

**An occupational perspective  
on user involvement  
in mental health day services**

A thesis submitted for the degree of Doctor of Philosophy

*by*

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## **Abstract**

This participatory action research project enabled service users to influence the modernisation of local mental health day services. The modernisation programme was based on principles of social inclusion, and there were limited understandings of how it could be applied locally. Interpretations of policy gave priority to the relocation of services and facilitating individual recovery.

An occupational perspective informed the design, implementation and analysis, emphasising what people chose to do. Critical ethnography informed the role of the researcher. Service user involvement was understood as a democratic process, drawing on direct experience for service development. A forum, established for four years, worked on and supported three research strands, focused on social networking. Service users captured their use of a social lounge using photography in Strand A. In Strand B a checklist was used to investigate social activities. User-led social groups were explored in Strand C through individual interviews. All the findings were systematically analysed and service users were involved in this for Strands A and B.

The findings of this research emphasised the importance of social networking within the day services. Strand A indicated the benefits of a safe space, before getting involved and moving on. The final report from this strand led to ongoing funding being allocated for a safe space. For Strand B many social and recreational activities were identified by service users. Stigma was recognised as an ongoing barrier to sustained inclusion. A poster was designed and displayed locally to share the findings. Themes from Strand C demonstrated that user-led groups required active collaboration with mental health services to survive and thrive.

A final stage of analysis aimed to uncover the details of taking an occupational perspective. The findings indicated that varied occupational forms involved different service users in different ways, enabling more people to participate. Making the functions of the different events explicit was important for negotiating participation. Meanings were expressed in shared and individual reflection as the research unfolded. Understanding and attending to these aspects facilitated meaningful service user involvement in this research, enabling many people to influence the development of the services they received.

## Declaration

This work was generously supported by the local NHS Mental Health Trust, the “Oak Tree Foundation”, Brunel University and the University of Limerick. Elements of the work presented in this thesis have been presented between 2004-8, as detailed below. The local impact of the research and the national presentation in London in 2006 generated three more research projects. Two awards were received to fund Strand C and a third award funded travel and fees for the conference in Northampton in 2006.

### Book chapter

Bryant W (2008) Occupational, social and intrapersonal alienation explored in the community. In McKay EA, Craik C, Lim KH, Richards G (eds) *Advancing Occupational Therapy in Mental Health Practic*. Oxford, Blackwell Publishing.

### Peer reviewed national and international conference presentations

Bryant W, Vacher G, King M (2005) Sustaining partnerships in mental health day services. *Association of Occupational Therapists in Mental Health Annual Conference, Stockport, UK*

Bryant W & Lim KH (2005) Involving mental health service users in evaluation: challenges and realities. *Canadian Association of Occupational Therapists Annual Conference, Vancouver, Canada*

Bryant W & Vacher G (2006) Involving users of mental health day services in research using photography. *College of Occupational Therapists Annual Conference, Cardiff, UK*.

Bryant W (2006) Research in action: using photography to collect qualitative data. *14th Congress of the World Federation of Occupational Therapists, Sydney, Australia*.

Bryant W (2006) Participation, inclusion and occupation in mental health research. *5<sup>th</sup> Occupation UK and Ireland symposium, Northampton, UK*.

Bryant W, Clark J, Higgins P, Pearson R, Tibbs A (2006) Involving day service users in research: investigating social and recreational activities. *Association of Occupational Therapists in Mental Health Annual*

Conference, London, UK

Bryant W, McKay E, Beresford P, Vacher G (2008) *Informing service development through participatory action research with mental health day service users*. Workshop presentation accepted for 8<sup>th</sup> European Congress, Hamburg, Germany.

### **Awards**

Institute of Social Psychiatry Award 2006 - £1000

Elizabeth Casson Trust 2006 - £1000

Vice Chancellor's Travel Prize 2006

### **Invited regional conference presentations**

Bryant W, Clark J, Tibbs A (2007) The social lounge and beyond. *CNWL NHS Foundation Trust Annual Occupational Therapy Conference, keynote speech*

Bryant W, Clark J, Tibbs A (2007) Getting better by going out. *SLAM Mental Health NHS Foundation Trust Annual Occupational Therapy Conference, keynote speech.*

### **Invited local workshop**

Bryant W (2007) Research methods. *For local day services and occupational therapy staff.*

### **Exhibition**

Bryant W, Clark J, Cowburn V, Fletcher R, SP, Tibbs A, Wright M (2006) The social lounge and beyond. *Moving Forward, Brunel University.*

### **Emerging research projects**

Service user perspectives on experiences of rehabilitation (2007): qualitative research project initiated by local occupational therapists in partnership with Brunel University.

Service user-led research group investigating living with psychosis (2007): research project initiated by service users in partnership with Brunel University.

Mental health day service users' evaluation of community social networks and recreational activities (2007): participatory action research project funded by another London Borough and set up in partnership with Brunel University.

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- AE Letter for day services review (C45)**
- AF Core values**
- AG Programme, Social Networks Day 2004**
- AH Flyer for exhibition**
- AJ Timeline**

## List of pseudonyms

These pseudonyms have been created to facilitate a focus on this research. They cover people, groups/organisations and places. It may be possible for people involved to locate themselves in one way or another but it is hoped that this will not distract too much from the research itself. Names indicated by an asterisk \* have not been changed, with permission where required.

