Equal Lives? Disabled People Evaluate an Independent Living Strategy for Essex Social Services

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Abstract

This research report summarises our recent evaluation of an independent living policy for people with physical and sensory impairments who use Essex Social Services. Local disabled people were trained to help perform this evaluation. The focus of the paper is to provide a practical account of the steps taken to include service users as equal partners in the research process. We share our different personal experiences and views, as professional researchers, research sponsors, Social Service managers and - most important of all - disabled people involved as Co-Researchers. We present our ideas for improving this process from the lessons we have learned.

Keywords: user research, independent living, disability, disabled people, social services, evaluation

The Equal Lives Strategy

In 2001 Essex Social Services launched a five-year strategy called *Equal Lives* (Essex Social Services, 2001). This strategy set out plans to develop services to meet the specific needs of the 121,000 people in Essex with physical and sensory impairments. Equal Lives is a budgeted strategy that is explicitly and systematically shaped around ten headings of independent living identified through extensive service user consultation. The strategy seeks to enable and empower disabled people to "express and exercise choice and control through their lives" and is firmly underpinned by the principles outlined in the 'social model of disability' (Morris, 2003)

Essex Social Services and Service User Involvement

Improving the level of involvement of local people in public services is a major part of the government's modernisation agenda. The Department of Health's Research Governance Framework for Health and Social Care (Audit, 2003) has also stressed the importance of involving research participants in the research process wherever possible. Peter Beresford (2004) points out how, despite all the talk of participation and service user involvement in public policy for many years, the involvement of research participants in most social research is still marginal. According to Beresford (2003), the longer-term ideal should be that every research and evaluation project should be monitored for user involvement.

The service for independent living within Essex Learning and Social Care has been developing the input of service user voices for more than ten years. Service users are currently involved on all the planning groups, on readers' panels and in the Participatory and Advisory Group. Active support has also been given to the growth of local independent service user organisations. These organisations of disabled people are very strong in Essex and are active in pushing for change and apply pressure to many of the local statutory organisations and businesses to do this. Independent disabled researchers, such as Jenny Morris, have produced some extremely valuable commissioned research for Essex Social Services and are often involved on research steering groups (including ours). However, this is the first time that service users with physical or sensory impairments have been invited to play an active and equal role in the search and production of research evidence locally.

The Evaluation

One year after its launch Essex Social Services wanted to consult its service users on the impact of the Equal Lives Strategy so far. The Social Services research team was commissioned to design and conduct an evaluation from the perspective of service users with physical and sensory impairments. The overall aim was to evaluate the impact of the strategy in facilitating disabled service users to lead more independent lives and to identify early signs of improvement in services and opportunities for further improvement. An additional aim was to involve disabled service users actively in carrying out the evaluation.

Phase One (2002) – Telephone Survey

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A telephone survey of two hundred and fifty disabled service users took place in the summer of 2002. Two local independent disabled people's organisations won a tender to carry out these telephone interviews. Disabled people were trained and supported by the Essex Coalition of Disabled People and Independent Living Advocacy Essex to perform the interviews. The cost of this stage of the consultation was £3,000 to carry out the interviews, plus staff time. Results have influenced service planning and have contributed to improving the strategy's implementation, for example a 'Transport Options for Independent Living' working group was set up to look at the transport issues raised. The results also formed the service user consultation component of a Best Value Review of services for independent living and fed into Best Value Review activity in other directorates such as transport.

Phase Two (2003) – Qualitative Interviews
The results of the benchmark survey highlighted the scope for the Independent Living Service to define and develop its role in facilitating disabled people to lead an independent life. A qualitative approach was chosen for this second phase to allow deeper exploration and focus to some of the more sensitive issues highlighted by the survey. The issues included: barriers to employment and education, accessing social and community life, and the flexibility and timeliness of personal assistance.

The participatory research methods used in the initial survey were taken a stage further in the second phase. Individual disabled service users were recruited, trained and paid as co-research consultants. The research partnerships instigated with local disabled people's organisations were nurtured further in the second phase.

