

**Well-Being Services for People with Long Term Neurological Conditions: Co-researchers
Involvement in Research, Service Design and Development**

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Abstract

This chapter outlines the involvement strategies used in a participatory action project conducted in the UK, together with co-researcher evaluation of their experiences, presents reflections on the process of involvement in service design and delivery and its impact on community co-researchers. The study was jointly commissioned by a Primary Care Trust and a Local Authority Adult Social Care department in partnership with researchers in the Research Institute of Health and Social Care at Manchester Metropolitan University. The study, in line with the UK government well-being agenda (DoH, 2007b), was designed to reveal the ways in which services provided for people with Long Term Neurological Conditions (LTNC's) can enhance well-being rather than simply reveal or address their health and social care needs. In effect, this refocuses service provider perceptions away from seeing people with LTNCs as needy, or as problems to be solved (by addressing their needs) and more towards people whose well-being can be substantially improved with the support of professionals. People with LTNCs who were involved in this study included those with Parkinson's Disease, multiple sclerosis, cerebral palsy, stroke, dementia, epilepsy, motor neurone disease, muscular dystrophy, acquired traumatic brain injury among others with rare conditions such as Lesch-Nyham Syndrome. The study took a participatory action research approach (Kagan, Burton and Siddiquee, 2008) in which a key element was the input from the LTNC's service user and service provider communities. The experiences of university and co-researchers have been traced in this paper, pointing to the importance of considering the short and long term implications of collaborative working and the impact this has on project outcomes and service design.

Keywords: Involvement, co-researchers, service users, service providers.

Servicios de Bienestar para personas con Condiciones Neurológicas de Largo Término: Involucración de Co-Investigadores en la Investigación, en Diseño y Desarrollo de los Servicios

Resumen

Este capítulo bosqueja las estrategias de involucración empleadas en un proyecto de acción participativa realizado en el Reino Unido, evalúa experiencias de co-investigadores, presenta reflexiones acerca del proceso de involucración en diseño y realización de servicios y del impacto en los co-investigadores comunitarios. Este estudio, acorde con los lineamientos del gobierno del Reino Unido acerca de la agenda de bienestar, se diseñó para hacer patentes las formas en que servicios dados a personas con Condiciones Neurológicas de Largo Término (LTNC's) pueden realzar su bienestar y no sólo atender sus necesidades de salud y atención social. En efecto, esta estrategia re-enfoca las percepciones de los que dan los servicios para no sólo ver a las personas con NCLT como necesitadas, o como problemas a ser resueltos (atendiendo sus necesidades) sino más bien como gente cuyo bienestar puede ser sustancialmente mejorado con el respaldo de profesionales. Gente con NCLT que participó en este estudio incluyó personas con Enfermedad de Parkinson, esclerosis múltiple, parálisis cerebral, derrame, demencia, epilepsia, enfermedad neuronal motora, distrofia muscular, daño cerebral traumático adquirido, entre otras, con condiciones raras tal como el Síndrome de Lesch-Nyham. El estudio siguió una aproximación de investigación acción participativa en la que un elemento clave es la aportación del NCLT usuario del servicio y las comunidades que proveen servicios. Las experiencias de la universidad y de los co-investigadores se describen en este escrito, señalando la importancia de considerar las implicaciones de corto y largo tiempo del trabajo colaborativo y el impacto que éste tiene en los resultados del proyecto y en el diseño del servicio.

Palabras clave: Involucración, co-investigadores, usuarios de servicios, proveedores de servicios.

