



**INDEPENDENT EVALUATION:
DEVELOPING USER INVOLVEMENT IN LEONARD CHESHIRE**

FINAL REPORT

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Contact:

John Swain
Professor of Disability and Inclusion
School of Health, Education and Community Studies
Northumbria University
Coach Lane Campus
Coach Lane
Benton
Newcastle upon Tyne
NE7 7XA
Telephone: 0191 2156191 Email: john.swain@unn.ac.uk

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1. INTRODUCTION

1.1 Aims

To conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity.

Objectives:

1. To explore the effectiveness of current strategies in promoting Leonard Cheshire's commitment to user involvement, including the Disabled People's Forum and SURE, from the viewpoints of the different stakeholders within the organisation;
2. To examine the possible barriers to the promotion of user involvement within Leonard Cheshire;
3. To consider options and make recommendations for future developments in user involvement in Leonard Cheshire.

1.2 Ethical Principles

N.B. No participant is identified in this report. Readers are asked to respect the spirit of this research and the anonymity of those who have participated.

Ethical principles were adhered to within the research process. Informed consent was pursued through the use of information sheets and consent forms (Appendix 1). These were adapted to fit the particular situation of participants.

Though no individuals are named within the report, complete anonymity is difficult within an organisation such as Leonard Cheshire. It will be possible to identify individuals referred to in some quotations and to recognise the source of some quotations. It is essential that the report is read in terms of the issues raised – the structures, processes, outcomes of user involvement – and not particular individuals.

1.3 Evaluation Management

The research has been conducted as an 'independent evaluation' by a research team base at Northumbria University: Professor John Swain, Carole Thirlaway, and Dr Sally French. Professor John Swain is responsible for the management of the research team.

The management of the project has been conducted through a Steering Committee. In general terms the committee is responsible for ensuring that:

- the 'independent evaluation' is independent, that is not reflecting or controlled through any vested interests within the organisation;

- the research is collaborative, that is conducted 'with' rather than 'on' the organisation.

Specifically, the committee is responsible for:

- negotiating with the research team in the detailed planning of the research and ensuring that the focus and research process are effective in meeting the requirements of the organisation;
- managing the implementation of the findings of the research within the Leonard Cheshire organisation;
- the dissemination of the research findings within the Leonard Cheshire organisation.

1.4 User Involvement

Robson et al define user involvement as '.....the participation of users of services in decisions that affect their lives' (2003:2) and Beresford and Croft believe that '.....speaking and acting for yourself and being part of mainstream society, lies at the heart of social care service user involvement' (2002:389). The evaluation team, in the light discussions within the Steering Committee, took a broad view of user involvement. This was guided and informed by three interrelated frameworks.

- Formal/informal involvement – Informal involvement encompasses the say or voice that service users exercise in their daily lives. Formal involvement encompasses the mechanism/management/systems of user involvement within the Leonard Cheshire organisation.
- Structures, processes, outcomes – A second framework, adopted within the interview schedule, views user involvement as embedded in the structures, processes and outcomes of the organisation.
- Levels of involvement – The third framework conceptualises user involvement as a continuum, ranging from active involvement in management to personal control of services provided by Leonard Cheshire.

2. CONTEXT OF EVALUATION OF USER INVOLVEMENT

2.1 The National Context

The evaluation of user involvement in Leonard Cheshire needs to be understood and set within the broader national context of health and social care services and the priority given to user involvement across a wide spectrum of policy development. This review will commence with a brief historical overview of user involvement in health and social care services. Some key issues will then be described and will conclude with a summary of the various strategies to remove or minimise barriers that impede user involvement.

The Development of User Involvement

The development of user involvement in services for disabled people arose in Britain in two main ways. Following the election of Margaret Thatcher as Conservative Prime Minister in 1979, there was a shift towards a market ideology in health and social care. A quasi-market was introduced into health and social services to allow some degree of choice for patients and clients – who were now regarded as consumers. The idea was that services would be ‘needs-led’ rather than ‘service-led’ and that disabled people and other service users would be assessed for individual ‘packages of care’ within a ‘mixed economy of welfare’ including private, voluntary and statutory services. (Hughes and Lewis 1996, Furgusson et al 2004).

There is now a well-established legal and policy mandate for the principle of involving users. Statutory guidance on both the Children Act 1989 and the NHS Community Care Act 1990 repeatedly emphasise the need to inform, consult and involve people who use services. The Community Care (Direct Payments) Act 1996 took this further by enabling local authorities to allocate money rather than services, thus promoting disabled people’s control. Managers were, for example, required to consult with consumers regarding community care plans. These changes reflected the consumerist ideology of the political right and were viewed as a way of cutting costs, providing more flexible services and reducing state involvement (Beresford and Croft 2000). In 1997 these policies were, in essence, continued in New Labour’s modernisation agenda for health and social care (Mercer 2003, Carr 2004).

As a result of these policy changes the 1990s saw a considerable growth in user involvement initiatives particularly in the Social Services where thousands of disabled people now participate in a range of activities (Carmichael 2004).

A second development at this time was the emergence of well-organised and strengthening user movements including the disabled people’s movement (Davies et al 2000). The agenda of the disabled people’s movement goes far beyond the issue of services (however important they may be) to full democratic citizenship and the dismantling of a disabling environment in terms of physical and social barriers (Campbell and Oliver 1995, Barton 2004). Other social movements, such as *Survivors Speak Out*, *Gay Pride*, and the

Self Advocacy Movement have similar agendas. Talking of the disabled people's movement Drake states that:

".....it is important to give due weight to the contribution that the disability movement has made in changing the thinking of governments, bringing injustice to light and forcing a radical alteration of the policy agenda." (1996:187)

Carr (2004) also stresses the importance of collectivism in user involvement for disabled people and the ideas and philosophy of the social model of disability that underpin it.

Some Key Issues

Beresford and Croft note the tension between the ideologies of the government and those of the disabled people's movement. They state:

"These two approaches to participation, the consumerist and democratic approaches, do not sit comfortably. One is managerial and instrumental in purpose, without any commitment to the redistribution of power or control, the other liberational with a commitment to empowerment." (2000:356)

Brown emphasises the depth of this conflict:

"Service users have not only focused on the way they want services delivered but also challenged the relevance and appropriateness of the knowledge base upon which professionals traditionally draw. User movements have increasingly been involved in generating theory about their position in the world - theory which rests on the analysis and lived experience of people who use health and social care services." (2000:99)

In addition Brown (2000) claims that consumerist models tend to define structural problems as communication difficulties thereby reducing social and political issues to an individual level. Braye states that the consumerist model tends to give '....the illusion of participation without the substance.' (2000:19) and Carr notes that:

"Democratic initiatives involve service users influencing and making decisions, while consumerist approaches focus more narrowly on consulting people about the services they receive." (2004:5)

The range of services offered to disabled people under the consumerist ideology of social care is small and largely determined by financial, managerial and professional considerations and judgements (Godfrey and Gallagher 2000). Disabled people themselves regard this situation as wholly inadequate. As Evans states:

"It is important to us that our involvement is based on our terms and within a background of rights: the rights that we have as citizens like any other – the democratic right to participate in society and the right to have choice and control over our lives – this must mean we have as much choice and control as we can over the services we receive." (1995:116)

Carmichael stresses that '...user involvement is a means to an end and not an end in itself' (2004:201). Similarly Beresford et al (1997) and Priestley (1999) emphasise that user involvement is merely a vehicle for effective change in terms of the services delivered and the behaviour of those who deliver them. The Disability Discrimination Act (1995) and the Human Rights Act (1998) will, perhaps, go some way in assisting disabled people in their struggle for full participative citizenship. The power of legislation to bring about change can, however, be exaggerated.

Bewley and Glendinning warn against relying heavily on any one method as none are perfect and a variety are needed to reach all disabled people. They state:

"There are a range of methods by which disabled people and voluntary organisations are involved in community care planning and there is nothing necessarily inappropriate about using any of them. What disabled people involved in this project criticised was the reliance by social and health services on a small range of methods to reach and consult all disabled people on all matters; the burdens which involvement placed on individuals; the exclusion of more marginalised groups and communities; and the lack of clarity and debate about the purpose of each method and its suitability for achieving that purpose." (1994:16)

Many practical, organisational and cultural barriers need to be addressed if the involvement of disabled people in health and social care services is to become a reality. A central issue is the unequal power relationship between service users and professionals and managers (French and Swain 2001, Swain et al 2004). Carr asserts that 'Power issues underlie the majority of identified difficulties with effective user-led change' (2004:14) and that '...dissatisfaction and even conflict may be an inevitable part of the user participation process (2004:18). Similarly Priestley states that:

"It is impossible to discuss user participation without reference to power. If providers are committed to increasing user power then they must contemplate a corresponding reduction of their own power." (1999:158)

The power imbalance between disabled people and professionals and managers extends to the meaning of important concepts that affect disabled people's lives. Disabled people and professionals tend, for example, to have a very different idea of the meaning of 'care' and 'independence' with the view of professionals and managers predominating and being translated into policy and practice (French and Swain 1998, Goble 2004, Finkelstein 2004, Carr 2004).

Because disabled people are often dependent on the services they receive they may fear repercussions if they complain (Brown 2000, Robson 2003, Carr 2004). Likewise managers and professionals may fear the increasing power of disabled people and the anger they express. These tensions can be made worse if more than one group of users are involved who have different ideologies and historical roots, for example disabled people and 'carers'

where 'carers' usually have more power.

Robson et al (2003) note that a controlling style of management can be a strong and destructive barrier to user involvement and, conversely, a facilitatory style can be beneficial. Influential allies within the power structure also enhance the potential of users to influence decisions as can external groups such as researchers and disabled people's organisations. Robson et al (2003) point out the need for a stable and committed staff who will assist in taking user involvement initiatives forward. They note that such initiatives can be slowed down or stopped if the turnover of staff in organisations is high. The amount of time and support managers and professionals can give will, in turn, depend on how well they are supported. Carr contends that:

".....a fundamental political commitment to change should be driving the participation agenda. The intention to change as a result of user participation should be established prior to its implementation (2004:14)

Disabled people are constantly accused of being unrepresentative when they express their views or when they attempt to speak on behalf of other disabled people. Evans and Carmichael state that:

"Representatives from organisations of disabled people, including self-advocacy groups, were sometimes dismissed by social and health service officers as being unrepresentative of users because they appeared to be too articulate to be 'real' users." (2002:22)

Beresford and Campbell believe that the emphasis by health and social care workers on the representativeness of disabled people is a way of maintaining their power base. They state:

"We become representative in ways some providers do not want. We become confident, experienced, informed and effective. At the same time because getting involved is not something that most disabled people are encouraged or have had the chance to do the mere fact of being involved may be seen as making us 'unrepresentative'..... people's representativeness assumes importance if what they say threatens or challenges the status quo" (1994:317, 318)

Managers and professionals sometimes use lone disabled people from the workforce to represent other disabled people without any recognition of the conflict the position puts them in (Evans and Carmichael 2002). Furthermore disabled people are often used in a tokenistic way, for example having just one disabled person on a committee. Beresford and Campbell go on to explain that while service professionals and managers have a representative system of democracy, disabled people's organisations have a participatory model of democracy which is characterised by consensus decision making. The conflicts between the two systems of democracy are such that they advise separation between them:

"It makes sense to spend more of our energy participating in our own initiatives rather than being represented in service systems. that is where the real promise of participation, empowerment and our own representation in society lies." (1994:324)

A major barrier for disabled people is access to the user involvement process. Evans and Carmichael are particularly critical of the widespread use of public meetings in user involvement initiatives. They state:

“To engage in public meetings or other sorts of meetings demands, on the whole, familiarity and confidence with the normal style, format and language of these meetings. In addition very practical issues of physical access, transport, interpreters, signers, personal assistance and so on must be addressed by social and health services if disabled people are to be enabled to take part in consultation meetings.” (2002:20).

‘Knowledge is power’ but all too often accessible information is lacking. Information needs to be accessible to all disabled people, regardless of impairment, if user involvement is to succeed. Disabled people also need background information in order to participate meaningfully (Evans 1996). According to Bewley and Gledinning without background information:

“.....disabled people could not participate on anything even approximating to an equal basis with social and health service officers, moreover they risked having their contributions dismissed as ill-informed or reflecting ‘personal biases’.” (1994:31)

Suitable transport, accessible premises and realistic time scales are also essential for successful user involvement (Bewley and Glendinning 1994, Beresford and Croft 2002). The pace of work can also be exclusionary to many disabled people (Carr 2004:20). As Pound states:

“For people with communication disabilities the issue of time may far outweigh the relatively straight forward challenge to adapt the physical or spatial environment. The rapid rhythm and tempo of everyday life make few allowances for a calmer, slower, more deliberate form of interpersonal communication. For people with communication disabilities the slower tempo is not a choice but the only accessible pace.” (2004:163)

Disabled people have frequently been disempowered by previous experiences, for example time spent in institutions, and need time, support and resources to built up sufficient confidence to participate fully (Evans 1999).

The whole process can be distorted by the fact that user involvement is funded by Social Services (Carmichael 2004). Disabled people may be positioned as external consultants to approve the decisions of professionals and managers or organisations ‘for’ disabled people may be consulted in preference to organisations ‘of’ disabled people. Carr states:

“.....there is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off rather than an embedded and powerful organisational practice.” (2004:17-18)

Carmichael (2004) found that users’ views about user involvement were

generally positive despite the lack of tangible change in service provision. However, motivation can be quickly lost if their input has no effect (Beresford et al 1997). Evans believes that with appropriate support and resources disabled people:

“..... can become a significant force in bringing about change, addressing the power imbalance between service users and service providers and purchasers and in developing innovative examples of good practice in service delivery.” (1996:69)

An important aspect of user control is the introduction, after many years of campaigning by disabled people, of direct payments. The Direct Payments Act was passed in 1996 and obliges local authorities to assess disabled people for a cash payment so that they can buy in their own services rather than relying on the intervention of a ‘care manager’. Direct payment has challenged professionals and professional power (Brown 2000, Swain et al 2003, Hasler 2004) although the payments are cash limited and administered through Social Services. Furthermore, users are concentrated in the South East of England and some groups, for example people from ethnic minorities, people with learning difficulties, users of the mental health system and older people, are not well represented (Butt et al 2000, Holman 1999, Ryan and Holman 1998, Carr 2004).

Factors In Successful User Involvement

This review will conclude by highlighting the major factors necessary for successful user involvement according to key workers in the field. Robson et al (2003), for example, believe that the following factors are necessary to sustain change in user involvement:

- A user centred approach
- Influential supporters
- a commitment to work with difference

Evans has laid out some key principles for informing user involvement which include:

- The underpinning of the social model of disability
- User-led community development work
- Valuing user expertise
- Working with allies
- Building on existing user initiatives
- Changing from ‘knowing best’ to enabling users
- Bottom-up change
- ‘Riddling the system’ with user involvement
- Embarking on a journey of exploration
- Working in bite sized chunks.

With regard to the latter point she states:

“.....it is all too easy to get so overwhelmed by wanting to change the world that one fails to get started. Faced with the conservative nature of social services and health bureaucracies even the small changes user organisations make need to be recognised and celebrated.” (1999:9)

Gibbs and Priestley (1996) provide the following user involvement checklist:

- Does your organisation want to increase user power?
- Are your staff required to demonstrate a commitment to user involvement?
- If you impose limits on user power do you make these clear to everyone?
- Are your environments, processes and information accessible to disabled people?
- Do you involve disabled people's organisations as well as individual users?
- Do disabled people control your user involvement process?
- Do disabled people control your user involvement agenda for consultation issues?
- Do you provide user representatives with the same support systems as staff representatives?
- Do you communicate the outcomes of disabled people's involvement back to them?
- Has your organisation ever made changes against its will because disabled people wanted you to?

Conclusion

Thus the evaluation of user involvement in Leonard Cheshire was conducted in a national context that: emphasises and mandates the priority of such developments in policy and practice; is characterised by conflicting notions of user involvement and complex and fraught debates; and offers some key principles for development. This background underpinned the methodology of the evaluation and provided a framework for analysing and interpreting the findings.

2.2 User Involvement within Leonard Cheshire

3. METHODOLOGY: WHAT WE DID

3.1 Stages of the Evaluation

Stage One:

Mapping the Evaluation

The first phase of the project initiated a participative processes. This initial 'research mapping and access' phase involved:

- Initial contact with stakeholders within Leonard Cheshire including service users, Leonard Cheshire managers, trustees, directors and volunteers, Disabled People's Forum Staff and SURE representatives.
- A literature search to identify existing relevant research.
- Liaison with similar research presently being undertaken.
- Qualitative and quantitative analysis of documentation provided by Leonard Cheshire.
- Agreement of detailed project design and Code of Ethics.
- Construction of a list of key participants.
- Discussion around potential ways to disseminate the findings.

The Views and Experiences of Service Users and Providers

This phase addressed the evaluation of service user involvement through the collection of qualitative data from service users and providers. Focus groups and semi-structured interviews were conducted. The evaluation drew on recent significant developments in the field of research methodology with disabled people, including the use of narrative methods. The key questions were developed with the participants around topics of: the proactive approach to user involvement; user involvement at all levels of the organisation; impact on the lives of service users; and the effectiveness of the current main strategies within the organisation – including training, opportunities of users to meet, mentoring, providing information, support to users in learning difficulties services, and facilitation and support to SURE. Areas of user involvement to covered: governance; central committees; regional involvement; local services; staff and volunteer recruitment; Staff Agency and volunteer training; policy development; care and operational reviews; Choice; one off opportunities; and social care opportunities external to Leonard Cheshire. However, the agenda was flexible, and groups and individuals were encouraged to concentrate on the topics of most concern to them.

Stage Two

The second and final phase of the evaluation built on the conclusion of the Interim Report (August) and discussions at the Steering Group Meeting 7th September. The aims were to:

- Develop the recommendations of the conclusion of the Interim Report with specific possibilities for strategies in practice;
- Conduct 6 'case studies' of local developments within Leonard Cheshire in relation to user involvement;
- Focus on examples deemed to be good practice by members of the Steering Group in terms of the factors promoting and limiting user involvement;

- Consider strategies to ensure that the process and recommendations of the evaluation are utilised in the development of user involvement in Leonard Cheshire.

Five case studies were conducted. They varied in scope and particular focus, though the general focus was on the development of good practice in user involvement. The format for reporting each case study is similar:

- A descriptive introduction outlining the scope of the case study;
- An outline of the findings of the case study;
- Conclusion in terms of the implications for the development of user involvement.

3.2 Sampling

During Stage One of the evaluation Interviews/focus groups were conducted with the following participants.

Service Users

Individual interviews/group interviews/focus groups were conducted in residential homes, day services and care in community services.

Group interviews/focus groups - 10. Each group was made up of approximately 6 service users.

Individual interviews – 11

SURE meeting – approximately 25 participants

Total – 96

Service providers

Director General; Regional Directors (2); Trustees (2); Director of Communications; Head of Quality and Standards; Head of Volunteering; Manager of DPF; Deputy Manager of DPF; SURE Facilitator; Volunteer Training Officer; Mentor (2); Forum Facilitator (2)

Total – 17

Total number of participants 113

The number of participants in each case study in stage two is provided within each of the case study reports.

3.3 Interview Schedule

The approach to data collection was semi-structured and open. To structure interviews and discussion with focus groups, the research team drew on a detailed interview schedule (see Appendix 2). This schedule was used as a basic framework and adapted used flexibly to allow participants to control the direction of the data collection.

4. FINDINGS FROM STAGE ONE OF EVALUATION: VIEWS OF USER INVOLVEMENT FROM THE VIEWPOINT OF SERVICE USERS

4.1 Lack of 'ground level' staff

Most of the residents who were interviewed commented on the lack of 'ground level' staff and how this affected their ability to make choices in their daily lives. This is a major issue that affects all aspects of service users' lives and is probably the pivotal influence in the development of service user involvement. Time and again the reason for lack of choice, not been listened to, dignity and lack of control over lives is given as a staffing problem. This lack of choice could reach a very basic level as is evident in the following quotations:

"We have one bath a week, that's on a specific day."

"We have two (baths) a week....we'd like more but they can't do it."

"The toilet. That to me is basic. I was desperate and I rang the bell and at last they came. There are bells everywhere but the only time you don't have to wait is in the night. I just dread it every day and I think 'Oh god, here we go again!'"

There was a clear association between day-to-day user control over their lives and the level of support.

"I don't feel all the time that I'm fully in control of what I do and don't do. For instance, I can't prepare myself a meal and I can't move my chair without the assistance of a carer. If I want to go anywhere quickly, go to the toilet or something like that, and don't get there in time, they say 'You should have asked' but if there's not enough staff about it's literally impossible to get there, you have to wait for someone to take you."

"The other night for what I wanted it was no good ringing because there was no night staff who could get into the dispensary. It wasn't worth ringing and I just laid in pain all night."