People	
Pseudonym	Role
ADAM	<i>Service user: Day Services Forum, Social Networks Days, Strands A and B.</i>
ALAN	<i>Service user: Day Services Forum, Social Networks Days, Strands A, B and C , User Group</i>
ANDREW	<i>Service user: Day Services Forum, Local Implementation Team representative, Social Networks Days, User Group</i>
ELEANOR	<i>Service user: Social Networks Days, Strand A</i>
ANU	<i>Service user: Social Networks Days, Strand A</i>
TONY	<i>Service user: Strand A</i>
ANGELA	<i>Service user: Social Networks Days, Strand B, User Group</i>
DEAN	<i>Service user: Day Services Forum; Social Networks Days, Strand B</i>
GABRIELLE	<i>Service user: Day Services Forum, Social Networks Days, Strand C, User Group</i>
JULIET HELENA CHRISTINE KEVIN BETHAN DEE FIONA EDDIE MALCOLM	<i>Service users: Strand C</i>
	<i>Service user: Day Services Forum, Social Networks Days, User Group</i>

Geraldine*	<i>Day services development manager</i>
VICTORIA	<i>Oak Foundation Director</i>
EMMA	<i>Capital Volunteering co-ordinator</i>
LINDA	<i>Day services manager</i>
CAROLINE	<i>Day services manager</i>
SIAN	<i>Staff: Day Services Forum; Social Networks Days, Strand A</i>
SALLY	<i>Staff: Day Services Forum; Social Networks Days; Strand B</i>
FRAN	<i>Staff: Day Services Forum, Social Networks Days, Strand C</i>
LOU	<i>Service user presenter: Social Networks Day</i>
MANEESHA	<i>Staff (Oak Foundation): Day Services Forum; Social Networks Days; Strand B</i>
KEN	<i>Interviewer for Strand C</i>

