature of the activity and instead focus on the reasoning for involvement and the form the consumer takes.

The parenting research study

In keeping with the increasing attention on engaging local people in health services, community development type programmes have risen in popularity. The Home Office driven Sure Start programme is one particular example that aims to improve lives of families through involving parents in community activities. This programme

Table 1 Continuum/levels of involvement
Hickey and Kipping (1998)

Approach	Participation continuum	Levels of involvement
Consumerist – allows commentary on service outcomes leading to:	Information/explanation – information provided to consumers who have no decision making powers Consultation – consumer views are sought but not necessarily utilised	Consultation – views of consumers are sought in order to inform decision-making
<ul style="list-style-type: none"> • Increase consumer choice • Increase in responsiveness of services 		
Democratisation	Partnership – negotiations result in re-distribution of power enabling joint decision making User control – consumers lead the decision making process	Collaboration – active ongoing partnership with consumers in the research process User control – consumers lead the research process by designing, undertaking and disseminating the results of a project
<ul style="list-style-type: none"> • Decision making at a community level • Community members recognised as ‘Citizens’ • Citizens inform service content 		

has also provided scope for community nurses to realise new ways of working as advocated by the Making a Difference Document (DoH, 1999) and has encouraged NHS Primary Care Trusts (PCTs) to invest in parenting support training for staff. This in turn gave rise to a research study, commissioned to the University of Central Lancashire (Whittaker and Taylor, 2001), exploring the educational and training needs of staff providing parenting support. An explicit focus of the study was the incorporation of consumers’ perspectives not only as research participants but also as research partners.

Data collection

Approval to proceed with the study was gained from the Local Research Ethics Committee. Informed consent was obtained by writing to both practitioners and parenting group facilitators requesting involvement in the study. Letters were supplemented with an information leaflet. In addition agreement was obtained prior to the focus groups and again on the day of interview.

Data collection methods included separate focus group interviews with two Health Visitor and School Nurse groups ($n = 10$) and three established parenting groups ($n = 26$). Exploration of educational needs was informed by three categories derived from Carper’s (1978) Fundamental Patterns of Knowing and hence interview questions covered aspects of attitude, knowledge and skills development for practitioners. Practitioners were asked about their perceptions of what effective parenting was and how parents could be supported. Parents were asked about their experiences of health care provision in relation to parenting and their perceptions of how practitioners should be prepared for these roles. Focus group interviews were also used as a means to recruit local parents to join the study advisory group as research collaborators. Two parents from each group volunteered, resulting in an advisory group consisting of six parents, two lecturers and two practitioners.

Research findings

The findings were characterised by practitioner and consumer dissonance, a feature that reinforces the benefits of consumer perspectives on health care experiences (Tetley and Hanson, 2000). The findings are considered within Carper’s framework (1978) categories.

Knowledge category

Practitioners were concerned about having sufficient knowledge regarding management of complex behaviour in children whereas parents' priorities differed in emphasis. Parents were more concerned that practitioners could acknowledge their limitations and refer accordingly rather than demonstrate in-depth specialist knowledge.

Skills category

Here practitioners emphasised the need to have training in how to use specific resources and training packs to support their professional role. Whereas parents' concerns were about the basic foundations for practice, identifying sound interpersonal skills, and ability to include parents in decision-making as key areas.

Attitude category

For parents, skills and attitudes held by practitioners were closely bonded with the demonstration of a respectful attitude being the key to successful practice. Parents readily identified skilful use of interpersonal communication as the fundamental component of practitioner resources. They viewed this as a resource that would enable them to approach the relationship with a parent in a collaborative manner. In particular parents emphasised the need to be listened to. Whilst recognising this as an important aspect of practice, many practitioners underestimated the level of importance parents attached to it. Many believed that their pre-existing professional experience had sufficiently equipped them sound interpersonal skills and instead placed greater emphasis on the need to present an attitude that conveyed a depth and breadth of knowledge of parenting subjects.