Other people spoke of the lack of personal contact with staff that could affect their well-being, quality of life and their ability to make their views heard.

"Sorry to be negative but I find that if you go out you need a carer to come with you and there aren't always carers around that will come with you. They're always tied up."

"If you ask them a question they won't answer it. They say 'I can't answer it at the moment but I'll look into it.'"

“They can’t do much for us. All right they do what is necessary but if we want that little bit of extra help, like D might or I might need a bit of help with the computer, it just isn’t available.”

“You ask someone something and they say ‘I’ll talk to you later’ but it takes a while before they see you.”

“I wait, I can’t keep asking because it tires me out to keep asking.”

“By the time you’ve waited for them to come back you’ve forgotten what you wanted to say.”

This lack of staff contact and attention to their needs led some residents to feel less than human:

“You’re more of a number than a person. You’re a commodity. You’re just a commodity, nothing else. I mean you’re put to bed, you get fed, you get up in the morning and that’s it. You can book up to go out but that depends on whether the driver’s here or you can get a volunteer which we’re very short of.”

“Charity is a big thing and some of these charitable organisations have in the past been run very much on a ‘We know what’s best for you’ type of ethos and I think that Leonard Cheshire is struggling with this because obviously they have been looking after people with profound and severe impairments they’re coming from this idea that ‘We know what’s best’ and I don’t think they see people as human beings sometimes. It’s a terrible thing to say but what I mean is you become the object that they are looking after as opposed to an individual who is using services of Leonard Cheshire.”

In these circumstances, empowerment and user involvement in the day-to-day decisions over their own lives can be seen as ‘a problem’.

“One of the problems it (user involvement) causes is when residents become more empowered and aware of the opportunities of life they’re likely to ask for more. In asking for more, it usually involves staff, and resources are already very scarce and limited, and centred mainly in providing basic daily care in washing, dressing, eating and they occupy an awful lot of time. Empowerment creates problems of staff support. And if the choice of empowerment involves travel then that’s a further added burden. Not necessarily to pay the cost of travelling but to have the opportunity with limited transport or escort.”

Understaffing, too, can be used as a rationale for the lack of choice over support staff.

“I do depend quite a lot on support and care from the domiciliary service which is quite good in the limited capacity that they have.

There is somebody they send to me that I don't want but what they say is 'Well if you don't want her we haven't got anybody else.'"

The idea that the situation was deteriorating, rather than improving was a recurring theme with participants.

"Too many regulations, like we should be able to go out, to a degree, if there is no driver and we want to go out, we just have to wait until someone comes. When I first started the key workers would take us out on one-to-one trips. We have more people with higher care needs and it is not possible to go out on one-to-one very much any more."

"Each one of us has a key worker but they have less and less time to spend on us. There's less and less 'one-to-one' going on."

Staff turnover was repeatedly referred to as a central part of the picture:

"Trouble is when people leave they don't replace them in the proper way, they get agency in and if somebody leaves full-time they get somebody part-time."

For many service users, staffing levels needed to be seen within a broader context. Some of the residents were convinced that too much money was spent at the top of the organisation:

"The organisation is too top heavy. When I came here six and a half years ago, there were forty staff up at head office and now they have ninety. At the same time they reduce the staff here. They take the money away from where it's needed."

"What I feel is that if head office want extra staff, for anything in particular, they get them but if we want more staff we're told we can't have them. I think there should be a lot of job cutting up there. It's far too big."

Many residents perceived that their own needs were regarded as less important than issues such as paper work and staff training:

"I'd like to spend more 'one-to-one' with people but they don't have the time. It's simple things like communicating. Most of what they go for training for is common sense."

"Staff have been given more paper work and if that paper work needs to be done then things can't be done for the residents."

"It all boils down to not enough staff. There isn't always the time, they get so much more paperwork with these new Care Standards."

"There's so much training going on, training for anything and everything, and it takes staff off the floor while they go for training."

Some of the residents offered interpretations of the lack of staffing which made basic user involvement impossible. The greater care needs of residents, together with lack of staff to cope with this, was put forward as a major explanation:

“They seem to be taking more nursing cases which accounts for the lack of staff. They’re having to do too much. Then they move on. We had three people who all left at once.”

“They go for more disabled people to get a higher fee and they aren’t increasing the care staff to match.”

“There are a lot of highly dependent people now because of this ‘care in the community’ thing and there just aren’t enough carers for the amount of people.”

In the past residents had a say in who was accepted to live in the home but this choice has now been eroded:

“When I first came here six years ago the residents could have a say in who lived here, whether a new person was accepted or whether they were refused. The head of home and the head nurse would be there, there would be a volunteer from the outside world and one or more resident. People had a four-week assessment and not everybody got in on that assessment. Then it got changed and nobody gets refused now. So we have no say in whose coming into the home, therefore each one of the care staff has to do two feeds at mealtimes. All the people who come in are highly, highly dependent now. They haven’t got the nursing staff or the care staff to be able to cope with it.”

For many participants, then, the notion of developing user involvement begins with increased levels of staffing.

“We’ve having less and less control over our lives now to what we had a few years ago. It’s government legislation, and policy coming from Leonard Cheshire. We haven’t got the staff to enable us to do what we want to do anyway.”

“You have a key worker and she says ‘Are you happy Lynn? Are you doing this? But nothing happens, she’s just one of the carers. She’s too busy. They’re all too busy.”

“We want more staff, that’s what we want.”

4.2 Transport

Lack of ‘ground level’ staff also had a serious impact on the ability of the residents to enjoy life outside the home and to exercise choice in their leisure pursuits. A constant theme was lack of transport and drivers. Clearly

transport is fundamental to service users in determining their quality of life:

“The transport is very nice but we don’t get out enough. There’s a shortage of drivers.”

“Recently we had what is known as ‘Pop in the Park’ and we couldn’t get volunteer drivers or escorts for that. Since I’ve been here I’ve never known us miss that. Also I think they missed ‘Proms in the Park’ as well. They couldn’t get any drivers that was the trouble.”

“They often phone up and cancel because they haven’t got a driver.”

“I had an OU thing that I wanted to go to. I arranged it three or four weeks in advance but two or three days beforehand the driver pulled out and I couldn’t go.”

“There’s trips every week but they can only take three wheelchairs in the van.”

“The management here tries their best but it all comes down to transport. We have some transport but it’s not enough. It’s all down to money again.”

“I waited until half past twelve yesterday, just in time for lunch. I should have been here at ten. It was more or less just for the afternoon session.” (user of day centre)

“I live just across the road and I walk but I can’t do it both ways. By the time I get here I ache from head to foot - it’s good exercise but you shouldn’t have to do it.” (user of day centre)

“What I can’t understand is that they’re a big organisation, Leonard Cheshire, so why don’t they fund it (transport). This is what I can’t understand. Where is the money going? It’s a big charity and we do a lot of fund raising here for Leonard Cheshire and we’d like to know where the money goes. We should be part of it, we should know where it goes.”

“Living here on the outskirts of a large city, the opportunity that provides us with to follow the theatre, sport, parks and day centres and you go on and on. But in order to take those up what the service user needs is transport either from within the home or from the local area of bus, train, ring and ride. Volunteer drivers are always a problem.”

“Transport is another issue. Some places have transport but that’s not altogether easy because you’ve got to book it in advance and they might turn round and say ‘We haven’t got a driver today’. They’ve got the control. They always have the control. The service users don’t have control. The managers have the control all the time and so there is little choice.”

Transport issues are, of course, one of the arenas that extend the concerns of service users well beyond the Leonard Cheshire organisation. This has been recognised within the organisation, though service users questioned the effectiveness of broader campaigns:

“I think that Leonard Cheshire are well behind the times because they still talk in terms of specialised transport. They’ve recently done a consultation on it but they don’t campaign enough to improve public transport. For them the issue around transport is always ‘How are we going to get someone from a to b?’ I remember that in our area the customer services of Connex came to give us a talk so we got a link into different things like transport, things that were of interest to the service users at that time, but that fell on deaf ears because nothing comes from it.”

“Leonard Cheshire did a report on transport called Mind the Gap and the Disability Now magazine said Mind the Gaff because they launched it in a hotel that didn’t have access and they had to bring in a ramp at short notice as it was in an inaccessible hotel and the ramp was much too steep.”

The lack of ability to go out and meet other people could have profound effects of the lives of the residents. As one man said:

“One of the big things I would like to change is the absence of sex in my life. A lot of people who I meet with and talk with are substantially older. People here cannot provide for that particular need.”

Policy to change the way in which transport is paid for was also causing residents concern:

“I am on the regional committee as well, and head office want to change the transport policy, at the moment, and there are a few things that are still at the draft stage at the minute, but there are things like the resident being given some tag like taken the mileage money and things like that, but some of our residents would not be able to do it and so that is a big concern. And also, if you want to go out we do not know how much it is going to cost us, cause at the moment we all pay a block £40 per month, so that entitles us to go where we want, but if these changes come in to force, then we will be paying per mile.”

Another theme with regard to transport was lack of spontaneity and flexibility. This obviously has an impact on what people could choose do from day to day:

“I go out quite a bit and I use transport if I can book it up far enough in advance. You can’t be spontaneous.”

“They keep telling us not to get institutionalised but you can’t bloody avoid it and they make it worse for us. They say ‘We’ll take you down when we get the cleaners but you’ll have to be back by three’. We got in the vehicle, C and myself, and he dropped us off in the town and he said ‘You must be back here for half past three’. All we had was about fifty minutes and yet all afternoon they’d been sitting at the table with nothing to do.”

“A while ago we booked up in advance to go to the seaside and it was a horrible day so we went to Canary Wharf instead but we were a lot longer and when we came back one of the carers got into trouble because she’s been out all day. We changed the arrangements and were out longer than we would have been and it did cause problems.”

“We had to book it in advance and who knows what the weather’s going to be like? There’s no spontaneity. You can’t say ‘What a lovely day, let’s go to the seaside.’”

Anger was expressed about the way in which transport for hospital appointments had been discontinued. Many people had no choice but to use hospital transport that was even more unreliable and impacted negatively on their quality of life:

“They’re cutting transport for hospital service and the dentist and eye appointments. You have to order your own transport and pay for it yourself. By the time it gets here and brings you back it can cost about 40 quid.”

“In the past if you wanted to go to the dentist, or the doctors or anything, the transport was there. We have our own transport but they have day care to bring in, and take them back, and then they have to ship the cleaners back and forth. The home’s transport is used to bring day care people in, and then outings – there was one today. I’ve just come out of hospital and if you wait for an ambulance and they say it’s going to turn up at eleven it never does. I was there for three and a half hours waiting and then they made a detour to pick someone else up. It gets later and later.”

The homes are generally in rural locations that makes transport even more essential and can lead to limited choices if it is unavailable. As one resident said:

“We’re at the back of beyond.”

When transport and the ability to go out worked well, however, it was appreciated and enabled residents to have greater control of their lives:

“I think the transport is very good and we’re lucky to get transport when we want it.”

“On Wednesday we went on a mystery tour, we went out at quarter to ten in the morning and got back at quarter past four in the afternoon. We had a brilliant time. “

“They have shows and things, we go to zoos and parks and all sorts of things. We have a lady who does the planning. We look through various things and tell her where we want to go. It does make life more interesting.”

4.3 Agency Staff

The residents expressed a general dissatisfaction towards agency staff, who were perceived as unskilled and knowing very little about their needs. At a basic level, the residents had no choice but to accept whatever help was provided for them. Agency staff were seen as lacking in motivation and basic support skills:

“They’re only in it for the money.”

“They don’t know the job. They don’t know what to do.”

“They’re not interested because they know they’re not going to come back here again. It’s just a day’s work. They’re just passing through.”

“It’s mostly at weekends that there’s a shortfall of our own staff. Agency staff aren’t so dedicated.”

Difficulties in communicating with agency staff, for a variety of reasons, undermined possibilities of service users controlling the support they receive:

“I don’t like agency staff. Agency staff are paid more than our staff and I don’t like that. They don’t work. Sometimes we can’t understand them and they can’t understand you. They can’t speak English and it’s not very nice.”

“We do have a problem because they use the agency here. Some are very good but others if you explain something to them it’s as though you’re talking Martian, they don’t listen and they don’t understand the most simple things. It’s like hitting your head against a brick wall.”

Again staff turnover is a central part of the picture:

“You get up in the morning and you’ve got someone to get you up who you haven’t seen before. It happens quite often.”

Research participants provided some illustrative specific examples:

“They only understand what they want. They don’t listen. There was a chap feeding T. He’s a resident, he eats, and he’ll eat everything, but when he has a drink he has to have thickener in it because otherwise it

goes straight to his lungs. And the bloke's feeding him, and giving him a drink, and T's coughing. He's choking because the drink's going straight to his lungs, and I said to him six times 'He wants thickener in it' and all he said was 'Stop coughing T'."

"I can give you a classic example. On Wednesday morning I was due to go out. I had to be ready at ten o'clock and she came to me and she'd never dealt with me before and she tried to literally lift me out of bed without using a hoist. I said 'You have to use it' and she said 'No I don't.' I said 'You'll hurt yourself'. She wasn't listening to what I was saying and another member of the nursing staff came in and said 'Don't be so horrible'. I said 'I'm not being horrible I'm just telling her what I want her to do' and I never got a bath at all I just got a wash down. If only she would have listened to what I wanted I could have coped with it."

4.4 Staff Attitudes and Behaviour

The staff were mainly viewed by the residents as people who were doing their best under very difficult circumstances. However, some instances of poor attitudes and behaviour were expressed. This, in turn, had an effect on how well the service users could control their own lives. Central to this seems to be the power that staff can have in the carer-cared for relationship:

"Yesterday I had a really bad day when I could hardly lift my hands up and he (another resident) was helping me. And they turned round and said 'Why aren't you doing that yourself?' and I said 'I cannot lift my hands up sometimes'. I'd been using the computer and my arms were really aching."

"Certain people, especially the drivers, think they're God. There's too many chiefs and not enough Indians in this place. We have some wonderful staff and we have some crap ones. We have some people who are on power trips."

"I honestly believe that they think we're silly. They think we're stupid."

"She said to me that I ought to be grateful even though I can never work again or go and live outside here."

Attitudes such as these could lead to fear about speaking out and making their views known. This was a consistent theme for the service users:

"We can (make views known) through the Disabled People's Forum and we can through SURE. The only thing is you have to be very careful because if you say too much your name is mentioned and you are put down as a troublemaker. You have to be very careful what you say because you will get 'pay back' time. It won't be anything specific but you will be the last one to be fed, the last one to get your tablets, things like that. It's very awkward. I've got to the stage now

when I just don't care."

"You can't afford to upset people if you're dependent on them. They talk among themselves. They say 'What do you think he said to me?'"

"Some service users don't like to comment because they are frightened of bad marks against them – if they think they are complaining or things like that. It is fear of the unknown really."

"My involvement with the Disabled People's Forum, we had meetings locally in our areas, whereby the chairman felt threatened inasmuch as he is disabled and in a residential care home and he was frightened like 'If I write a letter stating these things I might be badly treated, I'll be singled out in the residential care home where I am and I don't know whether I can cope with that.' You get labelled. It's the old thing: you're stirring it for others, you're causing trouble, all those issues."

Some residents simply referred to a lack of support:

"I would tell the manager about things, but sometimes he just does not want to know. He tells us to sort things out for ourselves and I have tried that."

4.5 Health and Safety Policy

As with the transport policy, policies and legislation concerning health and safety were reported by the residents as having an impact on their ability to control their lives. The introduction of an excessively overprotective Health and Safety Policy has been responsible for the erosion of basic human rights throughout the organisation. This is a huge barrier to the development of any service user involvement or having control over your own life:

"There was an instance a couple of months ago where residents were suddenly told by nursing staff one evening that we had to be checked every hour throughout the night every night on the grounds that it was health and safety requirements. That was a gross infringement. There were objections from many residents and I know that it was not fully implemented in that manner. It was communicated dictatorial, institutional directives are fed down."

Specific examples were given:

"When I first went over there (to a bungalow in the grounds of a residential home) my chair was put on charge in the bungalow and they stopped that because of a fire hazard they reckon, dangerous. I've now been told it's all right to do it but I haven't got it back in the bungalow yet to charge."

They saw assessment as part of the control that others had over their lives:

“You’ve got to be assessed to go out, assessed to use the microwave.”

“ When I came here with my husband we lived in the annexe and we didn’t have to have any assessments. I’m now in a double room on my own and before I can use my microwave I’ve got to have an assessment on it, the same for boiling the kettle. What an insult! I did it in the community but I couldn’t do it here until I’d had an assessment.”

“You can’t go out on your own unless you have an assessment. I find it insulting, very insulting! C said I’ve got another one today. Then you get frustrated. People think we’re imbeciles.”

Service users saw the necessity of health and safety concerns, but also thought their lives were unnecessarily restricted, as the following specific examples illustrate. Part of the problem for service users is the application of blanket and universal rules and procedures that take no account of the individual or the local circumstances:

“As an organisation they need to think about our right to take risks because sometimes that’s what you want to do. A couple of times I’ve been advised that I shouldn’t do something because they don’t feel I’m safe enough. One was standing up to go to the loo. They insisted that I had to be hoisted. I can see the logic of that but I felt I could stand. You’ve got to accept that they are right at some point but they have got to accept your right to take risks for as long as you feel you can. It keeps coming up, health and safety.”

The universal application of a training policy was, similarly, seen as creating difficulties:

“It’s hard enough getting volunteer drivers without saying ‘Before you can do it you’ve got to do this course’. As I understand it that’s the problem. It’s starting to cause a problem. It was always there on an informal basis but now they’ve made it something official where people have got to give up time.”

The following two quotations articulate and effectively summarise a major body of opinion amongst service users. These participants place user involvement, or more particularly restrictions to user involvement, within a much broader context than day-to-day decision making. They also encapsulate and embody user involvement in wider power relations:

“Most of our lives is being informed and notified of restrictions rather than improvements in our lives. Restrictions that have come about through legislation or budgetary restrictions within the home, regressive, negative change. It’s all been driven by some higher level of authority either within or beyond the organisation and you feel overwhelmed. You feel smothered by the bureaucratic change that is coming down on your life. It might be coming down on carers but it

doesn't effect their lives. Very much disempowered. Unless we have a balance of the positive side, then life will become less and less enjoyable."

"I think they use health and safety to avoid what they don't want to do. We all know that in the present climate it is very difficult to get people to do this job. That's a separate issue, low pay and so on, but because of that it's difficult to get good quality staff and the staff call the shots and say 'we're not going to do that' so they have a problem with what they can provide and because of that they then use the health and safety and risk assessments and all those things so they can say 'Well actually we can't do that because of health and safety'. I think it's appalling. The ethos of Leonard Cheshire should be to help disabled people to support their own lives. I don't think they do that. The act of consultation looks like they are doing it so it covers up the cracks."

4.6 Ability to Influence the Management Hierarchy

The majority of the residents felt remote from the management hierarchy of the organisation and unable to influence it. They felt that the management of the organisation was remote and uninterested in their needs. The problems of user involvement are traced to ineffective communication and simply lack of interaction with higher management:

"We'd like them to come down and speak to us but every time someone comes down they want the questions given to them beforehand, so they can rehearse their answers, or for whatever reason, before they come. They shouldn't do it like that. They won't just sit down with you. They're frightened of the response they're going to get."

"When you write to people at the top they haven't even got the courtesy to reply. I tried it. It was a waste of time."

"Things could be better run by head office. People are interfering in our lives too much. I think they've got too many people up there and nobody knows what anybody else is doing. They haven't even got the courtesy to answer a letter."

"The trustees are still the 'twin set and pearls' brigade. There is a SURE representative who is automatically a trustee but I think that is the only disabled person. I don't really know who they are. I would have to make it my business to find out."

Throughout the interviews people expressed dismay at the demise of local committees and control being taken away from local level, the power now being held centrally and, ultimately, at Millbank:

“Everything has been taken away from us now. We used to have our own finance committee, our own management committee, but now it is all the area people that look after all the money, we don’t have to do anything.”

“You could get your point of view across and they would take notice, but now everything is taken out of our hands.”

“Because all of the policies are made outside and for a group, not for individual groups, because they are trying to get all the homes working the same, and it’s impossible.”

A number of service users had met Leonard Cheshire himself and all who had spoke about him and his personal approach in very positive terms. There was, with some service users, a clear view that the Leonard Cheshire Foundation had changed from ‘a family’ to a large-scale business organisation. There was a desire for smallness and a more personal approach:

“Since Leonard Cheshire died you know they’ve changed a lot really. They like to do things their way now. Of course I knew Leonard Cheshire very well. If anything went wrong we could always go to him and he’d get it sorted out. He ran the whole organisation but now it’s become more official. I don’t think we have as much control as I think we should have. A lot of people now have never known Cheshire.”

The complaints procedure was largely seen as an ineffective means of effecting change:

“We have a complaints procedure. The first step is to take it to the management here and if they don’t like it it’s not going to get to the top is it?”