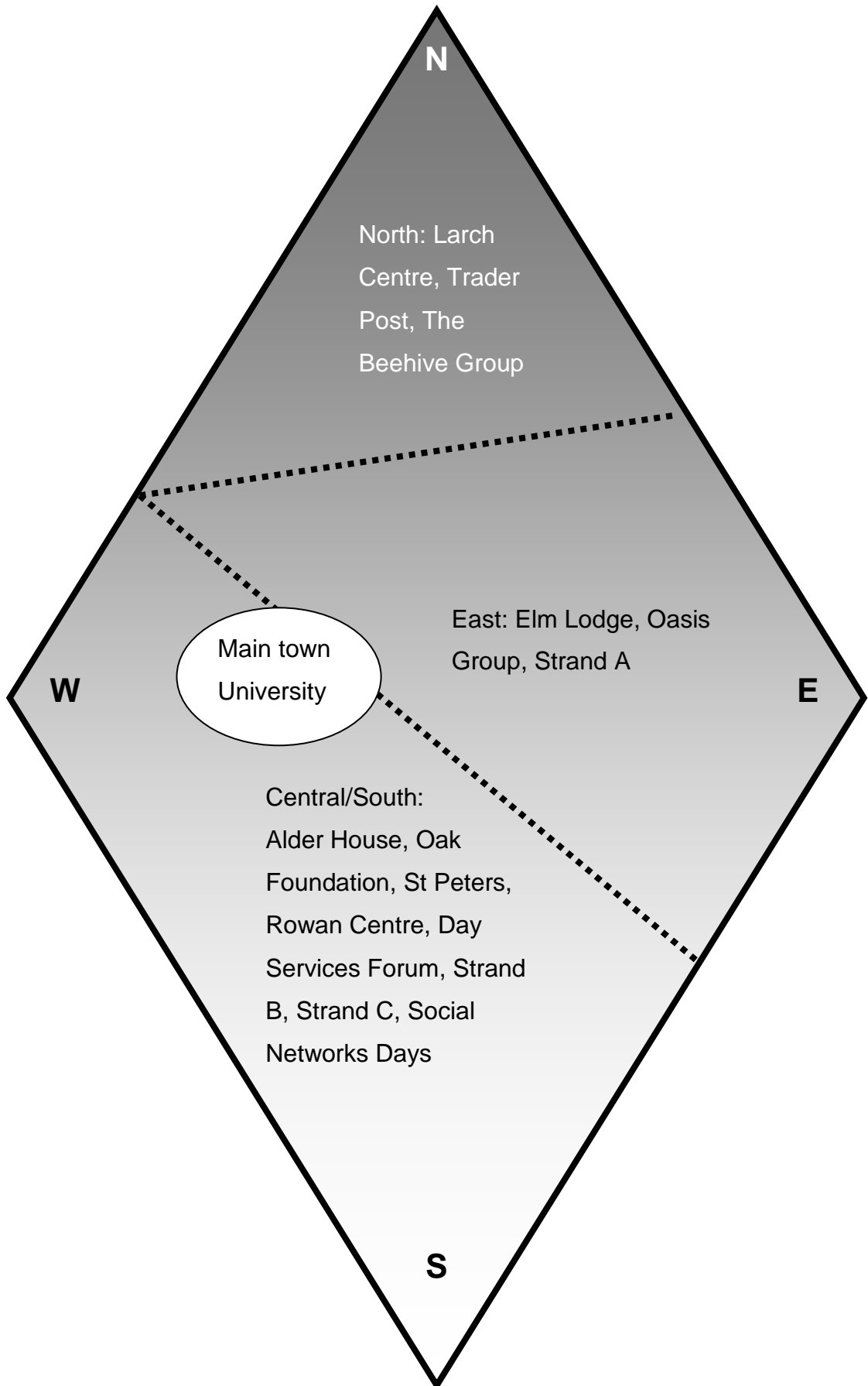
### Groups and organisations

<b>Pseudonym</b>	<b>Role</b>
OAK FOUNDATION	<i>Non-statutory, national mental health organisation providing housing, advice and social support/activities locally.</i>
TRADERS POST	<i>User-led social contact group: see Strand C</i>
THE BEEHIVE GROUP	<i>User-led social contact group: see Strand C</i>
PLANE TREE GROUP	<i>User-led self-help and social contact group: see Strand C</i>
LUMOS WORKSHOP	<i>User-led initiative: see Strand C</i>
OASIS GROUP	<i>For Asian people, based at Mead House, led by Maneesha, Oak Foundation: see Strand B</i>
User Group*	<i>User-led group for advocacy, local consultations and campaigns</i>

Capital volunteering\* *London-wide initiative to promote volunteering as part of social inclusion*

<b>Places</b>	
<b>Pseudonym</b>	<b>Description</b>
OAK FOUNDATION	<i>Base and venue for User Group in main town in Borough. Adjacent to St Peters, venue for second Social Networks Day and part of Strand C. Near to Lumos Workshop.</i>
LUMOS WORKSHOP	<i>Vocational rehabilitation unit, hosted by Oak Foundation, then service user led, then closed. See Strand C</i>
ALDER HOUSE	<i>NHS/Social care resource centre and base for community mental health team, centre of Borough in urban industrial location. Venue for Day Services Forum, first Social Networks Day and Strand B.</i>
ELM LODGE	<i>NHS/Social care resource centre and base for community mental health team, east of Borough in semi-rural location five minutes walk from shops and buses. Venue for Strand A.</i>
LARCH CENTRE	<i>NHS/Social care resource centre and base for community mental health team, north of Borough in urban location, adjacent to shops and transport links. Focus point for part of Strand C. Near to venue for Traders Post group.</i>
ROWAN CENTRE	<i>NHS mental health unit for inpatients, base for Geraldine, Day Services Development manager. Venue for Social Networks Days planning meetings.</i>
ST PETERS	<i>Church and community centre in main town for Borough, venue for second Social Networks Day and self-help group in Strand C</i>

# Map



## **Introduction to Part One**

### **Setting the scene**

This research aimed to involve mental health service users in the modernisation of day services, using participatory action research. An occupational perspective was taken, focusing on what people did and could do in relation to the research topic, design and process. This thesis gives a detailed account of the research and has been divided into three parts, setting the context, focusing on the research itself and finally analysing, discussing and drawing conclusions from the findings.

Part One starts with an analysis of literature and policy relating to service user involvement, mental health day services, social inclusion and social networking. This research required an understanding how mental health day services have evolved as policies have changed, and this is detailed in Chapter Two. An occupational perspective was brought to this research, which is explained in Chapter Three. To facilitate service user involvement, the chosen methodologies were participatory action research and critical ethnography. These methodologies are defined and critically analysed in Chapter Four. This approach was an innovation for research in both mental health day services and occupational therapy. It provided scope for engaging with service users and staff in a creative way. Chapter Five gives specific details of how this was achieved. There were three phases: consultative, active, and evaluative. Collaborative work underpinned each of these phases. The consultative phase involved building partnerships, identifying issues and strategies, and finalising the design of the research. The active phase involved three strands of investigation. Part Two comprises three chapters, one for each of the strands. Following this, Part Three accounts for the findings of the evaluative phase which involved a thorough analysis of all the material gathered. This analysis generated themes in relation to day services (Chapter Nine), the occupational perspective (Chapter Ten) and user involvement (Chapter Eleven). The implications for policy and practice, education and research are discussed in Chapter Twelve.



There are three aspects to the presentation of this work which should be commented on at this stage: the terminology used in relation to mental health, the use of the first person, and the approaches used to the literature at different stages. At the time this research was conducted, there was an emerging body of literature, for example Tew (2005), emphasising the importance of the social model of disability in relation to mental health. The participatory approaches used in this research, and the focus on social networks, indicated a basis in this model, rather than more clinically-oriented alternatives. For that reason, the term 'mental health problems' has been used rather than mental illness or specific diagnoses. 'Long-term' has been preferred to 'chronic' when indicating the duration. Further discussion of the use of the term 'service user' will be found on page 22. In line with this focus on people as complex, active agents in the research, it seemed to make sense to indicate my presence in the research by use of the first person. Finally, the complex, active engagement with the literature meant that, for each subject investigated, specific decisions had to be made about the focus of the search for evidence and the boundaries placed on the search. Thus, there are a number of accounts of how the literature was approached to highlight the decisions made for each subject.