Introduction

Service user² involvement in health and social care service design and delivery is now heralded as an integral part of service development with positive outcomes for service users, health and social care research and service provision in the UK (DoH, 2006, DoH 2005a,b). Such involvement has underpinned attempts to develop ‘wrap around’ health and social care services which are responsive to the needs of the person and are delivered to improve their lives. The idea is based on a recognition that those people who are in need of health and social care support and who are often marginalized within official support systems have valuable knowledge and experience which can be used to create services which focus on improved well-being and quality of life (INVOLVE, 2007). This constitutes a move away from locating the basis of power over service provision with health and social care providers and into a more equitable relationship where both experiential and professional knowledge are both valued. However, this ‘personalisation’ agenda (DoH, 2007a) tends, as it is conceptualized and implemented, to prioritize individual needs while often neglecting the holistic family and community context. Moreover, as long as the focus of service provision remains on service user ‘needs’ elicitation, the difficulties of articulating those needs (for service users), and satisfying those needs (by service providers) alongside the general mismatch between perceived needs satisfaction, well-being and quality of life (Hobbs and Sixsmith, 2009) makes it a very difficult process to navigate. The involvement of service users in this process can shift the focus from ‘needs’ by unpacking the meaning of well-being in everyday life and coupling this more firmly with improving quality of life through service provision. However, the difficulties of service user involvement cannot be ignored.

Current, and predominant, rhetoric surrounding ‘involvement’ is unrelentingly positive, firstly centring on the notion that involvement is an empowering process for people whose voices are seldom heard within the service context and secondly producing more responsive, person-centred services. Three key problems hinder effective involvement: firstly, people who receive services may have typically had little experience of participation in service design and so feel relatively inexperienced and lacking the requisite knowledge; secondly when service user

² The term ‘service user’ is preferred here to more recent descriptors of ‘client’ or ‘customer’ in order to simply signal the relationship between people with dementia and service provision. It is not intended as an holistic concept which characterizes a person.

involvement has been undertaken it can take the form of ‘consultations’ which are little more than opportunities to be told about what will happen; or finally, the difficulties of living chaotic lives or with chronic ill health can preclude or dissuade people from engagement with often demanding participatory processes (see Hobbs and Sixsmith, 2009; Woolrych and Sixsmith, 2008). A further barrier to effective involvement lies in the relative lack of experience amongst health and social care professionals who have had little experience of involving service users integrally in their service design and development. This can result in feelings of disempowerment for both service users and providers and a breakdown in the involvement process (Sixsmith, 2009).

This chapter outlines the involvement strategies used in a participatory action project conducted in the UK³, together with co-researcher evaluation of their experiences, presents reflections on the process of involvement in service design and delivery and its impact on community co-researchers. The study, in line with the UK government well-being agenda (DoH, 2007b), was designed to reveal the ways in which services provided for people with Long Term Neurological Conditions (LTNC’s) can enhance well-being rather than simply reveal or address their health and social care needs. In effect, this refocuses service provider perceptions away from seeing people with LTNCs as needy, or as problems to be solved (by addressing their needs) and more towards people whose well-being can be substantially improved with the support of professionals. People with LTNCs who were involved in this study included those with Parkinson’s Disease, multiple sclerosis, cerebral palsy, stroke, dementia, epilepsy, motor neurone disease, muscular dystrophy, acquired traumatic brain injury among others with rare conditions such as Lesch-Nyham Syndrome. The study took a participatory action research approach (Kagan, Burton and Siddiquee, 2008) in which a key element was the input from the LTNC’s service user and service provider communities.

Participatory Action Research (PAR).

The action oriented and participatory framework was adopted at the very outset whereby

³ The study was jointly commissioned by a Primary Care Trust and a Local Authority Adult Social Care department in partnership with researchers in the Research Institute of Health and Social Care at Manchester Metropolitan University.

people with a range of different LTNC's as well as health and social care providers were recruited to participate in the study design and implementation. Their participation continued into the realms of data collection, data interpretation, report writing and final presentation of results.

The guiding principles of this participatory action research project were:

- Development of a partnership with shared vision and expectations.
- Equality of all stakeholders within the process.
- Open communication on all aspects of the research.
- Commitment to social justice for all.
- Support and training for involvement.
- Willingness by all concerned to allow the PAR process to facilitate change both in themselves and in service delivery.

In particular, because of the intensive involvement both in the research process as well as input into service design and delivery, the support and training of co-researchers was of paramount importance. As such, the recruitment and empowerment of co-researchers was essential to successful completion of the project.