There was a widely held view that that the upper echelons had no personal experience or valid understanding of disability. This was often linked with the view that insufficient disabled people are employed in managerial roles:

“I don’t think they know what it’s like to be disabled. They’ve just got this paper in front of them and that’s all they have to understand. They’re not worried about what disability is or what disabled people need, their requirements daily.”

“Up in Millbank they need more disabled people. They’re all fit and walking.”

“There is one disabled guy up there but they don’t live in the real world, they are out of touch. Then they say ‘We do employ disabled people’.”

Many participants expressed the view that there was a great deal of potential amongst service users that was not tapped:

“I’m quite happy to offer my time anybody in using my time positively and I have been offering my time to the national office. They said to me ‘how interesting’ but then I’ve not seen or heard from anybody and that’s happened lots of times. “

Perhaps the most acute expressions of this relationship with management expressed it as a division between ‘them and us’:

“They wouldn’t lower themselves. We’re too low down for them.”

“It’s because we’re in wheelchairs you see - our brains don’t work.”

“They want to pat you on the head, that’s the feeling you get.”

In this context it is not surprising that many services users were sceptical of the notion of user involvement or that management is taking account of service users views:

“Decisions are always made before it reaches us. We are told, ‘you can have this or that’ or ‘you’ve got to do this or that’.”

“I think that there are instances where they are listening to service users and then doing what they want anyway.”

“Yes, we are consulted on different things and when I look at some of the policies and procedures that they come out with, like the risk assessment. They are there to protect the staff and because they are there to protect the staff you can put your two penny worth in and say ‘I don’t agree with this, I don’t think it’s correct’ but I don’t think it ever changes much.”

The following is a personal example provided in some detail by a service user. S/he describes the waiting and uncertainty of decisions that will be made to change his/her life:

“It seems to be falling apart a bit and they have this new idea of putting people out in to the community and I do not think that it is a good idea when you have been in a home for so long. I mean you become acclimatised to where you are and I do not know why they want to break homes up, because they are obviously happy places. I do not really want to go out on my own, I am too old to be on my own. We are just waiting for the confirmation of what is happening.”

As already evident above, user involvement is consistently viewed within a wider context, often questions of finance:

“Leonard Cheshire took this place over from the council, right, to make it better, that was four years ago, so we want to know what they are doing for us. We’re all in the same boat. We haven’t a lot of money – where is the money? What are they doing with it? We don’t see it.” (user of day centre)

“I think the main aspect of user involvement is money. They do listen but it can’t always be taken on board. The pay out of money for me to go to a meeting with a carer is quite high. I feel sometimes they do listen and other times they don’t. I don’t think a 100% they appreciate that service users want involvement. And I think for certain service users they can’t give involvement that would like to, particularly with communication difficulty.”

As illustrated in the following quotation, this could be couched in the vested interests of the organisation:

“I think they make some effort to include them (service users) but I wonder if it’s just about political correctness. It’s very difficult because it’s an organisation with roots in a patronising and medical model and until it addresses that, and changes that, and understands the philosophy behind it, I can’t see that anything it does will move things forward. It’s doing what it thinks it ought to be doing. There are some very strong human rights issues around, rights around privacy, and they’re trying to address them because they have to, not because they want to.”

One participant summarised this kind of view as follows:

“Although we like to think we have all these initiatives in place, the truth is that the majority of services users are at the other end of the scale, dissatisfied and unimpressed with how their personal life exists within the world at large and the organisation.”

4.7 Forums and Committees

We turn next to service users’ views of what can be called more ‘formal’ involvement. As will have been evident above, most service users understand ‘user involvement’ in the most immediate terms of the decision making and choice they can exercise in their daily lives. Nevertheless, again as evident in some of the quotations above, many service users did not divorce this more informal involvement from the more formal involvement in policy and management decisions.

Across all the views collected, the main undercurrent is negative. Many people interviewed suggested that user involvement committees and the Disabled People’s Forum were ineffective. This ineffectiveness was largely seen to be due to the power structures in the management of the organisation. From the viewpoint of many service users, they have little involvement in the daily decision-making that shapes their lives and similarly

little involvement in the management and policy-making that shape daily decision-making. There was a widespread view that formal involvement had no real influence:

“I don’t think these committees get anywhere. If they want any changes in this organisation, they send us forms but they’ve made up their minds anyway so what’s the point?”

“We can put our ideas forward but nothing ever comes of it.”

“The people at Millbank have already made their minds up so we might as well talk to the wall if you know what I mean.”

“I sometimes feel that I’m banging my head against a brick wall. I don’t feel I’m getting anywhere.”

This picture was exacerbated by the belief that the situation was deteriorating:

“We have less user involvement now than we use to. We have very little input. It’s been taken away from us. We have no input that I’m aware of to be quite honest. There’s a committee meeting once a month but the same things come out. I don’t think we’ve got any say in any of it. It’s lip service.”

Some service users had very positive experiences of the Disabled People’s Forum and committees generally both in term of bringing about change and in terms of personal interest and development. The following quotations suggest that some effective user involvement is possible:

“We’ve been able to influence the home quite a bit. We can make our own decisions and lead our own lives basically.”

“If we do not like certain types of food, some have said that they do not like this or this, we have managed to negotiate changes to the food and things like that.”

“Yes, I sit on that. It’s good I enjoy going to it. I also sit on the Regional Committee. Things don’t happen overnight. But I like going, I’ve learned a lot. “

“First of all we have a committee for the service users and we’re all involved. There’s about ten or eleven on the committee. It’s a service users’ committee and we bring up issues which we get from the rest of the service users and we feed them back to management. We have a dialogue in that respect.” (user of day centre)

“I’ve never been slow in using the services of the DPF. I find that is a good media for me to be able to get a reaction to a situation that may occur or to be able to get an in depth knowledge of a particular issue. And I find that it is an excellent body.”

Many services users emphasise the ways in which they have gained personally from involvement in more formal mechanisms. The strength and importance of such personal gains speaks through the following quotations:

“It’s a sense of achievement. You’ve done it. Nobody else has done it for you.”

“We were shown how to interview if we were employing our own carers and living in the community, things like that. How to advertise it and all that sort of thing. Empowerment.”

“I enjoy being involved. It increases my self-worth somehow, that I’m not just sent down here to vegetate.”

“Self-esteem by involvement. We are talking about involvement with the world at large in a way in which any able-bodied person who aspires to doing that might do.”

Training was often specifically mentioned:

“I’ve been involved in the setting up of NVQs for care staff and also NVQs for service users to be assessors. We get very good training from the DPF. There’s courses for committee skills, for DET training. If you can just forget for once the difficulties you are going to have, in getting support and transport. It is well worth it.”

For some service users, ‘user involvement’ can almost become a way of life:

“We have a lot of involvement with training and staff recruitment about committee skills about direct payment skills. I’ve done all of the courses, the facilitator course. I’m vice-chair of the SURE committee. I’ve done 6, 7 years with SURE. DPF, I was co-chair of that. Also I do Care and Operational Reviews under M.”

A second quotation from same service user illustrates how personal development turns to more collective concerns:

“I feel there is a lot of people out there can do what I have done, have a better quality of life. It’s nice to go to a meeting and see a fresh face and then in a few months go back and see how they have developed. Mostly I am keen about this communication for people who haven’t got communication.”

As illustrated by the following quotation, such formal user involvement needs to be understood within a broader context, and as so often finance can be paramount:

“The question I would ask is ‘How can they change anything when they’re cutting the funding?’ Any user involvement comes with a big

price tag if you're going to do it properly. Every part of the organisation had to make cuts but if you're appreciating its value then you don't cut it. The best way they could have shown that they are really meaning to be consulting with their users would be not to cut it. But that didn't happen."

Some residents reported that they were involved in interviewing staff for the homes. This was usually a valued example of user involvement:

"Yes there has been a great opportunity to be involved in staff recruitment within the home and sometimes within the region and sometimes nationally. And this is done often as a result of having had training provided by the DPF with regard to interviewing techniques."

However, questions were repeatedly raised about service users' power and voice in organisational decision-making:

"The users are involved in different ways. We have the SURE group and we have the Disabled People's Forum, and I think they have tried to widen that as much as possible, but I still think that those two organisations, albeit they filter through different parts of the organisation, I still feel it's very much internal and doesn't have the decision making powers. Leonard Cheshire have set it up or have got funding for user involvement and I think because they got that funding they had to do something with it. Well the user involvement is there but it's contained. Eventually people become aware of that and some of the people have left because they've seen that what they're doing is just continuing the circle because the whole organisation is still very patronising to people who it is there to support."

For some, the crucial difficulty was that faced by Forum staff in service provider-service user power relations:

"The people who run and manage the Forum are paid employees of Leonard Cheshire so as paid employees they are answerable to the trustees and the directors and therefore it is not independent."

Another view is that the DPF is problematic for Leonard Cheshire management and that the management are seeking to limit its power in promoting user involvement:

"I was very involved with the Forum as I was on the monitoring steering committee but recently they've changed the way the structure works. It's really funny because I don't know whether they changed the structure because they thought they'd got vocal people on the Forum who were raising issues that they would rather keep quiet. Therefore they said 'We want to get more user involvement' so they brought other users in. It's good to get other users in but there was a feeling at the time that they wanted to quash the louder voices and bring in a few more passive voices. It will still be seen as user involvement but the

users that they have involved are passive users, that actually agree with everything that's going on. Also those people may never say anything constructive about the service to improve it."

Another participant, suggesting that the DPF is limited in its effectiveness as it is radical, expressed a similar view:

"The Forum is forever promoting the independence, the empowerment of the individual service user and bringing to their attention opportunities and suggestions and giving them the mechanism through mentors and courses, things like that, that service users can take advantage of to develop their lives further. I do wonder whether empowerment, though it is preached and spoken of throughout LC, really is welcomed by everyone who have a role in helping service users achieve self-empowerment. But they feel that there is a negative side to that. Empowering residents only brings problems more work and things of that nature. They only empower people in a limited manor, not totally."

The effectiveness of mentoring is also seen to depend on broader factors and the situation in which the mentor is working:

"It depends on your region and your relationship with the regional director and your relationship with each home. One home might be really supportive and everyone wants you to come back and another home may see you as a threat. I think for me it's sometimes hard to get respect from staff especially care staff, sometimes I think they feel I'm interfering. They see me as a disabled person. (They are) unhelpful, not friendly, don't listen, brush you off."

"It depends on each home, some home are really nice and welcoming and they want my support and opinions and my help but some just want to push me out the door. I think it's to do with how established the home is and how old it is and how long people have been working there."

Many see management committees in general as an ineffective mechanism for user involvement:

"We get explanations as to why things cannot be changed as well as they might be. An explanation that is usually down to the absence of staff or the absence of suitable staff. It's usually a staffing issue at the bottom of it."

"Although I asked about the need for services users to have access to the internet years ago at local level this is typical that it has still not come about and I hear is being worked on. I see the management of the homes having access to this but the people within the home have nothing unless they happen to pay for it themselves."

“I was on the human resources committee. I had problems getting there because of the time the committee started, not having someone to be able to come with me, me having to organise that. I could deal with it but part of me said ‘Do I want to be doing this?’ My energies are precious to me and I felt that I was wasting my energy because I didn’t feel that my views would make any difference.”

Recent change that has shifted the power of decision making from local to regional bodies is widely questioned:

“I am on the local management/support group and we have just changed our name, ‘cause Leonard Chester have taken some of the managerial responsibilities away from all of the homes now and are doing all of the managerial responsibilities regionally now, so that we are just responsible now for fund raising and things like that.....We were able to decide what things we wanted, but we do not do that anymore.” .

Some specific concerns were raised about the DPF and SURE. It was seen by some, for instance, as distant from service users’ concerns:

“I think when the Disabled People’s Forum started the idea was wonderful but I do feel that a lot of them live in an ideal world: they all have full-time jobs, they all have personal assistants, they have lots of money and all the rest of it. They have no idea what it’s like to live in these places. They haven’t got a clue.”

“The biggest problem is when Forum staff take it on themselves to be the role instead of service user involvement and that has happened in the past and I do not know whether that is currently happening to the same degree.”

“At one time I liked the Forum but now I have to question it because I feel that it’s done us some damage in actual fact. The reason I think it’s damaging is that we are institutionalised whether we want to be or not because we live in an institution and we can’t help that. We have to survive in an institution.”

Some similar views were expressed about SURE. It is seen by some service users as not representative of the views of service users. This view was expressed by members of the SURE committee themselves. They put this in the broader context of not being provided with the facilities or resources to truly represent the views of service users in their areas. It is in this context that service users state:

“Well the body which users get represented is the SURE committee and I’ve had opportunity to get elected for that body. I never have for various reasons. I find them not a very communicative group. There is no interchange between the representatives of the SURE committee and individual service users that I am aware of at this home in all the

years I've been here since 1996. So I see that as a body that is representative in name but not necessarily in fact because there is no dialogue with the individual service user and individual homes."

"The only medium that is open to a service user for implementing change is through SURE representation and I don't see that as a very good representative body. I've never had a SURE rep come and tell me what is going on or seek mine or anybody else's opinion in helping them to communicate to the SURE committee "

Tokenism, for some participants, characterised their experiences in formal user involvement:

"I sat on an interview panel for the manager here. Only two people applied and the other three people on the panel had already decided who would get the job and I noticed that whatever I did say didn't change the way the decision was going. I felt a token, totally." (user of day care services)

For many service users, the barriers they faced in having a say in their daily lives was of paramount importance:

"We were used as a guinea pig for some training by a chap who had his own PA and his own transport telling us that we could control our own destiny, that we can, by craft and manipulations, no need to be aggressive, manipulate staff to our own ends. He's living in cloud cuckoo land. It doesn't work like that. If you make an enemy here you're making a bloody rod for your own back because you are highly vulnerable and you are so dependent on them."

4.8 Residents Without a Voice

There was a great deal of concern regarding people not having a say because of communication difficulties and also a lack of communication throughout the organisation between management and service users and between regions. Service users' concerns about user involvement were not motivated solely by a wish to have more say in their own lives. Many of the people interviewed expressed concern that some people, particularly in the homes, were unable to communicate and to make their needs known:

"There are people here who can't get their point of view across. They can't talk."

"A lot of the more seriously disabled people can't speak up for themselves."

There were numerous expressions of empathy:

"The reason I speak out is that I'm thinking about the people who can't speak, like H and W, and if things are really bad for us what the hell is

it like for them?”

“It worries me about the people who can’t talk. We stopped it but we get a lot of foreign staff here and they were talking in their own languages over us. We put a stop to it. It’s probably still happening in the rooms where the residents can’t talk. They can’t complain. I’m very concerned about the people who can’t do anything. I don’t know how we can check it, I really don’t.”

Participants spoke too of the lack of communication support and use of communication aids:

“There are people who have communication problems but they have communication aids but they don’t give them time to use them.”

The need for a more active approach to user involvement was frequently expressed:

“You’ve got to be assertive to get what you want and some people don’t have that kind of personality. They need advocacy.”

In general, participants expressed the belief that there is a potential for user involvement in decision-making that is not being facilitated:

“There must be service users at every home within LC who are not being reached. Service users whose verbal communication doesn’t exist or is very restricted are often not consulted because the one thing that many people haven’t got is the time it would take to communicate with that service user. I believe that the response could be got in time.”

“Leonard Cheshire does need to address the communication issue. They could be a force for change but it’s not. It appears that people don’t address that. There are two ways to address that, you have a voice facilitator, somebody who can understand and can facilitate your speech, or you can have a communication aid. And they may need more time. I think they should be doing a lot more.”

People whose first language is not English can also be left out :

“I can speak but I can’t read it.....sometimes my friend tells me.”
(service user in a day centre whose first language is not English)

4.9 Lack of Information about Money

As evident in the analysis so far, financial issues have reoccurred throughout. It is a theme in its own right. Knowledge and a say in decision-making over finance can be seen as fundamental to user involvement. Several of the residents were concerned about lack of information regarding how their fees were paid in the home. This gave rise to a feeling of lack of control in their lives:

“Where is the money going? It’s a big charity and we do lots of fund raising here for LC and we’d like to know where the money goes. We should be part of it, we should know where it goes.”

“The organisation is too top heavy. When I came here six and a half years ago, there were forty staff up at head office and now they have ninety. At the same time they reduce the staff here. They take the money away from where it’s needed.”

“You can’t get a breakdown. I want to know what percentage is going on our residential care here because with all of us they must have £30,000 a week coming in. We’re also a charity so there must be extra money there. I’d like to know what is actually spent.”

“How much goes to the grass roots? What proportion goes to Millbank and the so-called administrators there. I know people at the top of these organisations, they’re on high wages, firm’s car. Millbank is a prestige place and it can only get three wheelchairs in. It’s all to do with the vanity of the people who work there. They don’t need it.”

4.10 Satisfaction with Leonard Cheshire Services

Throughout this analysis of the viewpoint of service users we have used their expressed views to contextualise the notion of user involvement within the broader context of the management hierarchy within Leonard Cheshire, financial issues and even considerations that go well beyond the confines of the organisation. We have tried to include representative positive views throughout. At this point we shall include quotations that express satisfaction with the care provided with Leonard Cheshire. Some service users in expressing such satisfaction also showed little concern about user involvement, particularly at the level of a more formal influence over decision-making.

“The thing I appreciate most here is the privacy. You are entirely private in your own room with en suite and it really is a treat.”

“As far as I’m concerned, I mean I can’t do anything for myself, I can’t get out of bed, feed myself or do anything, I can’t do anything to do with cleanliness, and I do find that they do it very well. They take care of you and do everything. And then we have lots of things to do, a lot of entertainment and we’re taken out. It takes your mind off how you are really. In that respect I find it’s very good. I’ve only been here a year and a half, but I find that they have been very good to me. “

“When I first came here we were all on one floor and there were two people in each bedroom and it was just like a cupboard. It was very difficult. It’s so much better to have your own en suite and your own space.”

“We have a wonderful staff here and they really are caring people and I think it is one of the happiest homes that there is. When I first came here, Mr. O was in charge and I was just on 64 and he said he liked the home to have a whole range of ages, so that it was like a family and he said that I would fit in with others and he would be glad to have me. So I came for a holiday really, for an assessment you know, and I think that I was all right and so I came to the home and have been happy here ever since.

“I want to be here, I like a lot of people around me. I’ve never ever lived on my own in my whole life. It wouldn’t suit me. They wanted to put me in a bungalow but I came here for assessment for a month and I liked it, I like people around me. I’ve never lived on my own and I wouldn’t like that.”

4.11 Conclusion: Analysing the Views of Service Users

The conclusion draws out some of the main over-riding themes from the above analysis of the views and experiences of service users. In line with the original aims of the evaluation, this report prioritises the views and experiences of service users. The full report contains many direct quotations from the participants. This allows their voices to provide some of the quality of the research process within the report. It is also based on the key principle that the development of service user involvement must essentially be founded in the expressed views of service users themselves.

Overall, there was considerable variation in the participants’ views and experiences, including differences in understandings of the term ‘user involvement’. The data we collected reflects a wide range of viewpoints and experiences. There were disparate and, sometimes, conflicting differences in the experiences of an individual and between individual service users. It is difficult to do justice to this varied picture, particularly as this report maintains anonymity (i.e. does not name specific institutions or individuals).

Nevertheless, there are some clear commonalities in the views of service users that are repeatedly expressed and can be taken as a foundation for the principles and practices in the development of user involvement.

- Despite a range of committees and forums user involvement was generally perceived as being low. There seems to be two reasons for this. The first is that involvement is defined in informal rather than formal terms. Second, formal involvement is seen as ineffective within existing power relations and management structures.
- User Involvement, from the viewpoint of service users, needs to be understood in the context of service users’ whole life styles and quality of life. It is associated with day-to-day control over their own lives and all the decision-making over what can be considered minutiae that this involves. What user involvement exists seems to be focused, at the

level of the homes, on such issues as choice of meals, choice of bedtime and decorating rooms according to taste. Service user involvement is closely associated with notions of empowerment and quality of life, in which lifestyle decisions are made by the individual. Thus the participants covered a very broad range of topics that are difficult to do justice to in this report.

- This evaluation has focused on service user involvement rather than the quality of service provision. It is clear, however, that from the viewpoint of service users such a distinction is incompatible with their experiences. The better the quality of services they receive the more, from their viewpoint, opportunities and possibilities there are for service user involvement.
- From the viewpoint of service users, staffing levels were perceived to be the main reason for lack of service user involvement. Lack of transport and drivers was also a consistent theme.
- Views concerning the efficacy of committees, SURE and the Disabled People's Forum were mixed but most people perceived them to be ineffective in bringing about change. The main reasons given for this, however, were not the ineffectiveness of the Forum and SURE, but: the existing power and management structures in which service user involvement can be tokenistic; and the lack of resources and support for existing more formal user involvement mechanisms.
- Associated with this view of established mechanisms for user involvement is the widely expressed view that service users lack access to the processes of management, such as information regarding the finances and financial decision-making in Leonard Cheshire. This is signified and experienced as a remoteness from the management hierarchy.
- Service users generally thought that they had little influence over policy decision-making in Leonard Cheshire. Involvement is seen as confined to 'consultation', based on commenting on rather than forming policy.
- Associated with this lack of involvement in policy making, was the view that policies, particularly national Leonard Cheshire policies were restricting rather than providing lifestyle opportunities for service users. For instance, increasing bureaucracy and Health and Safety policy were viewed as impinging negatively on people's lives.
- Finally, there was clear evidence of foundations for peer support in service user involvement. Many service users, for instance, expressed concern about fellow residents who were unable to make their views known.