In effect dissonance between practitioners and parents is characterised by a consumer concern for staff attitudes and ability to communicate effectively and a professional concern for depth of knowledge. But as a parent in one group articulated:

They need to understand parents more, listen and be able to communicate. Shouldn't go in and tell people what to *do*... There should be equal decision-making. (Parent 7)

The study findings suggested that parents are unlikely to accept professionals who have a strong knowledge base if they do not demonstrate an ability to listen and work with them (Whittaker and Taylor, 2001).

Experience of working with parents as research collaborators

The reality of working with parent collaborators was interspersed by dilemmas evident within the process. These concerned roles, responsibilities and the redistribution of power amongst advisory group members.

At the outset of the research study a consumerist approach to parent participation was adopted. Initially parents were engaged as research subjects and assumed the consultation level of participation (Hickey and Kipping, 1998). At this stage it was the lecturers who determined study aims, objectives, what counted as data and what would be used to develop a PCT report. Even when joining the advisory group it was difficult to move to Hickey and Kipping's (1998) democratisation approach, due to parents' unfamiliarity with this type of activity and inexperience created uncertainties for the parents. A shift along the participation continuum (see Table 1) from consultative to partnership activities was only apparent as parents gained more confidence. Parents contributed to the development of a questionnaire for use with professionals. This partnership resulted in a redistribution of power and enabled parents to contribute to the decision-making. However, with lecturers continuing to hold overall responsibility for completion of the project and any resulting educational programmes, parents most commonly tended to adopt a consultative role (Table 1). This was reinforced by the organisational philosophy, which regarded them as consumers of health services, who could comment on output, as opposed to citizens who can determine the content.

Another aspect of the process was the ongoing dialogue between various members of the advisory group. This dialogue involved face to face meetings, telephone and written communication. Meetings were organised at a local venue with consideration being given to childcare arrangements and remuneration for both travel and time costs for parents. The actual step-by-step approach is outlined in Fig. 1.

Ultimately the benefit of these experiences enabled lecturers to develop a new university module directly relevant to the needs of practice as it incorporated consumer perspectives. The specific influence of this process was seen in both module content and the educational processes utilised. The content of the module focused on the main theoretical principles underpinning many of the commercially available parenting training packages and the part both facilitators and parents play in

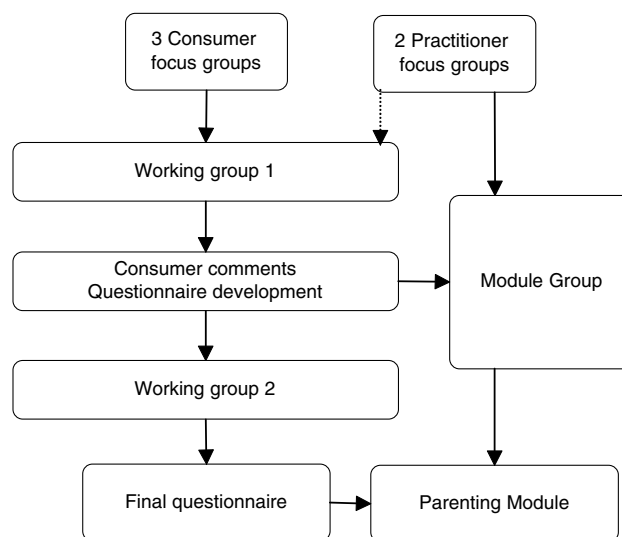


Figure 1 Process of user involvement.

the delivery of such training. A variety of learning methods were used to enable students to observe, practice and critique the key skills relevant to the parenting facilitator role. This effectively resolved practitioner/parent dissonance by simultaneously responding to practitioner desire for knowledge and parent pleas for practitioners who can appreciate parents as partners. Maintaining consumer involvement has unfortunately been a bigger difficulty compounded by the loss of financial resources once the original research study ended. Hope now rests with the development of a new faculty driven initiative that aims to identify and create the structural facilities required for making consumer involvement an operational component of educational provision.