Involving Co-Researchers.

The involvement of co-researchers was not a smooth process. The first difficulty arose with recruitment. For recruitment purposes, the local health and social care authorities provided a list of their service users so that the research team could independently initiate contact. A range of telephone, e-mail and face-to-face contacts were arranged to ask if they would be interested in forming part of the research team. Unfortunately, these requests were met with suspicion and skepticism and no recruitments were made. They reported that while they felt involvement was a positive aim for service development, and that contributing to research was a necessary precursor to improving well-being through service provision, they ultimately were ill equipped to participate themselves because they felt:

- Inexperienced in service design and development, preferring to defer to the knowledge and expertise of service professionals.
- They did not really understand what research was about and so were reluctant to commit to activity they were unsure they could handle.

- They had little to contribute from their own experience as service users.
- They lacked the necessary skills, stating their embarrassment to speak in meetings, lack of confidence in discussing the issues they feel are important, frustration in not being listened to and inability to properly read and understand official document because of professional jargon.
- They were unable to keep as fully informed as service professionals, thereby not having all the relevant information to make appropriate decisions.
- They had no time, with most being devoted to getting on with the everyday tasks of living with a demanding and often variable LTNC.

They also said that:

- Their communication and mobility problems would disqualify them from participation.
- That no-one would listen to the result of the research or service design and development outcomes if they were involved. Here, they felt that the work would have more credibility if it were entirely conducted by university experts.
- Finally, that former efforts of the local authorities to involve them in service design had previously been one sided and fruitless, particularly citing that service change would not happen because of bureaucratic barriers and cost. Consequently, they argued that service user wishes realistically play no part in setting the agenda for change.

This high level of negativity towards participation was based on health, psychological and social grounds as well as past experiences. In order to progress beyond these barriers a joint ‘consultation’ event involving health and social care personnel, university researchers, service users, their carers and family members. The aim was to present information about:

- The National Health Framework for LTNCs (set out in March DoH, 2005, by the Dept of Health; DoH, 2007c, 2008) and progress towards achieving its 11 quality requirements.
- The research enterprise linked into the current research project aims and objectives.
- The value of service user experience input into design and development.
- The potential role of co-researchers.

After presentations covering this information and follow on discussions, a series of workshops were conducted to establish:

- The meaning of ‘well-being’ from participant perspectives.
- How the well-being of people with LTNCs can be measured.

This consultation event was effective in engaging service users in both the service development and research enterprise by ensuring they felt informed, understood how they could contribute and enabling them to experience participation in the research itself. Evaluation of the event was extremely positive as service users felt for the first time that they understood that their participation had real value, their experiential knowledge was essential to effective service design and development, that university training and support would enable them to master any skills they would need but did not feel they possessed. Most importantly, the workshop exercised convinced them that research was not only enjoyable, but equalized relationships between themselves as service user and service providers since both groups were new to research. In addition, service users felt they understood much more clearly that the NSF Framework for LTNCs could actually become a mechanism for improving their own lives, rather than simply more bureaucratic rhetoric with no tangible positive outcomes for everyday life. Consequently, they wanted to see it implemented in ways which would benefit all people with LTNCs. In effect, the consultation event motivated participation on grounds of:

- Knowledge gained
- Skills development
- And desire for effective personal and social change

The analysis of data collected in the well-being workshops was then produced in a short pamphlet (also made accessible to those with visual and auditory impairments). Once this was distributed, service users felt their views had been listened to. In this way, the integrity of the research was established as a potential way forward to improve service provision and a number of volunteers voluntarily contacted the research team to begin work as co-researchers. In total, 6 service user and 4 service professional co-researchers were recruited as a result of the consultation event. This included managers and staff from physiotherapy and adult social care alongside those with Parkinson's Disease, Stroke and Motor Neurone Disease and Muscular Dystrophy.

Empowerment within the Co-Researcher Role.