This research seemed to be full of tempting outcomes at times, like a curator's exhibition (Madison 2005). But the outcomes, like an exhibition, are temporary and transient. The lingering shadows from the research are the thoughts we are left with after the show, when we return to our ordinary lives. In this light, Parts One and Two may be regarded as being like attending an exhibition or a play, with Part Three the reflection afterwards, where the show is considered in relation to other sources and experiences. I brought an interest in culture in every sense to this research, including shows and exhibitions. As an occupational therapist I was interested in the performance, the actions taking place, alongside the words people said. This could be considered to some extent in dramatic

terms – a performance at a particular time in a particular place. But I was also interested in changing the set, shifting the props, and creating new juxtapositions of familiar things. New experiences with familiar material were generated by using, understanding and exploring the opportunities and resources of the setting. I was familiar with day services and working with mental health service users from my own professional experience. As the research progressed I also considered more deeply what I personally believed about surviving life challenges, wondering about the balance between support from others and an internal drive to keep going.

One interesting juxtaposition was bringing my activist tendencies into the mental health setting. In the period leading up to the research I had resigned from commitments arising from these tendencies, knowing it would be impossible to do both. It took some time for me to realise that I had created another opportunity for myself, by initiating a participatory action research project. At the time this had seemed the only sensible way of doing research in the setting, yet it turned out to be as much about me as the setting, for I had welcomed the opportunity to work there, with all its complexities and uncertainties. The important thing for me, in terms of conducting the research, was that there were people within the setting who cared about what happened, and that they could probably find a way of working with me. I believed it was possible to work in good humour with anyone, as long as honesty, fairness and commitment were valued by all involved.

I also knew it was important to give people the benefit of the doubt, which in the mental health setting seemed to be the basis of tolerance and acceptance, even if it could be seen to be a risky position at times. My experience of working in institutions and the community had shown me that there were many ways in which people were made more vulnerable from their experience of intolerance and rejection. Being accepting meant focusing on how to make it possible to work with people in a way which was meaningful to me and to them. This required action to overcome the

barriers to becoming involved so that beliefs, hopes and ideas could be shared.

This thesis is concerned with possibilities and realities: new combinations of familiar ideas. The findings indicated that if attention is given to nature of participation, and in particular the occupations which are associated with participation, then it is possible to involve service users in service development in a democratic way. However, this requires collective effort. One challenge for day services in particular is how to ensure that the collective resource of service users, supporting and responding to each other, is not lost in the modernisation project which has emphasised an individual journey to recovery and social inclusion (Office of the Deputy Prime Minister 2004, Lingwood 2005a). For economic, cultural and political reasons the modernisation project, like many others, has emphasised products and outcomes. The essence of this research has been to engage in a process and not to make assumptions about the outcomes, particularly as products.

# **Chapter One**

## **The context for the research**

### **Overview**

There are several main topics reviewed in this chapter. This research was designed and implemented with a central aim of involving service users, and specific practical aspects are discussed in subsequent chapters. Theories and associated assumptions underpinning the idea of user involvement are discussed here. The service users involved in this research were all using mental health day services, the second topic in this chapter. These services had been configured over time in response to changing beliefs about mental health and ill health. The situation during the time of the research is reviewed and discussed here, followed by a history of day services in Chapter Two. Shortly after the research began, the drive for social inclusion of people with mental health problems became central to service review and development. The concepts of social exclusion and inclusion, social networking and the implications for the day services form the final topics of this chapter. Before these topics are addressed, some general comments about sources of information are given.

### **Accessing the literature**

Relevant literature has been reviewed throughout this research. This was in keeping with the conventions of qualitative research, which is to use literature as a point of reference for grounding, validating and questioning issues raised by the research (Silverman 2000). Actively searching for published studies involved the use of online databases and e-journals, most recently using the University facility, 'Find It', to simultaneously search multiple databases. This process involved targeting health, social care and policy databases, and following up further references from useful papers and key authors. The chosen key words endeavoured to reflect different terminologies used internationally, especially in relation to mental health service provision, for example 'partial hospitalization' in

North American literature. Day services are often provided by a multi-disciplinary team, and so the professional orientation of journals was not an issue. However, hand searching of journals was largely restricted to publications relating to occupational therapy and mental health as they were published.

Books and policy documents have also been used extensively to inform this research as it unfolded. The national media, in particular '*The Guardian*', was used as a source of information about new developments and emerging opinion. In addition to national policy, local strategic documents were used to explore how changes impacted on service provision. The topic of vocational rehabilitation and specific issues concerned with returning to work were excluded because of the chosen focus on social networks.

Because of the central importance of user involvement in this research, particular attention was given to studies which involved service users. Direct experience of mental health services is far more rich and complex than can ever be appreciated from the outside (Beresford 2005a). In evaluating all sources, origins of the evidence and its strength were carefully considered. This involved critical appraisal of usefulness, meaningfulness and authenticity (Lincoln and Guba 2000). This research was concerned with social and occupational perspectives on situations which were in constant flux, rather than a clinical trial, so an inclusive approach was taken for sources of information, knowledge and evidence (Rose et al 2006). The literature reviewed for this chapter fell into two main categories: firstly, key texts detailing the main concepts; and secondly, policy and research articles and texts from 1997 onwards. This date marked the change in UK government and signalled a shift in policy in health and social care.

## **User involvement**

Involving service users in service evaluation and development evolved from being desirable to being legally required under the Health and Social Care Act 2001 (Hui and Stickley 2007). Croft and Beresford (1992) placed user involvement in the context of a growth of interest in participatory approaches, emerging from the belief that in order to make collective decisions which are helpful and relevant to people's lives, it is important to involve those people in the decision-making process (Croft and Beresford 1992). Involvement has thus been historically associated with democracy. To participate in a democratic process, it is necessary to meet criteria for inclusion, usually defined in political terms as citizenship (Lister 2003, Dwyer 2004). For this research, it was also necessary to define who was eligible to participate and who was not. Defining eligibility in this context reflected beliefs and assumptions about mental health problems and citizenship, which in turn influenced the terminology used.