Concerns for educationalists

Identifying the consumer

The dilemma first experienced by the team concerned the challenge of who could act as a consumer for research purposes and later module development. Initial ideas had been that it was sufficient to use lecturers as consumers, given that they too were users of health visiting services. However, team debate on this issue highlighted the potential bias perspective lecturers may hold due to their professional socialisation.

The unsuitability of professionals acting as consumers was latterly highlighted by the finding of dissonance between the professional and parent

perspectives (Whittaker and Taylor, 2001). Similarly others have found evidence of dissonance between educationalists and service users, where each identified differing priorities for nurse education (Flanagan, 1999; Forrest et al., 2000). Educationalists within Forrest et al.'s study focused upon instilling professional qualities and knowledge in students, whereas service users, like the parents in this parenting example, valued 'interpersonal and human qualities rather than specific therapeutic approaches'. Flanagan (1999) highlighted the importance of the affective domain in patient care and how involvement of consumers can effectively alert educationalists to this important feature.

Experience of working with local parents made it apparent that different types of consumers exist i.e. lay consumer, experienced consumer and health professional as consumer. Whereby the 'lay consumer' is inexperienced in contributing to public service decision-making and the 'experienced consumer' is more accustomed to participating in this process. Health professionals offer yet another perspective and enter decision-making processes with experiences and 'insider' knowledge. Understanding the type of consumer in this way places a focus on consumer strength that results from prior experience. The three categories in part resemble Boote et al.'s (2002) notion that the consumer comes either as an individual, a group member or as a representative of a national/international organisation, although emphasis here rests more on strength, which results from the size of the interest they represent.

Approaches and skills needed by practitioners

Findings from the parenting research study cited in this paper also support the notion that communication skills are key to successful participatory practices. Parents in this study referred to the need to be truly listened to and wanted the opportunity to contribute to decision-making. Involvement in decision-making is indicated by Edwards et al. (2001) to be a relative concept, with the importance resting primarily on consumers' perception of their involvement. The practitioner therefore needs to be a skilled communicator, in order to positively influence perceptions and ensure that consumers feel respected, listened to and valued.

For educationalists there is a double challenge that includes appraisal of their own skills as well as a focus on developing students' skills. This action is essential if a real move towards shared decision-making within healthcare is to be achieved. The need to move towards more participatory methods for healthcare delivery also emphasise the value of movement towards androgogical as opposed to pedagogical educational approaches. A movement rationalised on the basis that the former is concerned with valuing prior knowledge and experience and encouraging students to become problem solvers and negotiators (Milligan, 1998).

The need for resources

The experience of involving consumers in the parenting study has highlighted the importance of resources, (Tetley and Hanson, 2000; Telford et al., 2002) such as funding, facilities and time. Funding was particularly important for reimbursing parents for travel to meetings and childcare costs. Funding also affected the types of facilities that could be used by the advisory group and the location of facilities affected the parents' ability to attend. Time should also be identified as a commodity. Volunteers were required to freely give their time and lecturers identified additional work time to plan consumer involvement activities necessary for achieving a sense of inclusion for all advisory group and curriculum development team members. Examples of activities included, booking venues for meetings in community locations, preparing jargon free material and ensuring prompt follow-up communication with parents.

Since completion of the parenting study further guidance for consumer involvement (National Institute for Mental Health in England [NIMHE], 2003; National Consumer Council, 2004) has been devel-

oped. Nurse educationalists may find these useful resources that help resolve some of the above issues, but implementing such guidance will remain contingent on the existence of organisational infrastructures that are ready to accommodate *out of the ordinary* requests such as crèches and meetings at community venues.

Conclusion

Overall involvement of consumers in the original parenting research study has been a salutary experience. It reinforced the value of this kind of activity and alerted lecturers of the need to transfer such approaches to curriculum development. However to accommodate such moves within curriculum development, educationalists will need to take a step back from what they are currently accustomed to doing. Particular consideration should be given to communication and time management skills. Equally funding bodies and workforce confederations must be realistic and acknowledge the financial costs incurred when involving consumers, since better end products are rarely achieved just through free lunches.

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