Summary of Evaluation Results

Many participants said they would like to have greater choice and control over their circumstances, but demonstrated low expectations for achieving this. As individuals, a number of people described their role in the decision making process as a relatively passive 'service recipient' type of role, rather than as equal partners. At a wider political level, some referred to how they felt that disabled people were generally excluded or ignored when it came to public consultation processes. Shortfalls in resources were identified by many as a key barrier that influenced levels of choice and control for service users. Some individuals described how assumptions based upon this and their eligibility for services had influenced them accessing Social Services in the first place. Others described the influence that they perceived this had had upon their levels of choice and control in the following key areas: the frequency and scope of care assessment and reviews; choice and continuity of key workers and frontline personal assistants and the timing and flexibility of home care.

The wider and more holistic topics set out in the Equal Lives Strategy such as: community participation (education, employment, leisure and social opportunities and access to the environment) were evidently not always consistently and comprehensively covered by social workers in the assessment and care management process. It was apparent that there was significant variation in the way staff (social workers and front line personal assistants) were exercising their professional judgement. Whilst some staff appeared to be flexible and creative within limited resources, others were apparently not. The main benefit that participants receiving Direct Payments highlighted was their choice and control over who they employed for their personal assistance and the scope and flexibility of how this assistance was exercised. An example of this flexibility was that an individual on direct payment might choose to use their personal assistance to go outside of the home and socialise, whilst someone receiving this assistance direct from Social Services may be much more limited in having any choice or control over this type of activity.

Appraising the Practical Aspects of the Process

As we did not have previous tried and tested methods for employing service users as co-researchers within Essex Social Services the process has been largely 'organic'. This has meant that the partnerships with Essex Coalition of Disabled People, the School of Community Health and Social Studies and the steering group have been invaluable in terms of mentoring and support. For example, the Coalition (who describe

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Involving local disabled people as research interviewers – the process

Financing of £6,000 was provided by the sponsors of the evaluation to ensure that high quality training could be commissioned and (more importantly) the research interviewers could be paid.

A steering group was set up to provide accountability to all the stakeholders (local disabled people, voluntary organisations, service managers and researchers) and to facilitate a team perspective to influence the development, methodology and outcomes of the evaluation.

Partnerships were made with local disabled people's organisations (Essex Coalition of Disabled People and the Pavis Foundation for Visually Impaired People) and with a local provider of research training (School of Community Health and Social Studies, Anglia Polytechnic University).

Essex Coalition of Disabled People was contracted to jointly support the disabled co-researchers:

- Performing disclosure checks
- Handling payment of research consultants
- Offering a safety point of contact for researchers to inform of whereabouts before and after interviews
- Insurance and liability cover for researchers

The School of Community Health and Social Studies was contracted to provide a two and a half day research skills training course for candidates.

Role specifications and rates for payment were drawn up to be as inclusive as possible and to attract local disabled people. The key requirements were:

- Working age adults living within Essex
- Identification as a disabled person (in view of the social model approach this was not impairment specific)
- Ability to communicate well (essential for interviewing methodology)

A recruitment campaign was designed involving various levels and media for communication (internal to staff and external to the public).

Access requirements of the co-researchers were detailed in order that the training venue and any meeting rooms were always fully accessible. For the interviews, individual interviewers were matched with interview participants in their area and according to their access and communication requirements.

Briefing co-researchers about the Equal Lives Strategy, social model of disability and the aims of the evaluation was done by the research team. At the same time the co-researchers were given the opportunity to be involved in the development of the interview schedule.

Ongoing communication with co-researchers was facilitated by the research team and mainly occurred at steering group meetings in addition to frequent e-mails and telephone conversations as required.

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themselves as 'guardians of the social model') insisted that the co-researcher specifications should be as open and inclusive as possible. Both organisations gave invaluable additional support to the co-researchers and have facilitated links between the co-researchers and other local disabled peoples' networks and service user researchers respectively. This networking has had intrinsic benefits for the co-researchers introducing them to new social contacts and even opening up new employment opportunities for two people. This has also meant that the evaluation has gained from being placed in a wider context.

Whilst we did not have time to complete a full and systematic literature review prior to this evaluation

we did search for examples of similar service user involvement and research training within Social Services around the country. Two studies one in Staffordshire (Bradley and Boath, 2003) and one in Wiltshire (Evans and Carmichael, 2002) that were particularly helpful. We consulted with service users and researchers involved in both and gained some useful tips for training service users as researchers.