The initial welcome meeting with all co-researchers ended with service users requesting extra support be supplied to them independent from service provider co-researchers as they had

struggled to contribute to the meeting. In response, a series of service user workshop/training sessions were organized. The first workshop centred on the co-researcher role which resulted in the shaping of their own plan for this role. The second workshop focused on research as a process. Interview evaluation of these initial workshops indicated that co-researchers cohered together as a social group with a shared vision, a joint purpose and a feeling of moving forward and contributing to the great social good of people with LTNCs. Their excitement, enthusiasm and acceptance of the value of different forms of knowledge were tangible. Initial workshops with service users were followed by a further set of joint service users and service provider sessions concerning:

- 1) The study aims and objectives and how these might be achieved. Intensive discussion on the nature of well-being suggested the inadequacy of framing this entirely in terms of need satisfaction. Co-researchers felt that attainment of improved well-being depended on more than the satisfaction of felt needs (which they felt were difficult to conceptualize and articulate beyond the confinements of service oriented need assessments), and included the pursuit of personal goals and leisure opportunities. This session ended in the resetting the study objectives to more clearly fit the lives of people with LTNCs
- 2) Qualitative methodology, its aims and uses in researching well-being with people with LTNCs. This produced co-researcher input into the design of the methodology (semi-structured interviews) and the setting of interview schedules used to help people with LTNCs tell us about their experiences both of well-being and service provision. Three service user co-researchers then asked to extend their role to become interviewers and interview other people with LTNCs.
- 3) A further training session was then conducted on 'how to do interviews' and was supported in face-to-face individual meetings between co-researchers and university research staff. This enabled training to reflect individual skills development. Ten service user and 10 service provider interviews were subsequently conducted by trained co-researchers.
- 4) Finally, a session overviewed ways of doing data analysis followed by two data analysis workshops in which co-researchers engaged in thematic analysis of transcribed interview data (re Braun and Clarke, 2006). This resulted in co-researchers contributing to the defining the concept of well-being and the most relevant indicators of service impact on

well-being

In addition to direct involvement in the research work itself, two co-researchers elected to sit on the study advisory board, inputting to discussion about the project, problem spotting and solving, and guiding the research towards attainment of its aims and objectives. Furthermore, 2 co-researchers were involved in the recruitment of the university research assistant

In general, the involvement of co-researchers enriched the study by reinforcing the notion that:

- A more experiential approach to understanding how people live their lives would be better able to highlight where well-being could be improved rather than relying on a needs assessment based approach.
- Well-being is an experiential rather than an articulated cognitive phenomenon. Asking people directly about their well-being is likely to reveal only well known platitudes. In addition, well-being is framed as much more than satisfaction or pleasure (ie hedonic well-being), and encompasses personal development and the achievement of goals and engagement in life (ie eudaimonic well-being, see Shah and Peck, 2005; Ryan and Deci, 2001).
- Well-being is a highly complex concept (Haworth and Hart, 2007) It is not simply an individual issue but a family and community issue very much as Prilleltensky and Prilleltensky, 2007) point out in their well-being manifesto for a flourishing society.
- It is difficult for people with LTNC's to think beyond what services normally provide and to bring to the table those wider social, psychological and community based aspects of well-being

These issues were all used to influence the conceptualization of the study as well as methods used, data analysis and interpretations.

Co-Researcher Reflections.

Ongoing research into the experiences of co-researchers was conducted throughout the study in order to focus on issues of power, control and the production of knowledge within the co-researcher context (see Reason, 1994). This involved initiation of reflexive sessions with co-researchers, conducted on an individual face-to-face level. Changes made to the co-researcher

role based on these reflections were accomplished within a cycle of research, reflection, action and change (Kagan, Burton and Siddiquee, 2008).