5. FINDINGS FROM STAGE ONE OF EVALUATION: VIEWS OF USER INVOLVEMENT FROM THE VIEWPOINT OF SERVICE PROVIDERS

5.1 Meaning of user involvement

As evident in the following sample of definitions, there was not a wide variation in participants' understandings of the concept of 'user involvement'. The strongest emphasis was consistently put on more formal involvement in the management and running of Leonard Cheshire, and this was reflected in issues discussed throughout the interviews. Most service providers, however, did include broader understandings of user involvement as central to service users' quality of life.

"I've never been any good at defining anything but we're really talking about the ability of users to be involved in all aspects of the running of the organisation and to have a feeling that users are empowered to feel that they have an ability to affect their quality of life in the organisation and so on and so forth."

"The idea is service users in Leonard Cheshire have a say in what happens. Having a say and a little bit more than that, about having power and control over their service and having an opinion."

5.2 'Hard to Reach' Groups

A major set of concerns for service providers revolved around the notion that there is a major potential for 'user involvement' that is not being tapped. These can be conceptualised as the 'hard to reach' groups. For the most part, the barriers to involvement are thought to be associated with the person's functioning and impairment. Inherent in the views expressed by some participants is the belief that the service users who do get involved, at least in more formal mechanisms, tend to be the more forthright and vociferous:

"If you are a disabled person you have to be quite assertive and not everyone is. If you're disabled or not disabled it might not be your nature to be assertive."

5.2.1 People with communication impairments

The problems of involving people with communication impairment was a recurrent theme from the service providers viewpoint, particularly in relation to user involvement in more formal mechanisms:

"They tend not to (go to meetings) and when they do it's perceived as being difficult and slowing things down."

The difficulties are exacerbated by the belief that the situation is deteriorating:

“Unless you can speak it is very difficult to have a voice in this organisation. Yet increasingly, certainly on the residential side our service users are incredibly disabled. And yet we say that all our services users can have equal right of input but then we make it very difficult still. We don’t sort of level up and down to make it a reality for service users.”

As reflected in the quotation, service providers did refer to some of the same barriers emphasised by service users – staff shortages, lack of time with service users, not listening to users and problems with staff attitudes generally:

“You have somebody who is non-verbal but can communicate quite clearly if you ask the right question and you spend a bit more time listening but what tends to happen is staff come in in a hurry and do what they think they want and then wonder why that individual gets angry. I recognise that there isn’t enough staff and there isn’t enough time but I think attitudes are even worse.”

In more general terms, the inclusion of service users with communication impairments in user involvement was an active priority from the viewpoint of service providers:

“It’s the articulate people who manage to make gains and you sense that there are significant numbers in the disabled community who would find it difficult to access some of these services because they feel disempowered and lack confidence. They may lack communication skills as well.”

“I always worry that there are people who have potential who are unable to get over a hump who have been in a residential home for some years, who have a lot to offer, who have communication difficulties, for whom everything takes a long time and who will never manage to be seen as having something to offer. I’m quite sure there will be plenty of users who have no wish to be involved, very many, many of them, but it would be very sad if there were people who did want to who, for whatever reason, had great difficulty in making people aware of that.”

Participants also frequently referred to the lack of support from communication workers and communication systems/equipment:

“Well it’s difficult to reach service users who have communication difficulties in an organisation, we’re not strapped for cash but we don’t invest a great deal in communication workers and, in terms of recommendations, if we want to be a more empowered organisation, we must invest more in communication workers because there are a lot of people who could contribute a lot whose principle disability is actually communication. There’s other people who use various communication systems – boards and things.”

“I have a personal thing about people who are non-verbal. They need to have more of a say and more equipment and more people who are trained to work with individuals. Some people have a new bit of equipment but it’s in the cupboard. There is a funding issue around staff having more time to work with individuals.”

5.2.2 *People from ethnic minorities*

As illustrated by the two following quotations, service providers had different opinions about the involvement of people from ethnic minority communities. The first suggests institutional racism, but the second sees no problem:

“They are not very well represented. In the South West the ethnic minority rate is something like 3%. We don’t do anything as an organisation to support people from ethnic minorities. In the region there may be a few people but I’m not aware of them.”

“I don’t think there is any greater or lesser input from people from ethnic minorities in proportion to their numbers. The numbers are quite low in this area. In our residential homes ethnic origin is completely irrelevant. I don’t think it’s a significant factor at all. I can’t see why it would be.”

5.2.3 *People with learning difficulties*

In general terms, service providers spoke of concerns in relation to people with learning difficulties as a separate set of issues. A service provider with direct and specific experience cited an example of good practice:

“I’ve worked in one home and I thought it was really good. There was a lot going on, a lot of interaction with the community. People were committed to the home. There were lots of people going into the home and service users going out. But that was only one home. The staff were very supportive of me. They had shared flats and individual rooms and a garden centre on the site to work on.”

Reservations were expressed about the degree of say that service users with learning difficulties exercised over daily decision-making:

“It is difficult to do real work which isn’t tokenism. I came to the conclusion in my previous work that there were areas where people with learning difficulties could be much more empowered, particularly decisions around meals, meal times, when people go to bed, when they get up, who their friends are, whether they have friends over to stay and interviewing staff. These are key areas that we did a lot of work on. When you have three or four people with learning disabilities within a service catering for 40 people it’s very difficult for them to find a voice.”

For some participants, working with people with learning difficulties was not central to the remit of the Leonard Cheshire organisation:

“Leonard Cheshire doesn't have a huge number of learning disabled service users. There are some people who specialise in it. I think we would all agree that it's not our primary role, Leonard Cheshire is more for people with physical disabilities.”

5.2.4 Older people

Issues relating to the involvement of older service users was not a recurring theme for participants. One participant offered an explanation from the viewpoint of service providers:

“In terms of our mission it's the younger disabled people that we aim principally to support. We don't have a great deal of success in getting the older people to our meetings. Well, why should they bother? Why would they want to go to a boring Leonard Cheshire meeting when they are getting on with their lives, they're living in their own homes, they're getting some support. They get care and support in cleaning around the house.”

5.3 Benefits of User Involvement to Service Users

User involvement was a crucial principle in the provision of services by the Leonard Cheshire Organisation. It was seen by some service providers as crucial to quality of life:

“ Well, there is nothing more important than being in control of your own life and so there's nothing more crucial for us as an organisation to address. It's stating the obvious. It's incredibly important. It's everything.”

“Group empowerment and group identity and individual identity. Getting away from the idea that 'it's your problem', 'you have a problem' and recognising that you have rights and that there is other stuff out there and that you don't have to sit in an institution. I think we need that to start with because if you feel good about yourself you are going to expect more out of life.”

5.4 Benefits of User Involvement to Leonard Cheshire

The notion of user involvement is, for service providers, about the Leonard Cheshire organisation fulfilling its aims more effectively. It is founded in the idea that Leonard Cheshire sets out to meet the needs of disabled service users and thus the involvement of users in defining their needs is to be welcomed and fostered. The concept of 'mission' seems apposite:

“ We fulfil our mission more clearly. We're about providing services for disabled people which meet their needs. If disabled people can be

empowered they can be clear about what their needs are. It is clearly to our advantage. Sometimes you have to educate people who have been very institutionalised to think in a new way and it feels a bit odd to be forcing people into making more risky decisions in a way which was what we were doing.”

“I don’t think any organisation can function properly if the people they are there to serve are not part of the organisation at all levels.”

5.5 Pressures on Leonard Cheshire to Change

Pressures to develop user involvement, both external to Leonard Cheshire and from within the organisation itself, were quite widely recognised and discussed by participants. The topic generated conflicting opinions from service providers. Some participants suggested that the development of user involvement in Leonard Cheshire had been generated solely within and by the organisation. Others felt that Leonard Cheshire was responding to external pressures, which were seen by some participants as a positive influence but by others as negative and restricting. The opening illustrative quotation focuses on the implications of external pressures:

“The other powerful influence in terms of external pressure is the commissioners and they were very clearly saying that, in terms of future development ‘don’t build these big services which are away from town centres, they aren’t what we want to purchase, they aren’t what disabled people in the future want to be living in.’ So that was a very powerful influence, and the other one was the changing national regulatory framework which Leonard Cheshire operates within. The pressure is on us in terms of the regulatory inspection.”

For some participants, external pressures limited the capacity of the organisation in its mission to meet the needs of disabled people:

“I suppose a general feeling of – legislation is making everybody feel in parts about it. And that raises the profile of people with disabilities but that is not what we as an organisation are doing. We are reacting to outside forces when we should be creating more of it ourselves.”

“I don’t think they have changed so much in response to service users as to the funders. It’s social services suddenly saying ‘We don’t like residential care we believe in care at home services.’ And we’ve responded to that without necessarily having the expertise to do it properly.”

There is some recognition of the pressures from within Leonard Cheshire, though these tend to be traced to particular individuals and particular developments.

“Probably bad publicity and the Disabled People’s Forum and the disabled people’s movement. I think C, the manager of the Disabled

People's Forum, is quite a powerful woman and I think she's done amazing things, I could never do what she's done, she started at the very beginning. Now the Forum is much bigger but at the beginning it was her against the organisation."

5.6 Extent of User Involvement

As evident above, 'user involvement' from the viewpoint of service providers is generally conceived in terms of the formal structures of management. In general terms there is a belief that the general intent of 'user involvement' is both central to the Leonard Cheshire mission and is being realised to a significant extent in different ways:

"Yes, there has been a gradual, progressive increase in the involvement of users. There are more and more disabled people in central office, the chairman is disabled, when I first started the chairman was not. One of the strengths of Leonard Cheshire is the process used in monitoring. We have these Care Operational Reviews which are on a four year cycle. Homes and care services are assessed quite thoroughly by a panel of visiting people and there has been great progress in ensuring that most of those panels have a disabled person on them. It's been quite a major advance I think. It's not an adversarial process. It's a process by which people can learn."

"All the users have an involvement directly related to their own disability in so far as we have the ISP - the individual care packages that are set up within the homes."

User involvement can be seen as the province, in large part, of the Disabled People's Forum:

"I think the organisation tackles it in different ways. We have the Disabled People's Forum which tackles service user involvement from a bottom-up way. They try to get the individuals who receive the service to be involved in challenging decision making, challenging policy making and having an involvement in day-to-day decisions within the homes that affect them. But, perhaps more importantly, to create the confidence in the individuals to, not just challenge decisions and policies in a structured way, but to be more empowered and to take more control in their lives."

This can be reinforced by the belief that, from the service providers' viewpoint, user involvement in Leonard Cheshire is strengthening:

"The regional changes six years ago was not user-led, definitely not. Without a doubt now some services are more user-led than they were six years ago – there is no doubt about that and I'm sure it's the case in every region."

The idea that user involvement is variable (between individuals, residential homes, localities) is widely expressed:

“It varies with the individual. I think the more vocal you are the more influence you have. Some people have quite a lot of involvement, say in the Sure Committee, or in the Disabled People’s Forum. Some people who are not so empowered, for whatever reason, have less of a say.”

“I think it can be tokenistic and again I think it depends on the region. The South West is particularly good I think because it’s got a good regional director, other places are not so good, they’re not so supportive. They can either go by the book or actually push to get some change.”

There is also a recurring viewpoint that expresses the opinion that user involvement is not a driving force within Leonard Cheshire management. The organisation, as a business, is simply responding to external and organisational pressures:

“If all our service users really did have proper choice about where they go we would have to improve our service to offer the very best or we would go out of business. But we know too often in our heart of hearts that the funders will be too idle to move and the service users will get used to whatever it is and everybody will sink into this sludge of institutionalisation. Nobody ever really says I off I’m not putting up with this nonsense.”

5.7 Pressure to Close Homes

A recurring topic for service providers was the actual and projected changes towards the closure of large-scale institutions and the provision of smaller homes and supported ‘independent living’. As throughout this analysis, the views expressed by participants were varied and often contradictory. For some service providers the changes are positive and will provide a better situation for the development of user involvement:

“There is a big move, especially in the South West, about new provision. They’ve got to do it by law actually, I think that’s what pushed it, which is good. I would like to see more people living in their own homes, or in smaller group homes and getting what they want out of life.”

The following two quotations express similar views, but also emphasise the difficulties of developing user involvement within large-scale residential institutions:

“My experience is that you can put however many resources you want into a home with 38 people in it, and however much attention to empowering individuals and trying to have - service user based staffing

and service users based food preparation - it will all fail, I think, it will just fail. It doesn't work so I've failed – that's how I feel. The new homes will have a maximum of ten in a group, and it has to have its own separate staff group so you would get two of those groups of ten on one site and they would only be for the most profoundly disabled people. Anyone who is able to live in more independent accommodation would do so.”

“That's quite a complex idea really because you would expect it to be a user-led change but my perspective is that when you have a large service with 40 people in it you invariably have various institutional practices and you challenge and challenge it and you still get fairly institutional practices. You can get it in a little place but you can't avoid it in a large place, so therefore small is better, I'm quite sure about that. You get much more flexible ways of working. Much more user-led. It's not because the staff are different, or the service users are different, or more empowered necessarily, it's just that things are organised in a different way.”

For some participants, the changes themselves have not been user-led and have been imposed on users. It is recognised that service users have not been involved in the decision-making that shaped their lives:

“I think the disabled community in general are very keen, particularly the articulate members, to ensure that disabled people can live as independently as possible, and because of that I think there has been less demand for places in large residential homes. The government policy is to turn large residential homes into smaller ones and that's being done over the next five to ten years. I'm not sure that the disabled community within Leonard Cheshire has had much influence on it. There are many people who had lived in the large homes for many years who find it very threatening, they have needed a lot of counselling and support if they are to leave what is, after all, their home.”

“It wasn't initially driven by users but the process of part education, part looking at options, being interviewed by a disabled person ultimately has made it user-led. The philosophical thinking on all of these changes has been led by disabled people – but I don't think it's been led by the existing Leonard Cheshire service users. They have been dragged kicking and screaming.”

5.8 Committees and Forums

The following quotations set the scene by describing the present arrangements for service user involvement, from the viewpoint of service providers:

“As you probably know there is a users' committee, SURE, and this is a committee purely of service users which Leonard Cheshire has been

integral in enabling that to be set up. This committee meets three times a year and there are local SURE committees all over the country. This is for disabled people to be able to express, to communicate among themselves, their frustrations and concerns and to make sure their voice is heard within Leonard Cheshire. The chairman of SURE is a trustee and there are two or three other quite severely disabled people who are trustees.”

“The DPF was set up by Leonard Cheshire and was originally funded by lottery funding. That’s a very proactive organisation that encourages disabled people, rightly, to seek solutions to problems of access and any problem they may have where they feel disadvantaged compared to able-bodied members of society. It also has a training and a mentoring role. Through this organisation mentors will work with disabled people to try and help them tackle some of the problems and prejudices that they feel they are facing.”

There is a widespread opinion amongst the service providers we spoke with that the present arrangements/mechanisms for the formal involvement of service users are not as effective as they could be. A variety of reasons or factors were offered by service providers to explain perceived inefficiencies. Some pointed to what they saw as the motivation of those directly involved:

“Well, SURE themselves are service users and they are elected within the region. To cruelly generalise, they are people who are fairly bored, they live in residential services predominantly, the idea of a trip to London is very positive. I may be completely wrong but that is my view. Rather than getting people who have really clear and important things to say and that can really contribute and really challenge.”

Others spoke of the lack of motivation of service users to be involved as committee members:

“What they don’t like is the travelling. But I think that we assume that service users are different from anybody else and a lot of people thoroughly dislike travelling for four hours to go to a boring conference. A lot of people absolutely loath committees and would do anything not to be on a committee.”

The formality of meetings were thought to cause some service users to be inhibited and afraid:

“Sure Committee has a direct route to the trustees and the Chair of Sure is on the trustees so that is a direct link. But the trustees are quite intimidating. I think it would be helpful if there were two Sure Committee members. It’s quite scary being with them. They are all non-disabled apart from the Chair and he is not the best person to represent disabled people.”

Some service providers saw the Disabled People's Forum as an expression of the power relations between service users and service providers and, from the viewpoint of management, an adversarial relationship:

"I think what happens is the DPF sees itself as part Leonard Cheshire and part not Leonard Cheshire looking in and making a judgement. They are paid by Leonard Cheshire and I would say they are 100% part of the organisation. But they act as if they're not, as if they're one step removed. They are all disabled people which is great but there is no sense of loyalty to the organisation from a lot of these employees and that does cause problems. I don't get the sense that the DPF is always very good at working with Leonard Cheshire to make it become a better organisation. I think they ought to think much more about how they can work with the Directory General, with the directors, rather than just shouting from the sidelines and actually losing their power base by being seen as – well not being taken seriously. There are some things they do extremely well. But the directors' board, right at the top, sees the DPF pretty well as a pain."

"We need characters who can constructively work with the service managers, empowering disabled people so that they can challenge sitting there and watching the telly. There are a lot of qualities needed to move things forward in a proper way. They challenge the manager, the manager is horrified, the manager phones me up and says 'What is this DPF?'"

"Every member of staff is required over a period of time to go on disability equality training. All the trainers are disabled so it's done properly. The DPF was the driver in introducing that yet again. There are problems with the DPF as well as it being an organisation which has added a huge amount to Leonard Cheshire. The manager of DPF and I, most of the time, get on very well. She, herself, is a very strong personality, very strident views, what you see is what you get, she hits you with it which I quite like but it doesn't go down well with everybody in Leonard Cheshire. Sometimes she has been very blunt with me about something she doesn't like me doing, and I have to take the rap on that, but that's OK."

Given the perceived limitations of the present system, a number of participants had substantial suggestions for developing user involvement. This first quotation focuses on the DPF:

"I'm not clear what the organisation wants from this but in terms of where I think we should change, I do think there's an opportunity with our current regional committee re-structure to force regions to think much more critically about user empowerment. Rather than having regional committees we should have service user forums-type committees which are given real clout and which hold the regional directors to account locally. The Disabled People's Forum is a fantastic opportunity and it's not achieving it, and it needs a bomb put

under it in my view. It's a real frustration that the Forum could be doing so much more than they are doing "

The control by disabled people as service users was a central theme, as illustrated by the following quotation.

"What should happen is that we should have very many more disabled trustees and, rather than the trustees going to a small group of disabled people and saying 'Here are our policies what do you think?' we should have very carefully selected disabled people who are themselves very empowered and excellent role models for disabled people who are actually trustees. So they're not consulting with somebody, they're in control. I think that is the way the organisation ought to go in order to achieve real empowerment to disabled people."

One critical view of the DPF takes the position what is required to develop service user involvement is more localised, individual support:

"I think that the local help that they have received is beginning to pay dividends and that is the sort of help more individual mentoring and stuff."

The use of IT, rather than committees, was suggested as a means of service users being able to express and share their views about Leonard Cheshire services:

"If we are really concerned that we are offering the right services, and the best service, we should be listening to what customers want. And it is more difficult to listen to 25,000 individual ones at the trustee meeting for instance, so you have to have a representative. So you have to have this enormous system of election - that whole system puts off a lot of people from joining in whose voice would be very valuable. I just think we need to be clever in thinking of other ways of doing it rather than this very old-fashioned committee reports to another committee reports to another committee. I certainly do. How many organisations dealing with disability would expect everyone to get on the train and go somewhere? It's bizarre. It's (the Internet) cheap now. It would mean that service users could talk to service users. It opens up channels of communication that we haven't dreamt of."

Another suggestion was the holding open meetings around the country, rather than at Millbank:

"We don't even move around the country for our trustee meetings. We never go and listen to the service users. Everybody's expected to come to this office for every national meeting. The trustees never have a meeting in Edinburgh so that any service user who wants to can come and have lunch with or whatever so we could have another view other than the rep. We don't think across like that."

Developing the same theme, another service provider was again critical of the reliance on committees in management and suggested a more open and flexible approach:

“We have magazines and we have this and we have that – but it is the good boys and girls who get to come and put their viewpoint across. With the result that I think there was a lot of cynicism about we want to do this differently. I think that was part of the problem we had with the DPF concept in Wales. It was seen as a nice little job for one or two people – and bears no relevance to ‘I hate liver on a Monday’ in a home in Newport or whatever. It wasn’t individualised. We want a customer service. I have complained now for the past 3 years about the amount of time the regional director for Wales spends on the train coming up and down from Neath to Paddington for meetings that start here at 9.30 in the morning. They wouldn’t do it the other way round. They wouldn’t come to Neath for 9.30 in the morning. So if we find that difficult, how much more for somebody who has got to get up two hours before we do?”