The focus of the formal training sessions was upon research skills and in particular practical interviewing skills. This course was well received by all the participants regardless of their previous educational and employment background. On reflection, given the lack of previous research experience of most of our co-researchers, the course was possibly slightly over ambitious in both the breadth and depth of its content. From the relative security of the training rooms the co-researchers were thrown in at the deep end of real world research. With the exception of a couple of briefing meetings and an information pack the co-researchers were required to embark upon setting up and completing their interviews. The pressure of tight timescales meant that there was little time for the co-researchers to practice or consolidate their new research interviewing skills.

The method for recruitment using the local media

Information pack included

- What is research?
- How to do research
- What is the equal lives strategy?
- What are the aims and objectives of the evaluation?
- What is the social model and how to work from a disability equality perspective?
- How to handle tape recording of interviews and tapes
- Understanding confidentiality
- Organising appointments and interviews

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was successful with over sixty disabled people contacting the research team for further information. In view of the high response rate we decided to extend the research training to as many people as feasible within the resources available and so twelve people participated for two days in the research skills training. With the exception of

one person, none of the co-researchers had been employed recently and all attributed this to disabling barriers.

Rewards from Involving Service Users in Research Process

We have reflected upon our experience as researchers, managers and service users, working together in research, and these are a few of the outcomes that we have identified.

Enhanced Validity of Research Evidence

As anticipated, it is clear that research participants felt comfortable being interviewed by disabled co-researchers and appeared more willing to share their true experiences and views. It appears that people 'identified' themselves with their interviewers and appeared to make assumptions about shared experience and understanding. However, as discussed later, this could be a disadvantage.

> *Having disabled people leading such a project and disabled researchers is far more likely to lead people being interviewed feeling able to relax and say what they really feel about services they are receiving, than they would do if they were interviewed by non disabled researchers.* (Philip Miller, ECDP)

The disabled researchers were able to use their position as 'outsiders' to Social Services to advantage by reassuring research participants that the research was 'impartial'.

> *They definitely talk more freely about issues surrounding their daily life.* (Jane Johnston, Co-Researcher)

Sometimes as 'insider' researchers (employed by the organisation sponsoring the research) this can be confusing, or even threatening, for research participants. In fact, one of the research interviewers whose impairment is not visible said that she had been mistaken for a social worker despite having explained who she was.

It is not only the raw data that is enhanced, but the involvement of people with direct personal

experience of services adds a further dimension to the analysis and interpretation of the data. This complements the more 'objective' knowledge of the researcher. A common statement made by research participants illustrated the significance of this: *'they [social workers] just don't know what it is like to be disabled'*. However, at the point of the interview this could be a drawback as the co-researchers found in practice.

> *I feel that service users were more forthcoming with information because they feel that I had empathy with their situation. Feel sometimes that this can interfere as they make assumptions that you understand, just because you are disabled too.* (Zo Nicholas, Co-Researcher)

As mentioned previously, there were occasions when research participants appeared to over identify with their interviewers and 'expected' them to understand their situation. The interviewers had been trained to recognise this and taught strategies for eliciting more explicit responses.

Although we did not have the resources, this time, to include all of the Co-Researchers in the detailed analysis and report writing stages they were involved as critical readers of the various drafts and summaries. This contribution actively impacted upon the conclusions that were drawn and was very helpful. Two of the Co-Researchers have also agreed to be actively involved in the dissemination of the results at meetings with staff and relevant conferences.

Positively Promote the Social Model Approach within the Equal Lives Strategy

This outcome was underlined strongly by the various disabled people's organisations and service user representatives who were consulted from the outset. At the first steering group meeting a firm resolution was made that the methods used for this evaluation should be rooted in a social model approach.

We were overwhelmed by the calibre and experience of the disabled people who responded to our recruitment campaign. This bought sharply into focus some of the findings around access to

employment that were highlighted by our first survey. All the co-researchers have given extremely positive feedback about their overall experience in this project. Some of the gains they have described are outlined below.