The reflexive process revealed that service user co-researchers had gained a good understanding of the complexities of research practice and procedure, knowledge of the constraints and opportunities surrounding service provision and confidence in their own ability to speak up at meetings inside and outside the context of the research. As Stolle (2001) suggests, they had gained in negotiation skills (evident when one service user co-researcher re-engaged with local committee work), presentation skills (two co-researchers were involved in presenting the findings of this research at a local conference) and social skills (one co-researcher reported that she had been better able to deal with family issues as a consequence of learning about active listening and taking the other's perspective). In this sense, a degree of capacity building for future involvement in local service provision and university projects had been achieved. Moreover, co-researchers felt they could engage in critical thinking, by challenging their own beliefs, divorcing the discussion of contentious or sensitive issue from their own emotional responses and actively interrogating their own thoughts and those of others around them. They found benefit in the reflexive process itself, using this to understand more about their social positioning within service provision, family and community contexts. In terms of subjectivity, they felt more able to accept and make profitable use of their developing sense of self power in their everyday living environments. This was most evident when one co-researcher found employment having thought through the value of the skills she had mastered and her new found confidence in herself as a working class woman with much experience to offer which she brought to bear in her job interview. Both service user and service provider co-researchers described how they had used reflexivity in other areas of their lives, especially concerning their work and family situations. The co-researchers confided that the experiences they had encountered in the research had brought new meaning into their lives, staved off boredom and given them a broad social platform of concern. For some, this was one of the few times when they felt they mattered and could make a difference to the social fabric of their communities.

Benefits articulated by service provider co-researchers were a little less forthcoming. Those articulated were:

- A better understanding of the experiences of people with LTNCs (this was the most widely cited benefit of involvement),

- Clearer envisioning of the value of service user involvement in the design and development of services and
- The necessity of thinking differently around service oriented promotion of well-being.

In general, they felt they would be less dismissive on service user concerns in the future stating that they would prefer to think around ways to improve services rather than simply following tried and trusted techniques which were not always effective. They would, they felt, seek out service user input in the future. For them, co-researching had opened up a new way of thinking about implementing change.

The Difficulties of Co-Researching.

Despite the positive outcomes of involvement, a number of difficult issues arose for co-researchers and university researchers alike as Sixsmith and Boneham (2003) and Kagan (2008) have found in previous work. For service user co-researchers these revolved around:

- Continuing to see university researchers as leaders of all aspects of research and as fountains of knowledge in the area and looked to them for validation. This happened despite repeated efforts at creating an environment of mutual sharing and learning.
- Dropping out. Intensive individual contact was maintained with co-researchers alongside group meetings in which hospitality featured strongly (lunches, refreshments, social chit chat etc) in order to engage co-researchers with a strong commitment to the project. Nevertheless, one co-researcher dropped out stating they did not have the time or energy required to participate and another dropped out on ill health grounds. In this project, the loss of two co-researchers depleted the human resources considerably, but was not critical to project continuance since both dropped out towards the end of the project.
- Disagreements between co-researchers created an antagonistic atmosphere and breakdown in communications halfway through the project. Mediation between them, delivered via the research team, achieved some reconciliation but personal grievances remained. The bringing together of diverse people in a common project is not always guaranteed to create strong friendship bonds and the likelihood of dealing with difficult relationships should be factored into the involvement process.

- Periods of ill health meant that promised work was not always completed (ie no planned co-researchers involvement took place regarding the carer interviewing). Project researchers maintain contact on a personal basis where possible with people throughout any bouts of illness. This meant they could re-engage with the project when they felt better, if that was what they wished.
- Some reported that, at times, the stress of expectation (their own as much as unintended researcher based pressure) weighed heavily on them. Some worried about influencing the design of services in ways which might result in poorer service provision for people with LTNCs. Others undertook research tasks with a work-like commitment, neglected other duties in their lives to fulfill their co-researching tasks. This created feelings of guilt because of relative neglect of family and friends. In these cases, researchers on the project acted as listening ‘buddies’ to help them see their work in a more positive light as well as to find a good balance between their commitments.
- At times, co-researchers reported they felt undervalued because their work was unpaid, yet preferred to remain as volunteers to maintain an independent stance within the research context. While this ambivalence caused some tension at an individual level, independence meant co-researchers were free to leave the project or avoid undesired tasks. This issue of payment was problematic for the university research team who felt co-researcher work was of very high quality and deserving of payment.
- Finally, there was a feeling of emptiness when the project ended. Here, the researchers were able to provide them with contacts to future project co-researching involvement in order that they continue their work within the health and social care and university settings.