5.9 Developing Effective User Involvement

The notion of developing effective user involvement, for most service providers, was closely associated, sometimes synonymous, with more formal mechanisms, particularly the Disabled People’s Forum and committees. This section, then, builds on the previous section that focused specifically on ‘Committees and Forums’.

5.9.1 Strengths and Limitations

Despite frequently voiced reservations, there is a body of opinion amongst service providers that user involvement is developing well and the Disabled People’s Forum has been an effective driving force:

“Yes, I think that some of the work, particularly the Disabled People’s Forum, is doing to empower (and I use that word intentionally, I didn’t like it originally but it really has meaning) to empower disabled people so that they feel they have an influence on their own destiny. That’s tremendous and the people who run that organisation are very committed and so long as they’re able to get access to these people with communication difficulties, I think we can say we’re doing pretty well in helping service users to be involved in the charity and in their lives.”

“I think the question for me is, if the DPF didn’t exist, because it’s the principle driver for empowerment, what would be different? And I think it would be a different organisation, I’m sure it would because we have, partly internally and partly externally, sitting on our shoulder, this moral voice. At regional directors’ meeting we might be having a discussion about something and somebody will say ‘Yes, but what would Clare

say if she was here now?’ She’s a remarkable person. She’s a good find. It’s difficult to track incremental change but I think we would have developed in a much slower way.”

Some service providers adhere to a more individual, informal view of the effectiveness of user involvement:

“For me it’s about giving people a voice, listening and doing what they want so I work with individuals on moving out of the home, I work with people on relationships which is what I’ve been doing recently. There’s a couple who are going to get married but they haven’t shared a bed, they were going to have to have separate rooms after being married. But now they are going to move into a bungalow which is a really exciting thing. It’s in the grounds of a different home and for them at the moment that’s quite a big step.”

However, the idea that ‘user involvement’ in Leonard Cheshire is tokenistic was a frequently and strongly expressed opinion:

“Well there is always a checklist, tick the box, for every meeting that happens, that you’ve got service user involvement. It then depends very much on the service user concerned to how well briefed they are, how easy they find it to communicate. I think for that reason it can be pretty tokenistic at times. I’ve seen it happen on local committees. I know some that are pretty tokenistic. Regional committees where we have service users elected to the committee. Some find it very difficult to attend and one has missed three meetings although he has been elected by the process. And again on trustee bodies and when there is an appointments board, everything has to have service user involvement but I worry that it is too much tick in the box.”

As is evident in quotations above, there is a widely held view that the level of user involvement is variable, depending on location within the organisation and the approach of the particular manager:

“It depends very much on the service manager. Some service managers like some service users more than others and some service users have a reputation for saying the same old thing 100 times – we heard that last week and the week before and still nobody’s taken any notice of it. That means with the whole quality inspectorate, internal assessment of things, really must pick up things. If somebody has been saying for years ‘I loath having this on a Monday’ or whatever, if we are not picking that up and really challenging it at an early point it makes a mockery of all the systems we have got in place. And it comes back to being a customer and having a choice. But so often there isn’t a choice and we know it. “

5.9.2 *Some specific strategies*

Service providers put forward a broad range of specific strategies for developing user involvement. It was difficult to find a common viewpoint. Nevertheless, some strategies for development did recur and many would require fairly major changes within Leonard Cheshire. First, the process of policy making within Leonard Cheshire was widely criticised. The main view is that user involvement is limited to consultation, that is responding to draft policies. Service users should be involved in the writing of policy from conception to completion:

“What Sure Committee was saying is that they want involvement when the policy is actually being written.”

A provision that is widely valued within Leonard Cheshire is Mentoring. It is recognised as being flexible and client-centred. There is, however, a shortage of mentors.

“At the moment we have a mentor in each region and there may be 12 different homes and then there is Care at Home, there could be a thousand users or 500. So there isn't enough time for mentors to support everyone. I think ideally you need a mentor in each home and then a mentor for Care at Home. A mentor usually sees somebody straight away but they may not be able to support that person for several months. It depends how urgent it is.”

The representativeness of user involvement in Leonard Cheshire management was repeatedly questioned. It was widely felt that this is insufficiently resourced. SURE, for instance, is constituted of ‘representative’ members from different regions, but is not provided with the time, resources and support to undertake the background work required to fulfil this role:

“It is hard to tell (whether user involvement is effective). Unless the organisation is confident that it is getting a very wide-spread user voice. It really can't say yes to that. It doesn't know.”

“The whole idea of the whole organisation getting different viewpoints is a much rarer thing. It happens in response to a problem not as a positive natural thing.”

The reliance on committees in management is also questioned. A recurrent suggestion is the use of technology to widen the possibilities of such involvement:

“We assume that ease of travel is part of our lives and not part of any meeting. Yet I've had time and time again people who have been let down by drivers at the last minute, volunteer drivers, and it makes me think we wouldn't accept this and why should service users accept it. Then there's the problems of should be we doing our meetings in the way that we do them, expecting everybody to turn up to a certain point, sometimes it means people travelling for 4 hours. Well it's hard enough travelling for 4 hours if you are able-bodied. It's really difficult

to find a volunteer to come with you to do the driving and everything. And it's very stressful and we could make that easier by video conferencing and all sorts of things."

There is seen to be a need too to disseminate information more widely within the organisation, and consideration needs to be given too to the accessibility of information:

"The means of dissemination of information within LC are something we know we have got to improve upon. Everything is going on within its particular cell and everyone within other cells knows nothing about it – and everyone outside knows nothing about any of it."

A need to employ more disabled people in management positions was also repeatedly emphasised:

"I think we want more disabled people working at Millbank. Also I think it's about people working at the top not knowing what disabled people want. It's not having enough experience. I'm not saying that all people at the top should be disabled people but there should be more of a balance."

5.10 Involvement of Leonard Cheshire Outside the Organisation

There was a widely expressed opinion that Leonard Cheshire had a wider role to play than providing services for 'customers' and is in a strong position to contribute to campaigns on 'disability issues' with disabled people, beyond the specific concerns of the organisation itself. It was notable that participants made little reference to the possible contribution of disabled people outside Leonard Cheshire to the organisation or the lives of service users.

"Within Leonard Cheshire there is a very powerful policy unit who work with and have an input into the civil service and health and social care policy. That group is led by a disabled person and I'm sure it's very effective in giving their voice to the civil servants who are involved in writing policy. At a high level there is, undoubtedly, an input from Leonard Cheshire, it's one of its strengths. At all levels one would hope that anybody who is disabled would feel that Leonard Cheshire is not just working for its own few in fact we are establishing a new strategy because we recognise that we are very privileged in being the largest charity for disabled people, undoubtedly, and also the largest employer in the voluntary sector."

"There are three things. One is the outside world where LC should be fighting on their side and acting as their ambassador, singing the same song. Being able because they say we are giving a service to X thousand who all think like this. They should be reinforcing the user service voice. Then there is the very local thing that whatever service you get from LC you shouldn't think you have to go to a committee and put right. "

One participant spoke at some length about the difficulties experienced of working with organisations of disabled people in the community. The problems and lack of collaboration was regretted, though explained in terms of the stance taken by organisations of disabled people:

“DPF has been one key way in which we’ve been forced to think but there are two other very important pressures. One of them is from radical disability groups and I knew that to be the case when I first came to Leonard Cheshire. I didn’t realise how hated Leonard Cheshire was by these groups, we were detested by these groups who, when I actually managed to get my foot in the door, were accusing me of locking people up, incarcerating people and throwing away the key, that sort of thing. There was part of me that fully sympathised. I didn’t agree with them but I fully sympathised with the position they were coming from and I knew that there was a massive amount of work for us to do in order to change. But I also felt that they didn’t want to listen to the information about the realities of being totally, totally dependent and unable to communicate – you can’t live on your own in that situation. It was a little more complicated than I felt they accepted. However, they became for me, and increasingly the organisations, a powerful influence over our unacceptability in some of the things we did and the big institutions which we were still running.”

5.11 Conclusion: Analysing the Views of Service Providers

This conclusion draws out some of the main over-riding themes from the above analysis of the views and experiences of service providers. The full report contains many direct quotations from the service providers to allow their voices to speak to service user-service providers relations in developing service user involvement. It is also based on the key principle that the development of service user involvement must essentially be founded in changing service users-service providers communication and relations.

As with service users, there was considerable variation in the participants’ views and experiences, including differences in understandings of the term ‘user involvement’. Indeed it seemed that there was an even greater range of disparate and, sometimes, conflicting positions in the experiences of service providers. Furthermore, in general terms, there are clear differences between the views and experiences of service users and those of service providers.

Nevertheless, there are some clear commonalities in the views of service users that are repeatedly expressed and can be taken as a foundation for the principles and practices in the development of user involvement.

- The dominant view of service user involvement from the viewpoint of service providers is in terms of formal mechanisms and structures, including committees at various levels, service user representation, and service user consultation. This stands in contrast to the dominant

view expressed by service users in which involvement is more informal and begins in the day-to-day decision-making in their own lives.

- The formal notion of user involvement (at local, regional and national level) is, however, also seen by many as limited and limiting. Involvement in management though involvement in committees is largely seen by service providers as not truly representative and tokenistic.
- A major set of concerns for service providers revolved around the notion that there is a major potential for 'user involvement' that is not being tapped. These can be conceptualise as the 'hard to reach' groups. For the most part, the barriers to involvement are thought to be associated with the person's functioning and impairment.
- The notion of user involvement is, for service providers, about the Leonard Cheshire organisation fulfilling its aims more effectively. It is founded in the idea that Leonard Cheshire sets out to meet the needs of disabled service users and thus the involvement of users in defining their needs is to be welcomed and fostered.
- A recurring topic for service providers was the actual and projected changes towards the closure of large-scale institutions and the provision of smaller homes and supported 'independent living'. For some service providers the changes are positive and will provide a better situation for the development of user involvement.

6. FINDINGS FROM STAGE TWO OF EVALUATION: CASE STUDIES

6.1 Case Study One – Eastern Region

Introduction

The purpose of this case study is to examine the working relationship between the Regional Director, SURE and the Disabled People's Forum (DPF) and its affect upon the development of service user involvement in the Eastern Region.

The Eastern Region is possibly the largest region in the Leonard Cheshire organisation. It includes the shires of Cambridge, Nottingham, Lincoln and Derby. The regional office is situated in Lincoln. It has two SURE representatives and, from the DPF, one Facilitator and one Mentor.

Before the appointment of the current Regional Director the region was struggling financially, fees charged for services being unrealistic in today's market economy. The new Director has turned this around dramatically and this has had an impact upon service user involvement in that he is now able to direct money to support initiatives in this area. He subsidises the cost of travel for the SURE representative and allocates money direct to service user committees to use as they wish, but in particular to support service users to access meetings and communicate their views.

The researcher carried out a number of interviews. These were made up as follows:

Regional Director

SURE Representative

DPF Facilitator

DPF Mentor

Chair of Residents Committee, LC Residential Home (service user)

4 Service Users

Service Manager

Findings

How the DPF and SURE view the current practice in the region and their thoughts on future developments

The team were asked how they believed the DPF and SURE had made a difference in relation to service user involvement:

'With SURE and the DPF working together, is we are all there when we go into a service. You've got SURE, you've got the Mentor, you've got the Facilitator. After the meeting everyone sits down, relaxed. If there's any problems, if they come to you and say 'I do need some training', I know I can say, 'there's G here, there's H here.' If they want to take an issue further, 'you can come to R.' We are all here so if they have got inquiries we are there for them.'

'When they see someone empowered they spread the word to someone else. The Forum has really taken off. We suggest what they might want to discuss next time...we show that everyone is working for their best interests. All of us together as well. Like I'll tell R if there's anything in the region that needs to be addressed, she'll tell me and if anyone needs training I'll tell H, and she'll do the same to me...and because we work so closely together ... the difference we've seen in our service users.'

The team went on to describe how the team initially got together:

'Collectively we can bounce ideas off each other. The DPF and SURE historically were not very happy bedfellows. When we got together in the beginning – the size of the region - it was a very difficult task if we were all going to go our own way and do our own thing. We got together and collectively decided that as a team not only could we achieve so much more we could also get more service users into what we were doing and what we were trying to do. It's worked extremely well. I'll get a service user saying, 'can I have a word?' and it'll be a role for G to do. We look at the bigger picture and if this replicated in other services she (R) will take it to regional level.'

The researcher asked if the team felt that communication was one of the strengths of the organisation:

'Yes, and sharing information. We don't keep things to ourselves. We don't have gatekeepers of information. We are quite open with each other. When we met up three years ago we sat down together and defined our roles so you know your boundaries. I couldn't go into somebody's boundary and talk about a training issue but because we initially sat down and talked about that I know who I can go to.'

When asked about changes that have come about as a result of input from the team:

'I think there is an awareness that we are there to empower service users and that has come about over a period of time. I could hold a Forum meeting every week but it's not necessarily effective and it has to be quite carefully thought about how you're going to do it and what service users want from a Forum meeting. At one point the danger was that we would lead them – 'you can tell us' – but we have turned that round to empower them. We'll take on board what they are saying and then say, 'what would you like to do about that?' It 's amazing what they can do about it and what they want to do about it.'

Asked about specific examples:

'Yes, easy read policies. When we go round we make sure everyone has the easy read because if you give a service user with an impairment a huge document ... one of our mentor's done a simplified version, compact, what they need to know. It's not about people doing things for you but about real independence. It's about having support when you want it and being able to say what you want from independent living.'

'...quite an eye opener for staff what our concept for independent living was. After the conference (Independent Living Conference) you have to put this into place. We've been going around and saying, 'how's your idea of independent living coming on, why can't they have a kitchen area?' Our Regional Director is very keen to take the whole thing of independent living on board. He's very keen to have another conference next year and also incorporating Disability Equality Training.'

The SURE representative talked again about the dissemination of policies:

'Actually the way that policies were given out people didn't actually see the policies. I developed an idea of sending each policy to the regional representative of the residential home and day service but still I gathered that they weren't feeding it back to residents or days centre users so we had to come up with another way. So I went round all the groups, so did the DPF, and said, 'what about having policy groups within the home?' because you know now the homes are splitting into units ... and they have a little meeting that they could bring the policies to ... and have a ten minute discussion on a policy and that has been set up in the region and that is really working.'

The researcher was told that the policies are also put on tape so that service users can listen to them again or they can turn off and come back to them later.

The team was asked who they thought they reached:

'Everyone who wants to be reached. We accept that a percentage of people have no interest whatsoever in the DPF and I think it's important that we take that on board. I don't work out the success of my forums on the number of people that are there...I've actually had a full house at one ...and we had five yesterday but all five people had got something to say.'

Continuing on to changes that are intended to include more people and give service users more control over meetings:

'That's another way we are changing things with them. They have got quite a few issues there. At one point the residents' committee were selected members of the residents who were invited to sit on the residents committee. So we identified that if you were a resident in the service you were automatically a member of that committee. Whether you went or not was entirely up to you. We are doing quite a lot of work at the moment on getting these set up in preparation for the support groups and everything that is coming. By doing that we are trying to get residents to take control again. So we are trying to say to them, 'look you are allowing them (staff) to take control and you have got to take that back and you have got to start doing it so they know that the meeting is yours and it's going to happen and if you can't come, who is acting up on your behalf?' It's the shifting of the control because at the end of the day the home belongs to the residents.'

The team spoke of one home in particular where this is working really well and where service users are definitely in control:

‘Where it does work she (service manager) doesn’t go in the morning without ringing up to see if it’s ok. They have got her exactly how they want their home run and she’s more than happy with it because she’s very forward thinking anyway. That’s the situation down there. Whatever’s happening the service manager will consult with the residents. And that’s how it should be.’

The researcher visited this residential home and felt this to be the case and this will be reflected further on in this case study.

The team went on to add that they tried to talk to as many people as possible when visiting services, not only those who are Forum members:

‘And I’d like to add that when people come to a meeting, a SURE or whatever, it’s not just those people that we are involved with. We also go in and have a cup of coffee with everyone, be it the smoke room, the garden and we talk to service users. That way it’s not just how many people come to a forum, it’s involving everyone. So if they don’t want to come to a meeting they need to know the DPF and SURE are there and approachable.’

Other ways of making contact included leaving messages and cards at individual rooms to encourage contact when needed. Also the team help out with smaller issues, for example: turning the pages of a book; moving a bed; reading a bit, etc, when visiting residents in their own rooms. It is hoped that this will provide a basis to build on:

‘We have to start with very small things and build it up.’

When asked about those service users that were difficult to reach, it was those people with communication difficulties and those who have their care provided in the home;

‘You can go into a residential home or day centre and ask about coming to forum meetings but you can’t go and knock on the door of someone’s private home.’

Also:

‘How do you get someone, who spends most of his day in bed, out of the house to a meeting...We do have care at home at meetings but they tend to be the more mobile. But that’s not to say that the less mobile don’t have issues.’

‘I’d like them to have the same awareness of the DPF and SURE that we’ve developed, but how to do it? They do get the newsletters and we do get feedback. People in the community by the very fact that they live in the community have other things going on.’

Asked if they had any ideas as to how that issue could be addressed:

‘We are bringing out a newsletter, developing one with our names and contact numbers if they need us but that’s the only thing I can suggest.’

Service User Involvement, the DPF and SURE from the viewpoint of the Regional Director

The Director talked about the demise of the local committee and the how in the Eastern Region they were developing structures for service users to:

‘Take on the organisation from the bottom up’.

Service users were increasingly encouraged to take up positions of chair of local committees and were growing in numbers. When asked if the end of the local committees had been a backward step, he replied:

‘I think it has clarified the nature of the volunteer role, very much, and probably for almost every other issue it’s been helpful but the real deficit is in terms of where the service users have used that as a vehicle for their formal involvement in the organisation’.

He continued to explain:

‘To address that issue in the Eastern region, we’re planning to bring in a service user consultation group in each service. We haven’t introduced it yet; it will roll out next year. The idea is that every month the manager and the elected member of the service user group will meet in a structured way to view a number of issues. We are also giving each of the service user’ groups their own budget, paid for out of voluntary income, to enable them to buy in their own administrative support or to buy in their own advocacy support.’

This was in recognition of the growing numbers of residents with communication difficulties. The Regional Director felt that the idea of using voluntary income for advocacy support, to enable service users to bring their own managers into account, was a very positive move forward. Managers would be monitored over the next few months to make ensure the effective development of this strategy.

On the role of SURE and the DPF the Regional Director saw one important aspect as being one of information:

‘They provide us with information and feedback on our services, some of which is very uncomfortable. To me they are an asset.’

He did feel, however, that the roles were spread thinly because of the size of the region and that it was difficult, especially for the mentor, to cover such an area. It was inevitable that a great deal of time was spent travelling. The Regional Director remarked upon the good relationships that the Facilitator has built up with service managers. He valued her role and was frustrated that they only have her on a part-time basis.

When asked about providing funding to the SURE representative the Regional Director explained that because they are a large region and were now financially sound he was able to support her with some travelling expenses. He believed everything he paid out he got back in value. He believes in a strong user governance role and sees the way to achieve this is through SURE.

The Regional Director talked about a service manager who was appointed eighteen months ago and who has a very healthy relationship with the service users. This was the same service manager, mentioned earlier in this case study, who, it is said of, doesn't go into work without checking with service users first.

'She has the attitude that I would want all my service managers to have, whereby she's prepared to have a line of accountability to service users.'

The Regional Director is also very concerned with quality of staff. He has a target to stop the use of agency staff and managers report to him every Monday with the previous week's figures to be able to track where agency staff has been employed. He has raised the rates of pay for care staff and service managers are directed to fill vacancies as soon as possible with permanent replacements.

The development of service user involvement since the appointment of a new service manager at a residential home in the region

The Service Manager stated:

'Certainly when I first came here there was very little involvement. It hadn't been really encouraged that much but we've always had a good resident chairman. What I wanted to do initially was to meet with the chairman and the two reps just to discuss everything that was going on in the M. What we were doing, where we were going and what issues they had in terms of staff, and we've been doing that for two years. But we've just reviewed that now and what we've decided is that the use of that kind of meeting has run its course, and what we need now is a discussion group or a partnership group and that's going to be made up of any of the resident that want to join it, not just the chairman or the reps, and staff from each department.'

This group would deal with any issues and also look at any new policies that arrive. They would then feed back to other residents and staff.

The Manager went on to talk about training:

'We encourage the residents to join in with as much of the training that we provide for staff as they want to and I've actually got one resident as a risk assessor who did the whole risk assessment course alongside staff. She's on the Health and Safety committee.'