The term 'user involvement' is used throughout this thesis. In this context it has been used to indicate the importance of the participation of people with mental health problems. The use of the term 'user' is established in the UK, in contrast to preferred terms elsewhere, such as consumer (USA), client (Canada) or patient, traditionally associated with hospital-based services (Pilgrim and Rogers 1999). Service users such as Campbell (2006) have stated a preference for the term 'survivor', seeing survival in terms of surviving the mental health system, rather than the symptoms. For much of this research, the word 'people' was preferred above all else. However, the term 'service user' seemed a more specific and accurate term to use for this research, with its emphasis on service evaluation and development (Beresford 2005b).

Involving users in service evaluation and development was identified as a means of implementing the National Service Framework for Mental Health (Department of Health 1999). In this document, user involvement was not clearly defined, possibly because of its roots in both

consumerism and activism (Croft and Beresford 1992). Consumerism has driven an agenda for effectiveness and quality, with service users seen as consumers of products and services. Activism has emphasised the importance of service users' life experiences, not just as consumers of services (Beresford 2002). How much influence and to what extent services listen has depended on how service users are perceived (Beresford 2005a). A consumerist perspective emphasises satisfaction with services or products, which are controlled and determined by service providers. Service users seeking to reshape the services they have experienced are working as activists (Beresford 2002).

Perceptions of service users have reflected ideas and beliefs about mental health, mental health problems and capacity for participation (Sayce 2000, Hui and Stickley 2007). In their discourse analysis of forty-two publications relating to service user involvement, Hui and Stickley (2007) found diverse perceptions of service users in relation to user involvement. In UK government publications, there has been an emphasis on partnerships, whereas service users' writings have offered a much more varied interpretation of user involvement, reflecting different beliefs and experiences. In government publications, the word 'people' was only used in publications aimed directly at the public. This raises the question as to whether it is important to think of service users as *people*, in relation to involvement. Thinking of service users as people getting involved could give greater scope for recognising varied interpretations of what involvement means, rather than expecting a unified response from a group of service users. After all, service users are not a group with clearly defined characteristics, other than their history of service use, and even that will be unique to each individual (Stickley 2006).

Underlying models have been identified for interpreting the experience of mental ill-health (Sayce 2000). For example, if it is believed that a person's problems are caused by abnormal brain function, then responses are often centred on correcting brain function, separating it out

as a key issue. These beliefs and responses are influenced by prevailing political and professional discourses (Foucault 2001, Sayce 2000). Currently, in addition to the notion of brain disease, service users are viewed in many ways. They are viewed as people whose personal emotional growth has been disrupted or disturbed, people who are detained unfairly in an unjust and oppressive society and/or people whose civil rights are constantly under threat because of the stigma of mental illness (Sayce 2000). The private sector, which has to regard service users as consumers, is not well-developed (Pilgrim 2005a). For staff working in mental health services, these different views are often used depending on the way the service user relates to services. If the service user as consumer does not take the opportunities apparently available, then other explanations are brought to bear on their situation (Sayce 2000). Being open to different understandings of mental health problems is important in user involvement: Barnes and Bowl (2001) argue that it is essential to articulate the diverse experiences of mental health problems, in combination with associated stigma and experience of discrimination, to challenge assumptions.

In this research, participation was emphasised and so service users were perceived as citizens, being offered equal opportunities to participate based on their experience of day services. This also arose from the expectation that they would make choices about how to be involved. Thus they were regarded as potentially autonomous, seeking the information they needed and balancing the requirements of the research with awareness of their own capacities, in order to make decisions about the research and their contribution. Dwyer (2004) linked this notion of citizenship with the work of Titmuss, where:

*“citizens would generally behave in a responsible manner and look to enhance their own lives, and the lives of fellow members of their national community.” (page 52)*

In this sense, their ‘national community’ was the day services, although being community based, this extended to the wider community in some ways. Citizenship has been associated with an assumption that people



will behave rationally (Barry 1989). Mental health problems impact on behaviour and many rights are denied to people who are actively threatening to harm their own lives or those of others, a reason frequently used as a reason by society to deny citizenship (Foucault 2001). However, as Lister (2003) pointed out, in the context of human lives, excluding people has to be justified and reviewed, and cannot be done without careful consideration of individual circumstances. Excluding people from citizenship undermines the democratic process. Brennan and Lomasky (1993) examined voter behaviour and proposed that it was primarily driven by a commitment to the greater good rather than self-interest, especially as in a representative democracy, single votes had so little impact on final decisions. Thus, for this research, involving service users to improve services for themselves and others was a more significant consideration above their capacity to act consistently as citizens in terms of rational behaviour (Barry 1989).