- Making a positive and valued contribution towards improving services:

  I am looking forward to the finalised report and ...I would like to see a change in the way Social Services have been treating people in Essex. (Gareth Cooper, Co-Researcher)

- Increased confidence:

  This opportunity has given me back my confidence which took a bashing when I lost my job due to my disability. I would certainly do it again.

- Work and training experience to improve future job opportunities:

  A personal benefit is keeping me involved in a working environment and a chance to meet new people.

- Broadened outlook and experience:

  I would say this has changed the way I look at life...I first read about the interviews in my local paper...I didn't expect to get the job at first as most of the jobs I had applied for I had been turned away due to the fact I was disabled. I had been trying since I left school when I was sixteen to get a small job, but everyone kept saying no....I really didn't get my hope up ...so I was a little shocked to receive a letter a few days later saying I had been selected! I was really pleased that at last someone had noticed me and seen that my wheelchair wasn't going to stop me achieving my goals.

- Doors being opened to other opportunities:

  The experience has added to my learning curve, I have not lost anything – it has opened my eyes…. Opened the door to other things…. it has encouraged me to go forward with local

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expert patient program on a training course for tutors up in Leeds.

- Offering a positive role model to other disabled people:

    I offered a positive role model to people…. I challenged people's assumptions about disabled people.

Adding to Skills Mix within the research Team

The final team of co-researchers had a wealth of interpersonal and other skills between them including: a qualified nurse, a trained teacher and a disability equality trainer with previous research experience. In addition, each has bought to the project a variety of skills and knowledge that they were happy to share with other team members for the benefit of the project. These skills ranged from access to and knowledge of on-line conferencing to facilitate communication between team members and information on disability rights and the social model.

An opportunity that, had not been previously anticipated, was the amount of moral support and friendship we shared as researcher and co-researchers. Working as a team we all shared humour and stories of interviewing experiences. An important detail is that we all swapped contact details with each other and gained support from each other as well as from the research team and Essex Coalition of Disabled People as appropriate.

Enhanced Credibility and Potential Influence of Results

The research commissioner identified the power that involving service users can have from a strategic perspective:

    Hearing it directly from service users improves the validity and the weight of the findings from the perspective of councilors and service managers. (Nanette Wright, County Manager, Independent Living Service)

Through partnership in the research process the independent disabled people's organisations say they will be more persuaded by the findings:

I admit that we were extremely sceptical about how sincere user involvement would be in practice at the start of our relationship…many of our initial concerns have been dispelled and we have established a good working relationship between us. …When we were approached I expected us to take a joint role in the process and that is exactly what has happened in practice. (Phil Miller, Chief Executive, ECDP)

Conclusions and Lessons Learned from Future Participatory Evaluations

By giving the research team some flexibility with regard to timescales and also allocating a budget we have been able to pilot new ways of involving local people in future social services research and have learned a lot about how we would improve upon this in the future. There was unanimous agreement from all stakeholders that this has been a worthwhile and valuable exercise that has added validity to the results.

For one half-time research officer the scale of this evaluation would not have been feasible and the budget of £6,000 would not have attracted many hours of independent research consultancy. So in financial terms, although there have been hidden costs, this evaluation has been relatively cost effective. The main cost has been the additional time required to support the co-researchers and keep the whole team (steering group included) involved in the decision-making and up to date with the latest information.

Whilst the sponsors of the evaluation have been totally committed and have been patient for the final results, it has still been necessary to complete the fieldwork and analysis to tight deadlines in order that the results can influence the service plans for 2004. This has been stressful at times, as to refrain from putting pressure on the co-researchers, the fieldwork has taken longer to organise and complete. The lesson we have learned from our experience is that involving service users in research is a long-term investment that gives valuable rewards.

Our strongest recommendation would be to build in

a more comprehensive training programme designed to run in tandem with the research process. Ongoing training would give the co-researchers the opportunity to discuss and iron out issues that arise through their experience of interviewing to build upon the foundations of the theory. In addition, communication and support time needs to be anticipated and explicitly drafted into the research proposal and project time-scales. Networking with other service user researchers should also be made a mandatory part of the process as there are currently few off the shelf models available and learning from shared experience is vital.

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