'We are trying hard to get the residents involved with moving in processes. If we have a vacancy, maybe we have two or three people on the waiting list, we have a meeting. We go through the assessment papers and look at, you know, who is the right person for the vacancy. It is just in its initial stages at the moment. We had our first meeting for our last vacancy.'

The residents appear to have a strong voice in the selection and appointment of staff:

'They help with short listing of candidates and we have one resident actually on the panel and then we'll have two or three residents on the

informal panel. Every staff member who comes in goes through both. So they have a formal interview, and then a resident is designated to show them around the building. They'll come back and sit and have a cup of coffee with them. The residents will then talk to them, chat with them. The candidate will ask them questions that gives an idea of how they are going to interact with residents. At the end we'll get together then and go through all the candidates and it's then a group decision as to who we actually offer jobs to. This has worked extremely well. At the end of the day it is their home.'

Staff and residents have a diary meeting every week when heads of departments come together with a resident representative to look at what is going on, what is planned and who is visiting, etc. Any immediate issues can also be dealt with at this meeting. Another initiative that has been introduced recently is a team system. Residents and staff are divided into teams with a team leader. Residents then have continuity by having the same staff working for them and the units have their own meetings and deal with their own issues. Any requests from residents are taken back to the relevant departments. This is up and running now that the home is fully staffed. The manager also has an open door policy for residents to speak to her.

One area that the Manager thought had been a cause for concern had been that of the key worker.

'We had a big turn over of staff because at the M we have had to do a lot of work in changing the cultures. So we have had a lot of movement and it's only now that we're getting a stable workforce. We have some very good key workers but not everyone had a good one. They are just now being put into place.'

The Manager also recognised that not all service users wanted to be involved in management issues and that, for some, their main priority was to have the care that they required. Of the involvement of the DPF, she stated:

'I encourage the DPF to come in and I've asked them actually. I was talking to H, because one of our residents is really very keen on doing some work with access following the new legislation. I have asked H to come in and support him and go through the paper work, what kind of things, what we should be looking at in the local community. I've also encourage them to feedback to me because they are another pair of eyes and ears so if there is anything happening out there that I don't know about, that I want to know about, so that we can put it right. So I do see that they have got a good role to play.'

'I have just also encouraged T, who is our residents' chairman, to put himself forward for SURE. T would be ideal. He is very committed to ensuring that the residents that don't have a say, he keeps an eye on them, he makes sure that if he sees any problems, issues, whatever, he will come to me. So he is a very good advocate.'

The home has a buddying system in place to welcome new residents. Two residents have proved to be good mentors for other residents. The Manager

stressed that if this in house mentoring was not working than she would turn to the DPF mentor. She has also introduced to residents to a number of trainee counsellors. The residents choose to talk to these trainees if they wish and the Manager believed that some valuable work had been done with a number of residents on a one to one basis. Group work is also offered.

How the views of the DPF, SURE, Regional Director and Service Manager match up to those of Service Users, with regard to service user involvement

The chair of the residents' committee gave his views:

'L (Service Manager) is particularly keen on service user involvement, and I am too obviously. Basically we have a residents meeting. It's flexible because of when people can be there, whether they need help and this sort of thing. That will be a formal residents meeting with me chairing it. L will always attend the meeting towards the end. She always keeps about a half an hour spare, when we gather together a few main points to bring to her. In between that (the formal meeting) we have myself and a couple of reps, we have regular meetings with L, just us three in the office, when we'll be trying to bring other things, problems that we've heard about the home and that. The aim of that is to feedback to other residents because it's simply not possible to get everyone together all the time. L does the same with staff reps but we (chair and manager) think it will be a lot more useful if we have some kind of partnership meeting where there would be rep and staff reps to try, and not only looking for problems but looking at new ideas because you don't always want to be fielding problems all the time. We are trying things a little bit differently now. We've got teams. After some teething troubles most of the residents seem to like it. They weren't sure that they would. They thought they would not be seeing everyone but now it's settled down everyone is quite positive about it. You have to give these sorts of things a bit of a go. In theory we can have anyone in our meeting, but to say that there are 20 people out there all bursting to sit in a meeting with me, they're not. We can't pretend they are, but the opportunity is there. There will be a hard core of people that will.'

T went on to say that one of the barriers to service user involvement was the health of service users. He spoke of how the Regional Manager, and himself, saw the problem of encouraging more service users to be more involved often came down to lack of motivation. This was sometimes the result of physical, emotional or mental health issues along with, in some cases, a history of experience of people not listening to them. Another cause for concern was for those people with communication difficulties. The chair saw the RG trying to address this, for example:

'What M is planning to do, is to make some money available for communication at the meetings. In the past we've had staff in scribing for them (they have two deaf residents) but you don't want staff in a private meeting. You let off steam and some of it's off the record. So he will make a budget to have assistants in there. It will be good because the two deaf guys are the more political guys. So that will be useful.'

T talked about SURE:

'I'm putting up for SURE representative. I've been involved in other committees and different things and of all the things I think SURE can be the one that's most effective. I think the DPF is very good but I see it as more of an educational thing, getting people more aware of the issues. Very interesting. When we first started, people hadn't even thought about they could have a say in something. That's not long ago and I do wonder what non-Leonard Cheshire homes are like because LC, I'm pretty sure, is as good as it gets for user involvement.

About the DPF:

'I went on their training for recruitment. Everybody that's recruited here there'll be a resident on the interview panel and it'll be someone who has done the training for interviews which you need. People suddenly can't pick up and know things. They've got to be helped. The training was good. It was useful.'

T talked more about the role of the SURE rep which he is applying for:

'It's no good me just sitting in here thinking I know what's wrong with LC and I know what I want. You've got to get round the regions somehow, get reps within the homes to email me or something. It can't be just what I want, what I think. But I think SURE is probably the best way to have a say.'

He thought R the SURE rep for the region was a good model for how it should be done.

T went on to talk a bit more about how the service manager supported service users in that home.

'To be honest, no matter what you do if you haven't got a service manager who sees it the same way you see it you're starving because there's no way round it. Now (in this home) the structure's there, the structure is superb and it's just a case of how much we want to put into it. As much as you want to be interested you can be. It does just slightly worry me that LC is actually more go ahead than a lot of the residents.'

T ended by saying:

'At the end of the day there has be a degree of give and take because I'm not in independent living. It's not my front door. I am not the king of my castle but I can be one of the kings.'

Conclusion

The DPF and SURE believe that working together as a team is a more effective way of working and that it gives them a stronger presence within the region. The researcher felt that they were struggling with a time constraint and would benefit from an increase in financial support. This could provide for more human resources (another mentor for example) and an increase in hours of the present team with the possibility of the facilitator becoming full time.

The SURE representative, DPF staff, Service manager and Service Users see the Regional Director as being committed to service user involvement and improved services. It would seem that he has turned what was a struggling region, financially, into one of the most viable in the organisation. More importantly he can be seen to be using this financial strength to fund initiatives that will help empower service users. He is assisting with the SURE representative's travel expenses and allocating funds directly to service user group to support those with communication difficulties to have a say.

The Regional Director supports the DPF and would like to see the Facilitator have a full time commitment to the region. He also believes strongly in the role of SURE, and has a vision of it being more involved in the governance of Leonard Cheshire in the future. He is also committed to raising the quality in the standards of care staff employed, believing that paying realistic and competitive wages is an important factor in achieving this. He has a target for dramatically reducing the use of agency staff and replacing its use with a well trained, well paid permanent workforce that is committed to service users having real control of their lives.

The dilemma here is the period of time between staff leaving and permanent staff being recruited. It could be seen as disadvantageous to service users to be short staffed for a period of time. The Director believes, however, that managers would be quicker to recruit permanent staff if the easy option of contacting an agency was discouraged. The service manager of a home, visited by the researcher, totally supported this target and that home, now, has a full permanent workforce.

The researcher spoke to service users to ascertain if they viewed service user involvement in the Eastern Region in the same way as Leonard Cheshire staff saw it. There seemed to be a largely shared view of user involvement. Overall, there seemed to be extensive collaboration between service users, staff and management and a shared vision for a greater shift of power to service users.

6.2 Case Study Two – Ponteland Independent Supported Living – Bradbury Court

Introduction

Originally Bradbury Court existed as a Leonard Cheshire residential home. In 2001, after discussions by an inspector and the newly appointed Regional Director, it was felt that the building lent itself to being developed to provide for Independent Supported Living. All rooms had their own front and back doors (which lead out to the garden) and the rooms were large and had en suite facilities. Financially, the current residential home was not in a strong position. Grants for supported living were available for application so management decided to go ahead and give residents tenancy agreements. By April 2003 all nine residents were tenants in their own homes. Leonard Cheshire felt this to be a major step forward for the service users and from then on services would be provided in a different way.

Using this new type of provision each person would have his or her individual care needs assessed and a care package provided on an individual basis. There was consultation with service users over a long period of time as it was thought that this would be a daunting experience as some had been residents for many years.

At the moment, the tenants employ Leonard Cheshire to provide their care but this could change if service users became dissatisfied with the service. They have that choice. Health care is provided as delegated nursing by Leonard Cheshire but local health agencies are also involved. All tenants have individual social workers and care managers. Multidisciplinary reviews are held.

The researcher carried out a number of interviews to attempt to get a view of:

- a. How the tenants felt about independent supported living and how they handled the change;
- b. How staff viewed the change in provision;
- c. What was the input from the DPF and how did this support service users?

The extent of service user involvement, both during the period of change and since, was the central focus.

Interviews were made up as follows:

Service manager

4 service users

3 members of staff

Mentor (DPF) (Discussion)

Facilitator (DPF)(Discussion)

Findings

How service users felt about independent supported living and how they handled change

A service user was asked how she felt about the changes in living situation:

‘There wasn’t enough time to take in what the changes were. They didn’t give us the down side of it. They just talked about the positive side of it all the time.’

When asked what the down sides were this service user said it was the amount of responsibility that was put upon her:

‘We weren’t told about how much responsibility would be put on our shoulders, on my own shoulders.’

When asked if things had improved the reply was:

‘Oh definitely, tremendous. I have my own washer as you can see. I am in total authority what happens to my washing, how many time a week I use it. I have my own ironing board.’

This service user designed her own kitchen:

‘I designed it so I could be more independent’.

She uses local authority Occupational Therapists to help her in the planning and was in the process of changing her bathroom. When asked who pays:

'I apply for grants for it. When I had my kitchen done I had no cost.'

All the service users interviewed believed that they were better off financially since they became tenants. They were in control of their own money and have increased benefits, for example housing benefit, which is reflected in the overall financial package.

'I am responsible for my own money which makes it feel more like you are in control of your own life more'

'Now that I live in Independent Living I get to keep all my benefits you see – so I get a lot more money. I can save my money up and go on holiday where before I couldn't afford it. The financial benefit is the main thing.'

'We are much better off financially we can do things in a much more usual way because we actually have a bit more money to spend. Last year I did a course and managed to pay for the taxis fares there and back and I also managed to pay for a holiday with a carer when I went to Italy. If I really want to do something really badly I can afford occasionally to get a taxi to do it whereas before it was much more difficult. So I am leading a much more normal life. I can get involved in the community.'

When asked about benefits other than the physical environment the extra individual support given by Personal Assistants (Pas) was seen as a major difference:

'We have support to go out and do something normal and not go out with a great big group.'

'I feel I have got control of my life. I can plan what I want to do especially if I do it in advance. I thought of having a dinner party, but I wasn't very well for a while but next year I will be able to start doing that. They will help me to cook and they'll help me to plan a dinner party if I plan a little bit in advance. I sort of feel that I'm living in my own home, that my room's treated as my own home and I make my decisions about what I want to do.'

'The staff work as a team and they all know us as individuals. They are treating me as me, as an individual. We living here know we have an advantage that the people understand us better. That's what disabled people want. They want to feel that they are responsible for their life but there's a safety net if things go wrong.'

Although most tenants like to do their own thing, one service user preferred a more structured way of living:

'I prefer when it was structured. There are advantages and disadvantages. It gets a bit lonely in here 'cos you just do your own thing.'

When you go out you just go on your own – with a carer. Like in the other LC homes we do activities and go out together and that.'

Although tenants, in the main, prepare their own meals (with support if required) in their own homes, it was decided by them to request LC staff to provide a hot meal at lunch time each day which they buy when required. Service users also found this socially beneficial, giving them an opportunity to meet up with other tenants.

Tenants are involved in the interviewing process for staff appointments.

As to how members of staff see tenants now one service user said:

'We are seen more as independent individuals. The staff have adapted very well to the new situation.'

'It's a good place to live in and they are getting more user involvement and they discuss things with us more and they discuss individual needs more and we know we're looked upon as people not wheelchair people.'

'I think it will get better as time goes on but it's like everything else everybody learns from everybody else but I would say that most people would be happy here.'

Tenants talked about the importance of privacy:

'It's more private. You've got your own front door. It's your own living space.'

How staff viewed the change in provision

Staff thought the new provision was working well for service users:

'There have been notable changes. People are tending to do a lot more for themselves'

'They are left a lot more to their own devices but we are here if they need us. I think it works very well.'

'They (tenants) have meetings amongst themselves and if there's a problem it is addressed by the residents themselves and they will take it to the service manager.'

Referring to the PA support allocated to each tenant (about 12 –14 hours per person per week):

'The tenants will have really strong ideas about what they want to do with that quality time.'

'Most of what service users want to do we manage to arrange the support so they can do it.'

'Some people want to go out a lot more than others. In BC there is quite a big age gap between people. The youngest is 28 right through to A

who is in his 80's. There's different things for different people. I think we cater for everyone's needs.'

Another member of staff compared LC to other service providers:

'Obviously working within bad practice (referring here to her work in other places through an agency) you can see such a huge difference (at Bradbury Court) where personal and own choice comes into it and that's what it is all about when you're a service user. You should have your own choice and say within the care you are being given and unfortunately within some organisations and places it doesn't happen.'

The DPF and SURE

When asked about SURE, service users believed it to be important because of changes that happen to services:

'You don't know what the changes are going to be for the future, you know'

One service user thought that SURE could be more positive and there was room for improvement:

'If there are changes to be made tenants should be informed and I don't think they are informed in the way they should be.'

She would like to see more consultation and believed SURE could help with this. This service user believed the DPF protected the rights of disabled people:

'The government want to take away rights: the DPF put forward our rights. I feel more confident that it is there.'

Another service user said;

'It (the DPF) gives you a voice.'

It was felt to be especially important for people still in residential homes and people in Care in the Home.

A service user saw the mentoring service as an important part of the DPF:

'Oh yes that's how I am going to be involved to talking with the homes about how the changes have improved Bradbury Court'.

This service user is going into other homes in the North East that are going through reprovisioning, with the mentor, to talk about her experience of change:

'I am hoping to go to other homes in North East to try and support them in the changes in their own home. Give more of an idea of the benefits. It is quite an involvement.'

The mentor said that she had found some residents to be quite distressed after the reprovisioning programme had been presented to them. Things had moved on and the mentor and tenant were working together to prevent a similar situation happening elsewhere. This service user believed that LC, as an organisation, was empowering disabled people:

'They try to empower disabled persons... Putting new ideas forward for you to think about before you are actually making the decision'

One service user referred to the newly appointed facilitator:

'The new person appointed was once able-bodied but is now disabled and I think that's a very good thing indeed because she knows she is still

the same person she was when she was able-bodied, but she'll see both sides of the fence. I think this is a very progressive thing that's happened.'

Staff also spoke positively about the DPF:

'There's so many changes constantly happening. It's difficult to keep up to date sometimes, so I think it was good that she came around (the facilitator) because it's tough with everything changing all the time, just to know where you stand.'

Training from the DPF was seen to be 'very good on the whole' and although recent Disability Equality Training was evaluated positively one member of staff would have preferred to have learned more about the DDA and the law. Service users are invited to all training along with staff.

Conclusion

Service users saw Independent Supported Living as a very positive change of provision. After an initial period of anxiety, the tenants of Bradbury Court now offer a picture of improved service user involvement and being in control of their own lives. In addition they feel increased financial benefits and their physical environment much improved.

Tenants found the input from the DPF Mentor very supportive and are working with her to support service users from other residential homes who find themselves in a similar situation.

The DPF was seen as an important support system for service users and encouraged confidence to speak out for rights. The appointment of a facilitator who is disabled, and herself a LC service user, was seen as a positive move forward.

A disadvantage of the new tenancy arrangement is the unstructured organisation of activities throughout the day. A younger service user found life quite lonely when 'doing your own thing'.

Staff and tenants had experienced a definite shift of control from provider to service user.

6.3 Case Study Three – DPF And The Learning Difficulties Service Edinburgh

Introduction

The purpose of this case study is to highlight the good practice being carried out by the DPF's training officer in relation to the Learning Difficulties Service in Edinburgh. The researcher joined the trainer in Edinburgh to meet with service users and to take part in a music workshop, which was organised by him.

The two days were spent as follows:

1. Visit to the home of a former LC service user who has moved into his own home and who now buys his care from a different service provider, The Thistle Foundation.
2. This man continues to receive support from the DPF i.e. from the Training Officer and the Mentor for Scotland. This support, during transition into independent living, was regarded as essential by the DPF staff involved. The service user is engaged to be married to a LC service user and the mentor has significant input into their plans to live together. All parties thought it was important to address the issues jointly with the former service user's new provider.
3. Meal out with two service users from Argyle Street LC residential home. This home is going through re-provisioning to smaller units of two or four residents. The move was in part due to the fact that Argyle Street is situated in a district of adverse social problems and service users were often abused by local residents, especially the children. Historically it was bought cheaply as it was in the red light district of town. Apparently, it was thought that it would not affect the disabled residents, as they would not be going out very often.
4. Researcher escorted service users to music workshop where they met up with other LC residents past and present with their PAs.
5. Researcher interviewed a service user from a LC independent supported living establishment.
6. Researcher took part in workshop that was led by DPF Training Officer with music and activities provided by musicians from London, organised again by the Training Officer.

Findings

Visit to Service User's Home

M lived originally in Argyle Street Residential Home. He recently moved into his own home which he rents from a housing association and has 24 hours support provided by Thistle Foundation. He had been very clear in his request to have a place of his own. He did not like living in Argyle Street as he found the children living in the area very challenging. He found them noisy and they tormented him when he sat outside in his wheelchair.

M wants very much to live with his girlfriend Jackie and wants to get married very soon. When I spoke to his PA, she explained that the difficulty lay in the logistics of finding a large enough house which would accommodate M's 24 hour care team and J's care package which is substantially less. Added to this they have different service providers so the care aspect could be problematic with so many different people involved. The PA said that M was pushing hard to be married within the next six months. She also said that:

'M really does call the shots and makes all the decisions affecting his life'.

The DPF mentor is working hard with M's girlfriend and the staff of her present LC home to overcome the barriers. She is also working with J on relationship issues that keep presenting themselves. The Training Officer is also working with M on the same relationship issues.

While the researcher was at M's the LC Mentor telephoned and it was noticeable that M changed from being quite uncommunicative to being very animated and appeared to have an easy relationship with her in which he could voice his concerns.

One of the biggest problems in M's life is getting out to visit friends, especially J. Transport is very expensive because he lives in a rural area some distance from the city. However, he is soon to have his own van, which his PAs would drive and it can also be driven by M's father when he comes to visit. DPF staff facilitated the acquisition of this van when M lived in Argyle Street.

The Training Officer had arranged for M to join his old friends at the music workshop the following day.

Meal out with two service users from Argyle Street and DPF Training Officer

This was an informal night out when the service users were able to chat freely about their lives. They both appeared to be happy with the control they have over their own lives. They chose when to get up, where to go and when to use day services. They both look forward to moving to a smaller place (two flats instead of one larger home) and expressed the same concerns as M about the area in which Argyle Street is situated. Both L and R felt that they were being well consulted about the reprovisioning. They had visited possible properties, with their families and had put forward requests for consideration. One such request was for a garden.

They have a residents meeting once a month when they discuss this and other concerns. L said he gets the Forum newsletter on tape because he cannot read. Both he and R were well acquainted with the DPF, mainly through the Training Officer and Mentor.

Escorting service users to workshop

There was some concern over who was paying for the transport for service users to attend the workshop. The researcher was able to reassure that it was to be paid for by Training Officer and this seemed to solve the problem. Service users were given the choice to attend and three people accepted the invitation.

Researcher interviewed service user who has moved to Independent Supported Living (purchasing LC care package)

J told the researcher how she moved out of a LC residential home into independent supported living:

'I found it very hard. I was looking for somewhere to live for 5 years but I couldn't find one because there were other units I could go to but they said I was too handicapped and one said I was not handicapped enough. So then I got me place at LC and been there ever since.'

Asked about support:

'Yes, I have a support worker. She is called M and she is absolutely fantastic.'

J went on to explain:

'She stays. I am in supported accommodation which means there are support workers already there. I am with seven other people.'

'Yes I have my own house. The support workers are there if we need them.'