Involving service users, then, is shaped by perceptions of who they are and what can be achieved by involving them. Beresford (2002) emphasised the importance of honesty when considering why service users should be involved, especially whether involvement is taking place within a consumerist or democratic framework. A consumerist orientation to service user involvement is focused on issues of (customer) satisfaction, giving information and seeking user responses to an agenda set by the service provider (Hickey and Kipping 1998, Beresford 2002). A democratic orientation is characterised by service users taking an active role in decisions, so their involvement extends beyond partnership to taking control of the process (Hickey and Kipping 1998, Beresford 2002). These different understandings of user involvement have created tensions around the word 'involvement', (Campbell 2006, Stickley 2006). Stickley (2006) argued that service user involvement should be contrasted with 'emancipatory action' to highlight the assumptions operating within dominant systems such as mental health services. He believed that 'emancipatory action' should take place outside the mental

health services to give the best opportunity for success but recognised the difficulties, conceding that:

*“Undoubtedly, one key to successful emancipatory action is collaboration with sympathetic and enthusiastic statutory workers who recognise the need for service users to remain independent from the statutory system” (page 576).*

This issue, of being inside or outside the system, was important in the final analysis of the findings of this research, and will be explored further in Part Three.

Critiques of user involvement have often rested on issues of tokenism and representativeness (Stickley 2006). These issues relate directly to the democratic aspects of user involvement (Beresford 2002). It is often assumed that user involvement will mirror the model of democracy which has dominated public life, that is, representative or indirect democracy (Croft and Beresford 1992, Held 2003). For example, one of the people involved in this research, Andrew, acted as a service user representative on the Local Implementation Group, as set out in the local user involvement policy (Vickers 2007). In an example of representative democracy, Andrew was expected to represent service user experiences well beyond his own direct experience, and to some extent continued this role in relation to the research, acting as an advocate for it at key points. However, representative democracies can be undermined by people acting in self-interest, seeking power and seeking to resist change to retain power (Dunn 2005). Deliberative democracy appears to be a response to this possibility, incorporating ongoing dialogue in varying ways, emphasising flexibility and adaptability in decision making (Held 2003, Dunn 2005). The task of managing access to and availability of information, promoting critical judgement and monitoring decision-making, are central to this. Thus for this research, information, dialogue and reflection on decisions were very important and demanded very specific actions, emphasising the importance of participation for all.

Participatory or direct democracy has been specifically linked with user involvement, responding to issues of tokenism and representativeness (Beresford 2005a). Participation is all too often seen as an outcome rather than a process (Barnes and Bowl 2001), yet the process is where user involvement really begins. If everyone is given an opportunity to get involved, then diverse views and experiences are more likely to be incorporated (Beresford 1999a). This requires a focus on service users' experiences, rather than the services they receive, and consideration of the reasons for those experiences before generating solutions in a cycle of collective action and reflection (Beresford 1999a, Fleming and Ward 1999, Beresford 2005a, Tew 2005). Key to this is not only supporting people in accessing opportunities to participate and in their role as participants (Croft and Beresford 1992), but also questioning how power is viewed by participants and leaders. There is a contrast between power as limited resource to be shared, and thus exchanged between people, and power as a limitless resource (Hui and Stickley 2007). In participatory approaches to user involvement, power is usually regarded as a limitless resource, to be generated within each participant (Croft and Beresford 1992, Hui and Stickley 2007).

Overcoming the barriers to involvement requires a shift in perspective on equality – valuing everyone's presence and contribution without prejudice, and fostering a sense of ownership by sharing control of the process (Beresford and Wilson 1998, Beresford 2005a). Beresford and Wilson (1998) suggested that redefining the location of expertise is important as a first step for involving users, challenging the established status of professionals or independent experts. Boardman (2005) claims that this has been successful to some extent, but has raised new issues, especially for staff who are required to balance being responsive to user perspectives but also to be responsible for controlling limited resources. An issue for this research was consideration of how much scope existed for service users or staff to influence decisions. Pilgrim (2005b) suggested that user involvement has an inbuilt assumption that mental

health services will continue to exist per se, whereas the user movement itself would question that existence. In the wider context for this research day services were under question, although in response to economic considerations and the social inclusion agenda rather than the user movement directly.

## **Day services**

For this research, the local mental health day services were the focus, and thus defined understandings of what day services were. These understandings were also informed by direct experience of working in day services elsewhere and insights from others such as service users, staff and students. The service users involved in this research had experienced a range of day services over the years. Some remembered a day hospital which preceded the day services linked with three resource centres, Alder House, Elm Lodge and the Larch Centre. Others had experience of a social services day centre, which had also been replaced by the resource centres. The current services, places and people are in a list of pseudonyms on page 12.

In essence, service users generally had access to a key worker with whom they would agree a programme to structure the week and work towards overall goals associated with recovery. This individualised programme would often involve attending group sessions at the resource centres. Some aspects of the programme would be short-term and aimed at specific goals, for example relating to practical or social skills. Other aspects would be long-term and aimed at sustaining recovery and preventing relapse. Contact between the service user and their key worker would be concerned with reviewing progress. The group sessions would bring the service users in contact with each other, sometimes giving opportunities to develop friendships established elsewhere, for example in the acute inpatient unit, the Rowan Centre.

The roles of mental health day services were categorised by Muijen (1993) into treatment, monitoring and support. Treatment has been more commonly associated with health care settings, and support with social care. These different categories are reflected in the spread of day services between different service providers, within the statutory and non-statutory sectors. Locally, Alder House was funded by health, Elm Lodge by social services and the Larch Centre jointly by both health and social services. A further resource centre was funded and organised by The Oak Foundation, a voluntary organisation. These services were all considered in a review of services undertaken in 2002, which is discussed in more detail below (McKay et al 2003, Bryant et al 2004, Bryant et al 2005).