The problems encountered for service provider co-researchers were very different, as follows:

- They felt all work on the project should be done within their office hours but struggled to create the time and space to conduct research tasks to the standard they felt was appropriate. Negotiation with line managers helped to free time for research tasks.
- There was some conflict between work roles and research learning. For example, involvement of service user voices in the project bore tangible benefits, yet this was not always undertaken in other domains of service provision in which they were working. This caused a degree of frustration and a feeling of inability to achieve the best outcomes

for service users. Where such concerns arose, the research team talked through options for limited service user involvement and pointed to the use of involvement in future work.

- Some lack of motivation was experienced due to the burdens of an inflexible bureaucratic system and heavy work load. In these instances, the research team re-negotiated any co-researcher tasks to minimize their impact on work time and thus reduce such burdens.
- Perhaps the most problematic issue arose when co-researchers were distressed when analyzing their own service role in what could be rather depressing service users experiences. Re-aligning their perceptions towards the aim of the project to improve well-being through service provision was critical to helping co-researchers to envision the benefits of such work.

A number of disadvantages associated with involvement were experienced by the university researchers. In particular:

- The intensive level of work needed to prepare training and support for co-researchers throughout was not fully anticipated at project outset. In addition, formal evaluation of co-researcher experiences constituted a small scale study in itself. Nevertheless, intensive input was required to ensure effective involvement and this was prioritized over more administrative tasks.
- Researchers were sometimes exposed to upsetting situations where co-researcher illness or stress stimulated re-thinking of ethical issues about the rigours of participation in research, especially with people who are vulnerable to stress and ill health. In effect, researchers reported that the perceived benefits of involvement outweighed the felt disbenefits, but that they felt bound to support co-researchers in any way they could – often putting in effort in their own leisure time to smooth the process for co-researchers.
- At times, researchers felt that the involvement process was beyond their current skill base. In response, reading around the process of service user and provider involvement was strongly encouraged so that learning from previous PAR projects could help guide decisions and actions.

In hindsight, the project and the co-researcher process would have benefited from:

- The creation of a forum or panel of co-researchers who could be consulted regarding their involvement in future university, Local Authority or National Health Service projects.
- A more accurate anticipation of the time required to support involvement would have

made the whole process more manageable.

- There is a need for timely up-skilling in training methods/ negotiation skills in order to ensure the smooth running of the co-research element of the study.
- A buddying system could be implemented between co-researchers and research staff to address unrealistic expectations and increasing stress levels before they become problematic. This was done informally but did add to the university researcher workload
- Training in time management and counseling skills.

In Conclusion

The co-research involvement of service users and providers were crucial to the success of the project in envisioning and recommending the design and development of well-being services for people with LTNCs. Many psychological, social and community benefits to such participation were realized and the increase in co-researcher skills and confidence were evident. However, problems of empowerment within the research and service context were encountered as the mapping of service change progressed. Discussion, training and skills acquisition sessions were negotiated and facilitated with co-researchers with consequent positive and negative implications for the research design, data collection and analysis, and interpretation of findings. What was of paramount importance was the institution of the vision that co-researching was not just about bringing service users to the table, but equipping both service users and health and social care providers to discuss and work together on an equal basis. In this way, service user voices have been acknowledged and capacity building has progressed both within the community and in the service sector. This allowed service users and providers to relate together in different, more harmonious ways, involving openness, listening and attitude change (Kagan, 2008) as well as learning from each other and influencing the research beneficially. The experiences of university and co-researchers have been traced in this paper, pointing to the importance of considering the short and long term implications of collaborative working and the impact this has on project outcomes and service design.

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