When asked if she felt she has control of her own life:

'Oh yes now I do. I have got my independence. It's great because now my mum doesn't have to worry about me and I don't have to worry about her (her mum has diabetes).'

J told the researcher about how a member of LC staff (now retired) helped her to get into Independent Supported Living and when asked about the DPF:

'Yes, I know a heck of a lot about the Forum. D is so good. She's absolutely brilliant.'

J went on to describe one of the times the Mentor had helped her:

'She took me to Leeds to do a course, otherwise I wouldn't have been able to go because I don't drive. I think it was Disability Equality Training. It was really nice to be in a hotel for 3 or 4 days.'

J said she has also had a lot of training by the Training Officer.

The music workshop

This was well attended by service users from a variety of LC learning difficulties services (and past LC service users) from a wide geographical area. Music was provided by a band of musicians from London who had worked with the Training Officer in the past. They quickly established a very good relationship with those taking part and very soon everyone was participating (including the researcher). The evaluation, at the end of the session by service users, was very positive and a request for further events was expressed.

The Training Officer and band travelled to Aberdeen to provide a similar workshop. The Mentor for Scotland would be involved in this. The events are recorded by the use of a video recorder. Copies of the video are usually sent to services for use by participants after training events.

Conclusion

The researcher felt that the Training Officer had worked hard to support service users in this region to develop skills that could ultimately give them more control over their lives. He aims to raise awareness of opportunities for increasing user involvement both on a daily basis and by more formal means. The Training Officer also hopes to encourage service users to gain confidence in order to speak out and voice their needs. He is supported in this work by the Mentor, Facilitator and management of the DPF.

6.4 Case Study Four - Reprovisioning Of Accommodation In The South-West Region

Introduction

This case study will examine the reprovisioning of accommodation project in the South West Region of Leonard Cheshire. The reprovisioning involves three homes in the south West Region – Greathouse, St Michael's and Greenhill. A quarterly monitoring group consisting of the Regional Director and Development Manager, DPF Manager and regional staff and independent disabled consultant and a disabled volunteer and has met for 2 years. Some of these projects is still at the planning stage with some aspects yet to be finalised. For this reason the case study is largely based upon documents although an interview with one of the mentors and facilitator in this area, who is involved in preparing residents to move to new accommodation, is included.

In September 2003 a presentation was given by Clare Evans of the Disabled People's Forum (DPF) and Angie Carmichael (a disabled researcher) to describe the design of a pilot study for reprovisioning of accommodation in the South West Region of Leonard Cheshire. The presentation took place at the Jane Hodge Resort Hotel to the National Development Committee.

The design of the project is based on three principles:

- No assumptions about future options of accommodation.
- To assist residents to identify their individual future life plans independent of vested interests.
- To assist residents to have maximum choice about future options by supporting them in raising their aspirations and learning about a range of opportunities open to them.

An experienced disabled researcher, with links with the DPF and independent of service line management, has interviewed residents more than once about their aspirations for the future and their Individual Service Plans.

Residents have seen a video of living opportunities made by the Regional Director and have taken part in 'user only' meetings arranged by the DPF Facilitator to explore their reactions and understand the opportunities open to them. Residents are also receiving one-to-one support from a mentor to explore independent living options. In-house training on, for example, Disabled People's Rights and Making the Most of Assessment will also be provided. A quarterly monitoring group meeting of those involved in the research takes place to learn from each other, adapt the project and to extract the ideas for other Leonard Cheshire work.

The interviews between the residents and the researcher have now been completed. All residents were offered the opportunity for an individual interview with the researcher. The majority had two interviews spread over a two to three month period. A small number of residents requested three interviews to include a relative or in order to facilitate communication needs. A few residents declined to be interviewed or to take part in the consultation process. The time and place of the interviews were, wherever possible, arranged to respect residents' preferences. A key worker or other person

assisted with communication and support needs if necessary. Approximately 80 residents were interviewed.

Residents were asked whether they would like to live with 2-3 people, up to 10 people or on their own with 24 hour support. Thirty one residents wanted either to live alone or with two or three other people. Most residents felt that they needed 24 hour support although some did not know. There was a general lack of awareness over Independent Living options and the use of Direct Payments.

User-Led Transport Access Partnership Proposal

A funding proposal has been written the aim of which is to support disabled people to use accessible public transport in North and West Wiltshire, Kennet and Salisbury. The project has the following objectives: to disseminate information in a variety of formats about the opportunities to use accessible public transport; to develop a 'buddy' scheme to support disabled people when using accessible public transport; to develop and deliver a training programme for public transport providers with the support of relevant statutory agencies.

It is recognised that public transport in rural areas is a problem for all people who do not have access to a private vehicle. There is lack of information regarding accessible public transport and people frequently lack confidence because of experiences of discrimination from public transport providers. Lack of accessible public transport is something disabled people always identify as a major barrier in their lives. With the introduction of the Disability Discrimination Act, however, there is more awareness of access issues with regard to public transport.

Development Strategies

A development officer has been appointed for 21 hours a week over a 2 year period. A steering committee consisting of disabled people's organisations and statutory authorities involved with public transport will work with the Leonard Cheshire development officer. Disabled people will, for example, guide the development officer regarding the kinds of information disabled people need about public transport and the different formats that should be used when disseminating the information.

The development officer will be responsible for developing a system of volunteers to assist disabled people who wish to use public transport. He/she will also have responsibility, with disabled people, for designing training on disability equality and access issues to public transport staff and to support disabled people to deliver this training.

Systems will be developed to monitor disabled people's use of public transport throughout this project. General awareness of transport facilities will be measured at the start and the end of the project by means of a questionnaire. The awareness of public transport staff concerning disability

and access issues will be measured at the end of the study by asking disabled people about their experiences of these staff when using public transport. Disabled people will be actively involved in designing the outcome measures. The steering committee will meet regularly to consider what is being learned from the project and the information will be disseminated across all areas of the UK. The project will particularly focus on supporting disabled people moving from LC residential care to Independent Living in Warminster.

Independent Living/Direct Payment Proposal

This proposal targets residents who have expressed an interest in Direct Payments and living more independently and has been developed by the DPF Facilitator. The project will last for one year starting in January 2005. The idea is that the residents should form a support group that would meet bi-monthly and be supported initially by the forum facilitator. The aim of the group would be for the residents to support each other, exchange information and celebrate their achievements.

Months 1 - 4

There will be an initial meeting with service managers to identify residents and explain the process. A half-day forum meeting will be provided which will include videos and talks by Direct Payment users. A freelance trainer will provide a day or half-day training session on:

- Social Model and Rights and Entitlements
- What is Independent Living?
- Assertiveness and Confidence Building
- Managing Money.

It is also hoped that visits to supported living accommodation and other alternative types of accommodation will be arranged by the DPF mentor and be ongoing throughout the re-provisioning process.

Months 5 – 6

A two-day residential training course will be held at the *Jane Hodge Resort Hotel* to cover:

- All aspects of direct payments
- Diary of needs
- How to get an assessment
- Action plans

Months 7 – 8

A short experience of using PAs in the community will be arranged to consolidate the learning from the Direct Payments course. This could happen in two ways:

- Using a trained volunteer for small tasks such as shopping.
- Having a 'working holiday' in fully accessible self-catering accommodation with trained PAs.

Months 10 – 12

- On-going mentoring support
- Links with a social worker
- Workshops with a freelance trainer on, for example, how to access local community activities.

Regular reports will be made to the RSR Monitoring group which has been overseeing the reprovisioning process in the South West Region by meeting regularly over the past two years.

Using Virtual Reality in the Adaptation and Construction of Environments for Disabled People

This is a paper rather than a proposal and is, at present, at the stage of an idea. The idea is to use three-dimensional computerised visualisations as a tool to help include people become involved in the design and alterations of buildings.

Video Project

Aim

The project will actively involve service users in producing a video and other information about the reprovisioning process affecting the three homes to be closed in the South West Region. They will be assisted in making the video by Filton College in Bristol which will also provide necessary training. The video will have a wide audience but be primarily of interest to residents, family members, volunteers and staff of Leonard Cheshire. The DPF Manager and regional staff are supporting the independent disability consultant and volunteer in implementing this.

Outcomes

By making the video a number of outcomes will be achieved for both service users and Leonard Cheshire:

- Accessible information giving positive messages and showing a variety of housing and support opportunities for people who currently live in the three homes.
- Provide an interesting visual record of the reprovisioning process.
- Be a Guide to Good practice – a training resource to Leonard Cheshire and other professionals.
- Help to promote confidence and a ‘can do’ approach to managing change for all involved.
- Service users will be actively involved in all aspects of the project: including making decisions and participating in the design, content and production of the information and video resources.
- People will learn new skills that can be used in other projects or areas, thus furthering self-development and empowerment. This could also provide a useful pool of experienced service users for Leonard Cheshire to ‘tap into’ in the future.
- Service users will be able to celebrate their new skills and achievements.

Timescale

The timing of this project will be flexible. It is hoped that it will be completed by the summer of 2005. The only site available for reprovising at the time of the evaluation is in Warminster.

Media Skills Workshops

In order to provide residents with the necessary skills to be able to participate effectively with the production and editing of the video a programme of up to five workshops will be offered:

- What's involved in making a video? – content and ideas
- Basic camera and sound techniques
- Scriptwriting, storyboarding and production management
- Interviewing skills and talking to the press.
- Editing and making video accessible to all

Related project work

Residents not directly involved in the video production process itself, may wish to contribute and participate in other ways. This could be through:

- Poetry (exploring feelings or covering the mundane aspects of having the builder in)
- Painting (creative, fun)
- Posters (telling people about the video or launching it)
- Photography (create a diary of pictures)
- People's stories (experiential and anthologies using people's own words, which could be collected into a book for publication, or as part of a training pack)

Two people from each home will join the researcher to form the editors group. The group will meet regularly to advise and make sure that everything is working well.

Interview with the mentor

The mentor explained her role in the reprovisioning process as follows:

“My role is to support people who are facing this big change. Lots of them are excited by the change, they see it as a big challenge, and equally lots are terrified. I tell them what's available and show them any videos that have been made and give them examples of what is possible.”

The mentor has spoken to people in groups and individually. She emphasised the importance of giving information and the benefits of being disabled herself:

“Having moved myself quite a few times I know it is scary, it's very scary because you don't know what it will be like until you get there. I think it's important that the mentors are disabled in some way because you've got that understanding and experience that perhaps an able-bodied person

wouldn't pick up on. As a mentor you have the information at your finger tips or at least you know where to go."

The mentor emphasised the need for training in daily living skills when people have lived in institutions for many years. She stressed that, as the reprovisioning programme is likely to take some years, there is time to prepare people slowly and carefully. The only site for reprovisioning so far is a block of old people's flats in Warminster that are being adapted for semi-independent living which, it is hoped, will be ready by the end of 2005:

"I think there will have to be a lot more training, inviting people to learn more, and lots of reassurance that it's not going to happen tomorrow. It's important that people start making plans now but there is plenty of time. We can't really say what the time scale is."

The need for staff training was also recognised:

"I think it's very difficult for the staff and it has been suggested that they should have more training to reassure them. Those that have been working in residential care for many years are not aware of the modern ideas about independent living and what is possible. It would be quite helpful if the training was shared. I think it will happen."

The mentor stressed the individuality of every person and the different types of accommodation they require. Some people may move to other residential provision – one person had already moved to another Leonard Cheshire Home – some may prefer semi-independent living, such as that which will be provided at Warminster, and others will want full independent living with a Direct Payment. It is likely too that some types of accommodation may serve as a 'half-way house' on the way to full independence.

Conclusion

This case study puts particular emphasis on a multiple-strategy approach led by the DPF working with the Regional Director to user involvement in development of Leonard Cheshire provision. User involvement in reprovisioning in the South-West region is being carefully and systematically planned and involves a number of innovative projects, including video-making and a varied projects and workshops programme.

It is also clear that reprovisioning presents dilemmas in relation to user involvement:

- Reprovisioning only applies to some Leonard Cheshire service users. While resources are committed towards changes in services that could enhance the involvement of those directly involved, the involvement of people remaining in residential care is more problematic.
- Service user choice is problematic during a period of service development. Reprovisioning seems to be a move towards greater user involvement, but user involvement in the process and decision

making in reprovisioning challenges the management of Leonard Cheshire.

The support provided by a mentor and facilitator who are themselves disabled, emerges as a key element in what can be a complex and difficult process of change.

6.5 Case Study Five - Training

Introduction

This case study will examine two training courses run by the Disabled People's Forum (DPF) for the users of Leonard Cheshire. One is an established course on Direct Payment and the other is a new course to train service users as 'buddies'. Both of these courses were delivered by disabled freelance trainers contracted to the DPF.

Training service users and staff is a major role of the DPF. Some of the training is undertaken by the DPF staff themselves but freelance trainers are also employed. All the trainers are disabled people. A wide range of training opportunities are provided by the DPF and those directed at service users all concern user involvement. Below is a list of some of the training opportunities offered:

- User empowerment
- Committee skills
- Recruitment and selection of staff
- Direct payments
- Training the trainers
- Confidence building

Courses are also devised according to identified needs and requests from services users and staff.

Training courses are run on a national, regional and local level and are either day or residential. All expenses are met from the DPF budget. This includes paying for personal assistants from a local agency who are prepared to work late at night.

Both courses took place at The Jane Hodge Resort Hotel near Cowbridge which is run by the charity John Groome. It provided a comfortable and accessible venue with good food and quiet, spacious, accessible accommodation. In informal discussion with the participants some were very appreciative of the accessibility the hotel offered and compared it with other hotels which claimed to be accessible but where difficulties had been encountered. Other participants, however, found the hotel had a somewhat institutional atmosphere and would have preferred the courses to have taken place in a mainstream venue.

Training to be a 'Buddy'

This was a national residential course which took place over three days from the 8th to the 10th of November 2004. It was the first course of its type run by the DPF. The information for this case study was gathered by means of observation of the entire course, an informal interview with the trainer and informal discussions with the participants over meals and coffee breaks.

The participants

Ten participants (four men and six women) attended the course which was an ideal number for group interaction. They used various Leonard Cheshire services including Care-at-Home, residential homes, and employment.

It soon became apparent that most of the ten participants knew each other well and, in various ways, had met the researchers on this project. The participants were clearly very active in user involvement activities within Leonard Cheshire. Some people were involved in SURE, one was a Disability Equality Trainer and others were involved in Care and Operational Reviews. The trainer explained that this was something of a disappointment as the need for a course on becoming a buddy was identified by service users who were not already active in user involvement. Despite this interest, however, they did not apply when the course was advertised. The trainer also commented that she had never run a course with so many empowered disabled people on it and that she had not been required to make any adaptations for people with learning difficulties, or communication impairments. This-three day course clearly gave the participants a very good opportunity to come together, exchange experiences and ideas and extend their networks.

The course

The course was run by a skilled and experienced trainer. It was largely interactive and involved a great deal of participant involvement. Minimal but useful theory was included and 'homework' was supplied to give people a focus for their evening discussions. Useful handouts were also supplied and a board for Post It notes was provided where people could attach their own questions for future discussion.

A major task of the course was to explain the role of a 'buddy'. This was defined, not as a friend or befriender, but as a supporter with a focused and defined role over a short period of time. Initially service users will be referred to buddies by mentors when they are sufficiently empowered to focus on specific goals. An example was given of a service user who might wish to go on holiday abroad. The role of the buddy would be to work with that person to achieve that particular goal. Buddies will, therefore, work closely with mentors around goals that have previously been identified by mentors and service users working together.

Other sessions focused on the skills that a buddy needs, the ways in which human beings learn and develop, building trusting relationships, developing social networks, ending relationships, focusing on personal strengths and weaknesses, creative thinking, listening skills and assertiveness skills. A

Leonard Cheshire mentor and a Regional Volunteer Co-ordinator also came to the course to give sessions. The mentor talked of her own experiences in that role and how she saw the role of buddy developing. She put forward the idea that buddies might 'shadow' mentors for a time in order to learn their role. The Volunteer Co-ordinator spoke about the practicalities of becoming a volunteer within Leonard Cheshire. The buddy will work under the direction of the mentor but will also be supported by the Volunteer Co-ordinator in the region, as they will be classed as volunteers within Leonard Cheshire. Funding for buddies' travel and care costs will need to come from voluntary income that is limited and at the discretion of the Regional Director.

The buddies will be treated as other volunteers within Leonard Cheshire and will need advanced police checks and be required to attend other courses including the Protection of Vulnerable Adults course, Disability Equality Training and training regarding disability and the law. A formal application form with the names of two referees will be required and there will be a full induction process. Each person will be given a volunteers' pack, a full job description and relevant leaflets from the DPF.

Conclusion

This course is the first of its type to be run by the DPF and arose because of a need identified by service users. Although the course did not attract service users who were not already involved in user involvement activities, it is hoped that, as the role of the buddy becomes more established, more service users will gradually take part. The trainer was of the opinion that the management of Leonard Cheshire wants to see service users involved in user involvement activities other than committee work.

It was clear from the discussion between the Volunteer Co-ordinator, the trainer, the mentor and the participants that the precise way in which the mentor and the volunteer co-ordinator will work together with the buddy had not been completely established. It was emphasised that this is a pilot study and that mechanisms of collaboration are likely to evolve. There was some concern among participants about the way their expenses would be paid, for example, travel and telephone expenses. They were generally reassured although the limited nature of the funding was emphasised as well as the fact that it might vary from region to region.

The role of the buddy and the way that it could be differentiated from that of the mentor was quite difficult to grasp but eventually became clear. It was emphasised, however, that the role the buddy and the mechanisms surrounding the role are likely to evolve. People other than mentors may, for example, in time be permitted to refer service users to buddies. The major concern of the mentors was not to hold on to power but that buddies should not be overwhelmed by numerous referrals.

Although the participants were all keen to become buddies some acknowledged that the work was skilled and that in a different context they would be paid. The trainer explained that a great deal of thought had gone

into the term 'buddy' and that she would have preferred 'voluntary mentor' but there was a fear that this could lead to a perception that the paid mentors were not needed when this was not the case.

The course appeared to be a positive experience for the participants and the idea behind it seems sound in terms of user involvement principles. Disabled users will be working to assist other disabled users and receiving training, support and guidance from disabled people. This could become a powerful means of user involvement if other disabled people became involved. Adequate resources will, however, need to be provided especially if people with communication needs and learning difficulties are included as buddies.

The voluntary nature of the buddy role could become problematic especially if expenses are not adequately covered or the workload becomes heavy or demanding. Working closely with and in a similar role to other disabled people who are paid may also create tensions. It is recognised, however, that many people prefer to volunteer rather than be paid and that paid work may complicate financial benefits.

Direct Payment Training

This was a national residential course which took place over three days from the 29th of November to the 1st of December 2004. The information for this case study was gathered by means of observation of the entire course, and informal discussions with the participants over meals and coffee breaks.

The participants

Eighteen participants (ten men and eight women) attended the course. They used various Leonard Cheshire services including Care-at-Home, residential homes and the Employability scheme. Several mentors also attended the course in order to improve their knowledge of direct payments when working with service users. The participants were very mixed with some knowing a considerable amount about Direct Payments with others having far less knowledge. A sizeable minority of the participants had a speech or language impairment and two used 'electronic voices'.

The number of participants was, perhaps, rather too large as it took longer for many participants to get their views and ideas across. However, the trainers were thoughtful and skilful in allowing everyone to talk and the people with 'electronic voices' participated well sometimes bringing up controversial topics such as the role of personal assistants in enabling sexual relationships. This three day course clearly gave the participants a very good opportunity to come together, exchange experiences and ideas and extend their networks.

The course

The course was run by 2 skilled and experienced freelance trainers and a mentor. It was largely interactive and involved a great deal of participant involvement. Care was taken to emphasise that Direct Payment, and the

whole concept of Independent Living, had come from disabled people themselves - indeed from Leonard Cheshire residents. A board for Post It notes was provided where people could attach questions for future discussion and a useful pack of materials was given to each participant. The materials were not accessible to everyone but the trainers assured them that this would be attended to after the course.

The course consisted of various small group activities for instance exploring the difference between a 'personal assistant' and a 'carer' and answering the question 'What is Independent Living?' Attention was given to the assessment process and participants had practice in writing a 'diary of needs' to present to social workers when being assessed for a Direct Payment. They also practised writing advertisements and job descriptions for personal assistants. Legal and administrative issues, such as Health and Safety law, insurance and pay roll services, were also discussed and a quiz was included to consolidate the learning. The role of CILs and the help they can give, and various relevant pieces of legislation, such as the Disability Discrimination Act, the Direct Payment Act and the Human Rights Act, were emphasised throughout.

Two useful and informative videos were played during the course. One, entitled Direct Payments – Living Life to the Full by Direct Payment Scotland showed a range of life style possibilities for disabled people who had received Direct Payments. The other entitled Direct Payment: A Beginner's Guide by the National Centre for Independent Living covered all aspects of employing personal assistants. Both videos gave the stimulus for a great deal of discussion.