To clearly define day services and distinguish between those services funded by health and those by social care, Catty and colleagues undertook a systematic review followed by two mixed method studies (Catty et al 2002, Catty et al 2005a, Catty et al 2005b). The systematic review found no strong evidence from which to draw conclusions, but being a Cochrane review was hampered by the strict inclusion criteria, including only randomised controlled trials. As a result, the distinction between day treatment in hospitals and day centres appeared to be based on definitions taken from studies undertaken in the 1980s, prior to the widespread developments in community mental health care (Catty et al 2005a, 2005b). This seemed to be due to the lack of studies considered suitable for the Cochrane review process. It could also be because many of the initiatives in day services involved occupational therapists and nurses in partnership with voluntary organisations. None of these groups have had long-established profiles in formal mental health research or the resources to conduct large clinical trials. The history of day services in Chapter Two gives more detail on how professional roles have evolved over time.

However, Catty et al (2005b) did observe that day treatment and day centres had distinct functions, with social-services-funded day centres primarily engaging with people with long-term needs, and day hospitals offering treatment for more acute problems. In their study, day centres in the area worked on the basis of service users choosing their level of participation, whereas the two day hospitals offered group-based treatment and monitoring of medical treatment. This distinction reflected the policy influencing day service development, discussed further in Chapter Two. In the 1990s, day services were seen as providing a bridge between institutional care and community care, ensuring that people were supported as they made the transition between the shelter of the institution and the seemingly harsh, unprotected reality of community life (Muijen 1993, Brewer et al 1994, Bryant 1995). More recently, day services have been less about resettlement from institutional life and more about support after admission to an acute unit and sustained support for people with ongoing problems.

The other study by Catty et al (2005a) highlighted the value service users placed on the opportunities to make social contact and supportive relationships with other service users in the day centre setting. These findings were similar to those found in the 2002 review (McKay et al 2003, Bryant et al 2004, Bryant et al 2005). This review built on the findings of an earlier project (Payne et al 2000). The process of local research and review was prompted by the National Service Framework for Mental Health (Department of Health 1999). The earlier project was designed to identify to what extent the local mental health services matched the requirements of the framework from service users' and carers' perspectives (Payne et al 2000). Forty-five people took part in five focus groups, sharing views on all aspects of mental health services. In relation to day and accommodation services, the researchers recommended further specific reviews.

This took place in 2002 (McKay et al 2003, Bryant et al 2004, Bryant et al 2005), and for the day services, seventy-nine people were consulted in seven focus groups, including thirty-nine service users in four groups designated for people attending each of the resource centres and the day services provided by the Oak Foundation. The findings highlighted the importance of day services for users and carers: providing a reason to get up; structure to the day; opportunities for contact with other service users; and meaningful occupation. There were difficulties arising from the wide range of needs catered for, generating the recommendation that future developments needed to consider the core function of day services. Staffing problems generated tensions between crisis management and crisis prevention, with service users believing that it was necessary at times to reach crisis point before getting help (McKay et al 2003, Bryant et al 2005).

Data from the four service user focus groups were subject to further analysis to consider the implications for occupational therapy. This process indicated the significance of the concept of occupational alienation (Bryant et al 2004). Occupational alienation is a term used to describe the situation where people are engaged in occupations which they find meaningless, contributing to boredom, despair and apathy (Wilcock 1998a, Bryant et al 2004) and is discussed further in Chapter Three, on the occupational perspective, and elsewhere (Bryant 2008). In the 2002 study, occupational alienation was indicated by service users feeling estranged from what was offered by staff at day services, not being consulted about their progress and future, and the day services being segregated from the community. It was suggested that this highlighted the need for services to create a sense of safety and belonging in different ways, while also engaging in dialogues with service users about what they found meaningful (Bryant et al 2004).

The findings had a significant influence on the research detailed in this thesis, for several reasons including the fact that I was employed as a

research assistant on the team. Service users had already been invited to participate in research, albeit in a consultative one-off opportunity. Their views indicated that they valued day services but encountered difficulties which impacted on their recovery and mental health. These difficulties were in part generated by the way day services were configured and the components which were given priority. The recommendations from the 2002 review were initially used to shape the agenda of the Day Services Forum, a starting point for the participatory action in this research (see Chapter Five). Finally, greater understanding of the concept of occupational alienation informed the design and implementation of the Forum, Social Networks Days and the strands of this research.

The local strategy for day services (Pring and Vacher 2004, page 2) noted that day services aimed to “*support and maintain people in the community, preventing admission, social isolation and exclusion.*” The emphasis on social isolation and exclusion reflected the core values agreed by the Day Services Forum in 2003, which shifted focus to employment, volunteering and social networking, while also retaining the long established provision of therapy. These themes recurred in documents published locally and nationally to promote and support social inclusion as the primary focus for day services (Office of the Deputy Prime Minister 2004, Bates 2005, Lingwood 2005a, 2005b, Bates et al 2006, Murkin 2006, Bates 2007). In an internal report on a local staff away day in 2005, evaluation of the day indicated that while staff participating welcomed the renewed focus on service users and a flexible approach, there was reservation about the emphasis on social inclusion, especially in relation to employment.