Conclusion

In informal discussions with the participants most had enjoyed the course and had gained from it. There was, however, considerable scepticism, often based on personal experience, about whether the level of finance offered following assessment would allow for anything more than assistance with basic necessities. Some people also expressed the view that the course was too long and tiring – it was noticeable that some people missed some of the sessions.

The most striking aspect of this course (and indeed the course on 'buddies') was that it was run by disabled people for disabled people. Both trainers were disabled and both used Direct Payments themselves. The videos and all the course materials gave complete voice to disabled people rather than professional health and social care workers. This was very powerful and gave both courses an authenticity that is rarely encountered.

6.6 Conclusion: Analysing Case Studies

Information for the case studies was gathered with the express purpose of documenting 'good practice', or changing practice, within Leonard Cheshire. An independent evaluation can, and should, provide examples of perceived

good practice as well as perceived problems. Both provide a basis for reviewing practice, the provision and management of services, and in this case the development of service user involvement. It is evident from the case studies, particularly in the context of the findings from stage one of the evaluation, that Leonard Cheshire is a diverse, complex organisation. In line with social care in the national context, Leonard Cheshire is changing though this is disparate across the various levels and parts of the whole organisation. In such circumstances the dissemination of information about the processes of change and possibilities for good practice is of paramount importance.

CASE STUDY OF A REGION

The DPF and SURE believe that working together as a team is a more effective way of working and that it gives them a stronger presence within a region. The evaluation suggested that they were struggling with a time constraint and would benefit from an increase in financial support.

In this region the SURE representative, DPF staff, Service manager and Service Users see the Regional Director as being committed to service user involvement and improved services. It would seem that he has turned what was a struggling region, financially, into one of the most viable in the organisation. More importantly he can be seen to be using this financial strength to fund initiatives that will help empower service users.

The Regional Director is committed to raising the quality in the standards of care staff employed, believing that paying realistic and competitive wages is an important factor in achieving this. He has a target for dramatically reducing the use of agency staff and replacing its use with a well trained, well paid permanent workforce that is committed to service users having real control of their lives.

Service users and providers seemed to have a largely shared view of user involvement. Overall, there seemed to be extensive collaboration between service users, staff and management and a shared vision for a greater shift of power to service users.

INDEPENDENT SUPPORTED LIVING

Service users saw Independent Supported Living as a very positive change of provision. After an initial period of anxiety, the tenants now offer a picture of improved service user involvement and being in control of their own lives. In addition they feel increased financial benefits and their physical environment much improved.

Tenants found the input from the DPF Mentor very supportive and are working with her to support service users from other residential homes who find themselves in a similar situation.

The DPF was seen as an important support system for service users and encouraged confidence to speak out for rights. The appointment of a facilitator

who is disabled, and herself a LC service user, was seen as a positive move forward.

A disadvantage of the new tenancy arrangement is the unstructured organisation of activities throughout the day. A younger service user found life quite lonely when 'doing your own thing'.

DPF AND LEARNING DIFFICULTIES SERVICE

The Training Officer had worked hard to support service users in the region to develop skills that could ultimately give them more control over their lives. He aims to raise awareness of opportunities for increasing user involvement both on a daily basis and by more formal means. The Training Officer also hopes to encourage service users to gain confidence in order to speak out and voice their needs. He is supported in this work by the Mentor, Facilitator and management of the DPF.

REPROVISIONING OF ACCOMODATION

This case study puts particular emphasis on a multiple-strategy approach to user involvement in development of Leonard Cheshire provision. User involvement in reprovisioning in the region is being carefully and systematically planned and involves a number of innovative projects, including video-making and a varied projects and workshops programme.

Reprovisioning only applies to some Leonard Cheshire service users. While resources are committed towards changes in services that could enhance the involvement of those directly involved, the involvement of people remaining in residential care is more problematic.

Service user choice is problematic during a period of service development. Reprovisioning seems to be a move towards greater user involvement, but user involvement in the process and decision making in reprovisioning challenges the management of Leonard Cheshire.

The support provided by the DPF staff who are themselves disabled, emerges as a key element in what can be a complex and difficult process of change.

TRAINING FOR SERVICE USERS

The evaluation covered training to be a 'buddy' and training in Direct Payments. The courses appeared to be a positive experience for the participants and the idea behind them seems sound in terms of user involvement principles.

In informal discussions with the participants most had enjoyed the course and had gained from it. There was, however, considerable scepticism, often based on personal experience, about whether the level of finance offered following assessment would allow for anything more than assistance with

basic necessities. Some people also expressed the view that the course was too long and tiring.

The most striking aspect of the courses was that they were run by disabled people for disabled people. Both trainers were disabled and both used Direct Payments themselves, for instance. The videos and all the course materials gave complete voice to disabled people rather than professional health and social care workers.

7. DEVELOPING USER INVOLVEMENT IN LEONARD CHESHIRE

7.1 A Model for Developing User Involvement

The Steering Group for the evaluation discussed the possible implications of the evaluation of service user involvement. The Group put together the basis of a model for developing user involvement, principles for developing user involvement, and options for developing user involvement in practice. The framework developed by the Group is elaborated in this section.

The following are key elements of the model – see FIGURE ONE:

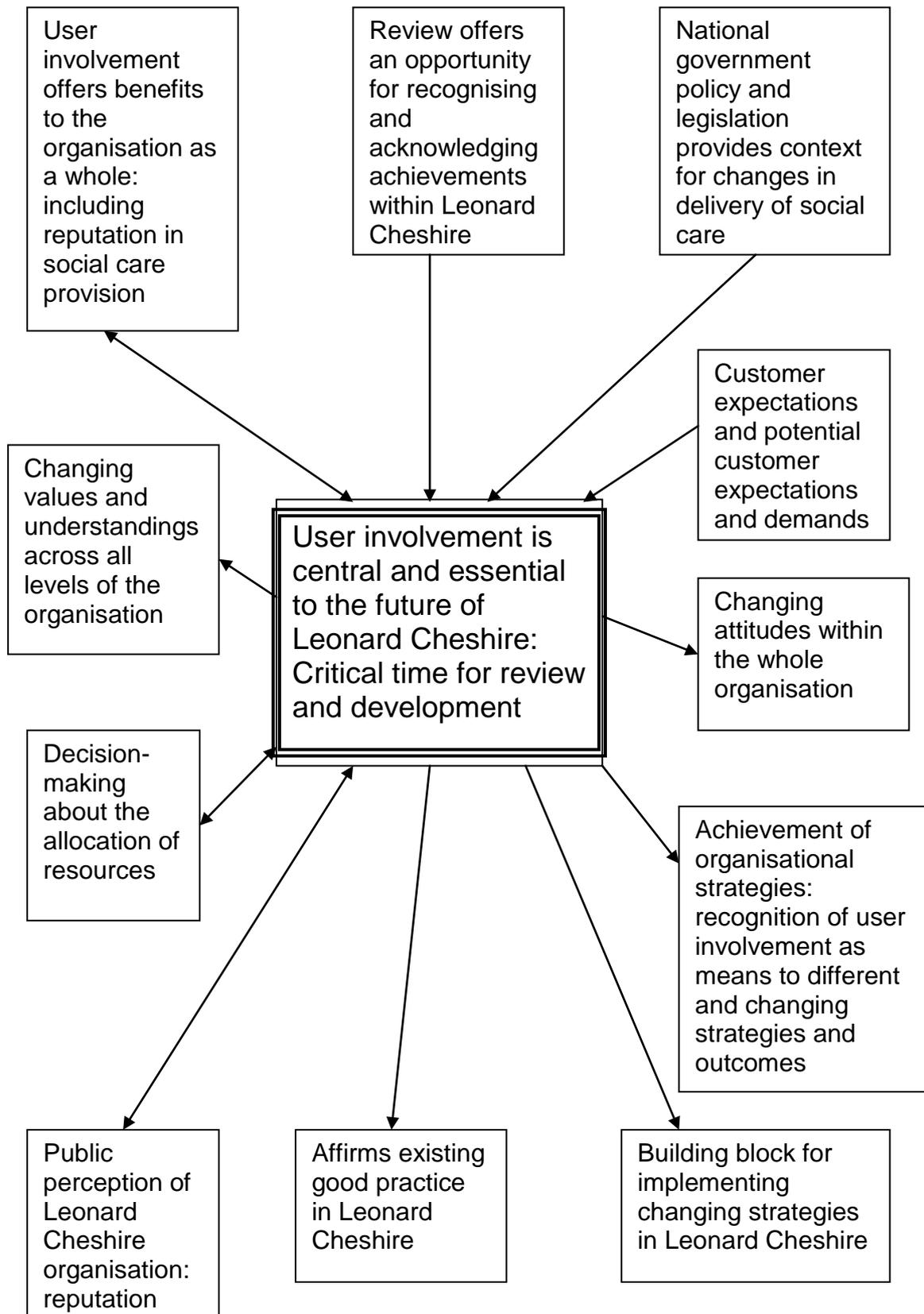
- The development of user involvement in Leonard Cheshire reflects the way social care is moving nationally. The findings of the evaluation need to be interpreted within this wider context.
- The changing wider national context also underlines the crucial importance of the development of service user involvement in Leonard Cheshire. This includes the changing expectations of disabled people and the changing demands of prospective clients.
- It recognises, too, that the development of user involvement holds benefits for the organisation as a whole.
- User involvement can provide the building blocks for changes at all levels throughout the organisation.
- The development of user involvement needs to recognise and build on existing good practice and the work that has already been carried out within Leonard Cheshire.

7.2 Principles for Developing User Involvement

The following principles are derived from the evaluation as a whole. They provide both the foundations for development and a framework for monitoring change following the independent evaluation.

- There is a clear and absolute requirement that the effective development of user involvement must be generated by and controlled by service users themselves.
- The Leonard Cheshire organisation, through structures and processes, can and does limit user involvement. Equally the organisation as a whole can and does facilitate user involvement. The development of user involvement needs to be seen as embedded in all decision making within Leonard Cheshire, including financial and management decision making at all level (local, regional and national).
- User involvement is embedded in service users lives. It is part of defining the quality of life for service users. Quality of life is determined within the say that people have over their lives, from the day-to-day decisions over basic needs (sleep, eating, toilet etc) to the control over their own finances and control over the support they receive.

FIGURE ONE
MODEL FOR SERVICE USER INVOLVEMENT IN LEONARD CHESHIRE:
'FITS SO WELL INTO THE FUTURE'



- There is no existing model of user involvement, that has been developed outside the organisation, that can or should be adopted within Leonard Cheshire. Any attempt to do so is more likely to be retrograde than enhance user involvement.
- There is no body of concern that can be seen as 'user involvement' that is separate or isolated from all decision making structures and processes within Leonard Cheshire - finance, management and so on.
- User involvement in policy making is crucial. A number of possibilities arise from this evaluation. First, service users should be involved in the writing of policy, rather than being simply consulted about drafts of policy statements. Second, the least restrictive possible policies and practices arising from legislation need to be implemented. Third, in adopting the least restrictive response policy making should, as far as possible, be made at a local level, with full user involvement.
- Approaches to user involvement also need to be open, flexible and individual (or client-centred). The provision of mentoring is greatly valued, in this respect, and this needs to be more widely available.
- Effective communication is fundamental to user involvement. This includes increased support, communication workers and use of communication equipment at an individual level. It also includes a creative and flexible approach to group meetings, including video conferencing, to open opportunities.

7.3 Options for Developing User Involvement in Practice

The evaluation, working with the Steering Group, were asked by Leonard Cheshire management to provide a list of possible options for developing service user involvement. These will be the starting point for the development of an overall strategy within Leonard Cheshire.

- Existing mechanisms, particularly the Disabled People's Forum and SURE should be to be strengthened. Though the work of the DPF is widely recognised as crucial to user involvement in Leonard Cheshire, a number of issues were raised in the evaluation, particularly concerning ambiguities in the position and role of DPF staff. A useful strategy have been developed by the DPF involving a change in name, to 'User Support Team', together with an associated developing of the role of the team.
- SURE members need to be provided with resources to support their work in representing service users' views. SURE members need to be provided with the necessary resources required to effectively represent the constituent membership. Furthermore, full consideration needs to be given to the different types of support required in facilitating SURE members to develop their role.

- The case studies, presented within the full report of the evaluation, need to be developed into evidence for good practice (evidence based practice). Consideration needs to be given to the dissemination of good practice within Leonard Cheshire. The aim is to enable those who implement strategy to use this research to reach out to those at the front line. This would be facilitated by a commitment from Regional Directors to lead by example of sharing good practice and innovation.
- In general terms, the organisation should make a commitment to delivering support services which reflect the “learning” from this independent evaluation about user “choice and control” to acknowledge perceived barriers to service user involvement and perceived good practice. In particular, this requires the provision of support, controlled by service users, to maximise their control over day-to-day decision-making.
- The development of service user involvement requires a partnership between service users and service providers at regional and local levels. This requires the re-enforcement of the partnership approach to working in the regions, and locally, between regional director, DPF staff, SURE reps, other service users and the staff association.
- Plans for the active development of service user involvement are required to generate targets, in relation to service user involvement, in operating objectives for each region/service. The extent to which targets are achieved should be regularly monitored, through a partnership approach facilitating the involvement of service users themselves.
- The development of user involvement needs to be viewed in terms of developing relations between Leonard Cheshire and the wider national context, to promote this approach to the regulators, and to further develop professional relationships with the social care sector, including the DH at Westminster and ADSS.
- The DPF staff team should be seen as a centre of excellence / resource both internally and externally. This includes the provision of resources for DPF to extend their expertise, particularly in the provision of training for staff.
- A review is required of the effectiveness of current Disability Equality Training in changing the understandings of staff of disability and disabled people.
- In terms of management and governance, effective lines of communication between SURE and Central Directors and Trustees are required. A review of the ability / opportunity for service users to impact on the trustee body / Governance of LC should form part of review of the trustee body.

8. CONCLUSION

8.1 Reflections: Returning to the Stated Aims

This conclusion provides a brief summary of the effectiveness of this evaluation in realising the agreed objectives for the project. Taking each objective, the summary attempts to pin-point achievements in promoting user involvement.

To explore the effectiveness of current strategies in promoting Leonard Cheshire's commitment to user involvement, including the Disabled People's Forum and SURE, from the viewpoints of the different stakeholders within the organisation.

- Clear and extensive evidence indicates a dominant view that the DPF and SURE have enhanced service user involvement.
- The evaluation has also pin-pointed dominant barriers to the effectiveness of current strategies.
- The evaluation directs the development of user involvement towards building on and strengthening current strategies.
- Though the evaluation has been extensive in exploring the viewpoints of different stakeholders, it has only been able to do so within the original remit and resources for the evaluations. Further research is required to build on the framework for development of user involvement established within the evaluation.

To examine the possible barriers to the promotion of user involvement within Leonard Cheshire.

- The evaluation has provided a wide and diverse picture of barriers to the promotion of user involvement. Two broad themes emerged as predominant.
- First, the hierarchical power relations and management structures within Leonard Cheshire set a historical context that limit and determine 'user involvement'. The ramifications from different standpoints of stakeholders have been expressed throughout the evaluation.
- The barriers to informal user involvement have also been expressed through the evaluation. It has provided detailed evidence of the various factors in the provision of care (staff shortages, lack of transport, staff attitudes etc) within Leonard Cheshire that limit opportunities and the necessary support for service user involvement in controlling the decision-making that shapes their day-to-day lives.

To consider options and make recommendations for future developments in user involvement in Leonard Cheshire.

- This evaluation speaks to the commitment within Leonard Cheshire to develop, and develop through, service user involvement.

- The evaluation has documented and promoted good practice in service user involvement.
- The effectiveness of the evaluation can only be realised through the response of Leonard Cheshire in developing user involvement through the model, principles and options for practice that have been generated through the process of evaluation.

8.2 Leonard Cheshire response to the Independent Evaluation: Ways Forward

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APPENDIX ONE

DEVELOPING USER INVOLVEMENT IN LEONARD CHESHIRE: AN INDEPENDENT EVALUATION INFORMATION SHEET FOR SERVICE USERS

You are invited to help in the evaluation of the involvement of service users in Leonard Cheshire. Please read the following information sheet and ask for any more information you may need. We will be pleased to answer any questions you may have.

Purposes of the evaluation

We aim to conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity.

To do this we shall

6. explore the effectiveness of current strategies in promoting Leonard Cheshire's commitment to user involvement, including the Disabled People's Forum and SURE, from the viewpoints of the different participants within the organisation;
7. examine the possible barriers to the promotion of user involvement within Leonard Cheshire;
8. consider options and make recommendations for future developments in user involvement in Leonard Cheshire.

What the evaluation involves for participants

You will be interviewed about your views and experiences of user involvement. Interviews will last about 40 minutes. With your permission they will be tape-recorded.

Do I have to do this?

You do not have to take part if you do not want to.

Topics we are interested in

The general topics we hope to talk with you about are: what user involvement means in Leonard Cheshire and how it is organised; what the problems are in developing user involvement and how they can be overcome; and what it offers for users and for Leonard Cheshire.

Feedback to participants

All participants will receive a summary of the final report of the evaluation.

Guarantees for participants

This evaluation is confidential. Participants will not be identified in any reports (verbal or written) or publications from the evaluation. Tape recordings and transcripts will be securely stored and will be destroyed one year after the completion of the evaluation project. You can withdraw from the evaluation at any stage, without question. You can also withdraw your consent for the use of any information you have given in the evaluation report.

For further information

John Swain, Northumbria University, Faculty of Health, Community and Education Studies, Coach Lane Campus, Coach Lane, Newcastle upon Tyne NE7 7XA

Telephone: (0191) 215 6002; Fax: (0191) 215 6193;

Telephone Direct Line: (0191) 215 6191

Email: john.swain@unn.ac.uk

Carole Thirlaway: Carolethirlaway@hotmail.com

Sally French: Sally.french2@btopenworld.com



**DEVELOPING USER INVOLVEMENT IN LEONARD CHESHIRE:
AN INDEPENDENT EVALUATION
CONSENT FORM**

Name of the evaluators: Professor John Swain; Carole Thirlaway; Sally French

I have read the information sheet on the evaluation of user involvement in Leonard Cheshire and agree to participate in a tape-recorded interview.

I understand that the information I provide will be subject to confidentiality and anonymity, that is my name will not be used in any reports or documents and the information I give will be used solely to evaluate the development user involvement in Leonard Cheshire.

I have been told that I can withdraw my agreement at any stage, without giving a reason, and that this would not affect my use of Leonard Cheshire services.

NAME:--{ Print}.....

{Signed}.....

APPENDIX TWO

DEVELOPING USER INVOLVEMENT IN LEONARD CHESHIRE

TOPICS AND QUESTIONS FOR FOCUS GROUPS AND INTERVIEWS WITH SERVICE USERS AND PROVIDERS

This is meant to be a comprehensive list, at this stage, of possible topics and questions that will need to be used flexibly depending on the particular participants and the context. The list will also need to be added to as different issues emerge.

TOPIC ONE: STRUCTURE AND ORGANISATION OF USER INVOLVEMENT

Specific prompt questions:

- How would you define ‘user involvement’ in relation to Leonard Cheshire?
- What types of involvement do users have in Leonard Cheshire at present?
 - In governance (including national, regional, local committee user reps)
 - In policy making
 - In service delivery (including staff and volunteer recruitment and training)
 - In evaluation (including care and operation reviews and annual individual service plan reviews)
 - External to Leonard Cheshire
- How effective are current user involvement activities, procedures and policies? Do service providers do what it says they do in the policy documents? Please give examples.
- What would encourage more service users to be involved in decision-making and service delivery?

TOPIC TWO: PROCESSES OF USER INVOLVEMENT

Specific prompt questions:

- Which service users are being reached and which are hard to reach in terms of involvement in decision-making and service delivery (for instance people with learning difficulties, people with profound and multiple impairments, people with hearing or visual impairments)? What are the barriers to involvement and how can these be rectified?
- In what ways have service users themselves promoted service user involvement in Leonard Cheshire? Please give examples.

- What external pressures have promoted service user involvement in Leonard Cheshire?
- What ways of working/training/events/processes for service providers have helped to develop user involvement?
- What ways of working/training/events/processes for service users have helped to develop user involvement?
- What involvement from people and organisations external to Leonard Cheshire has helped to develop user involvement? Please give examples.

TOPIC THREE: OUTCOMES OF USER INVOLVEMENT

Specific prompt questions:

- What benefits do service users get from involvement (e.g. skills, self esteem, empowerment)? Are there disadvantages?
- To what extent are service users' views taken into account when making-decisions within Leonard Cheshire? Have services changed in response to service users' ideas? Please give examples.
- What benefits does Leonard Cheshire get from user involvement? Are there disadvantages?
- Has user involvement within Leonard Cheshire had outcomes external to Leonard Cheshire (e.g. through publications)? Please give examples.