This reservation could be linked to the inherent tension within the modernisation agenda between working for the best outcomes for all, and recognising the very specific but diverse needs of long-term service users. Bates (2005, 2007, Bates et al 2006) repeatedly highlighted this tension, using a model of traffic lights to suggest different aspects of day



services. Unfortunately, giving the status of a red light to centre-based, designated services reinforced the negative view of day services voiced elsewhere (Office of the Deputy Prime Minister 2004, Spencer 2004, Lingwood 2005a, Lingwood 2005b). Spencer (2004) wrote:

*“modern thinking is that by getting ‘locked in buildings’, mental health services can actually work against social inclusion and perpetuate the stigma associated with mental illness.”*  
([www.nhs.uk/nhsmagazine/archive/oct04/feat13.asp](http://www.nhs.uk/nhsmagazine/archive/oct04/feat13.asp))

Ironically day services had been set up originally to avoid people getting ‘locked in buildings’ and there were efforts to emphasise the need to consider service users on an individual basis (Bates 2005, 2007), retaining specific services in specific places for those who needed them. Indeed, Bates et al (2006) believed that some aspects of day services would incorporate every colour of the traffic lights. Locally, an example of this was the Out and About group, which worked in a flexible way, sometimes being centre-based, sometimes meeting in mainstream venues and building on service users’ personal experience and knowledge of accessing these venues independently.

Modernising day services involved a focus on how staff used their time (Office of the Deputy Prime Minister 2004, Bates et al 2006), encouraging them to engage with service user priorities and realigning their work to fit the principles of the recovery model (Repper and Perkins 2003, Lingwood 2005a). This required consideration of community participation, social networks, employment, education and training, physical health, mental well-being and independent living (Taylor 2007). What is not clear is to what extent these issues were *not* being engaged with prior to the modernisation project. It seems possible that day services being located in specific buildings has overshadowed work for individual recovery, especially with the apparent predominance of collective or group-based approaches to the social, occupational and psychological needs of service users. Yet it was not clear that this question had been asked, for the idea of social inclusion appeared to be such a significant point of reference that all day services were expected to be reconfigured in

relation to it. Yet problems arose (Bates 2005), and day services buildings were a target for economic reasons (www.cfps.org.uk 2008, www.keepournhspublic.com 2008). Why was it so difficult to promote social inclusion? An understanding of the theories and beliefs behind social inclusion was essential, yet not well accounted for in the mental health literature (Morgan et al 2007).

### **Social exclusion and inclusion**

In relation to mental ill-health, a range of social perspectives had been identified (Tew 2005), with a common theme of highlighting the importance of society and social life. Within this range, some perspectives have been established for many years, such as recognising the interplay between family life and mental ill health (Tew 2005). A key influence is the social model of disability, which has ascribed many of the difficulties faced by disabled people to environmental factors rather than limitations arising from body impairments. The environment in this sense includes social barriers such as attitudes, as well as physical barriers (Oliver 1983). Recognising and challenging these barriers has been part of the social inclusion agenda (Office of the Deputy Prime Minister 2004, Lingwood 2005a, Thornicroft 2006).

However, there has been an equally well-established and strong agenda in relation to mental health problems which has sought to limit the social life of service users, in relation to risk management and public safety (Beresford 2005a). Thus mental health policies pull in two directions, one seeking to increase social inclusion and one to actively socially exclude people perceived as a risk (Beresford 2005a). Policies in relation to the modernisation of mental health day services have emphasised social inclusion and largely ignored risk management and public safety (Office of the Deputy Prime Minister 2004). It is possible that because day services do not have a role in detaining people under the Mental Health Act, this aspect of mental health service provision is not thought to be relevant. However, day service users may well have experienced being

detained under the Mental Health Act, and they shared a common experience of prejudice arising from public perceptions of the link between mental health problems and violence (Thornicroft 2006).

Politically, the social inclusion agenda was concerned with everyone potentially excluded, not just mental health service users. The Social Exclusion Unit was established in the UK in 1997, following a change of government. It was based on the belief that an integrated and co-ordinated approach to social exclusion was required to overcome rising inequalities in society. Aiming to focus government initiatives on the promotion of social inclusion, the Social Exclusion Unit brought together cross-departmental teams (Byrne 2005). This agenda was central to government policy: in a speech in 2001, the Prime Minister stated:

*“As a nation, we are wasting too much of the talents of too many of the people. The mission of any second term must be this: to break down the barriers that hold people back, to create real upward mobility, a society that is open and genuinely based on merit and the equal worth of all.”*

*(Blair 2001a, <http://www.number10.gov.uk/output/Page1579.asp>)*

The focus, on creating opportunities through social reform for people to reach their potential, was based on the understanding that they would take up these opportunities as responsible citizens. Thus their right to inclusion in society was dependent on responsible behaviour, characteristic of the ‘Third Way’ political movement (Dwyer 2004, Byrne 2005, Whiteford 2005). From this perspective, the ‘Enabling State’ facilitates opportunities for people to be socially included as productive members of society, in return for their co-operation with the process (Dwyer 2004, Whiteford 2003, Whiteford 2005).

*“Two themes run through all of this agenda: opportunity and responsibility. Both are about people, their individual development and potential; giving them the chance to develop their potential; insisting on their duty to make the most of the chance they get.”*

*(Blair 2001b, <http://www.number10.gov.uk/output/Page1579.asp>)*

Not fulfilling individual potential was characterised by social exclusion, caused by a number of reasons (Office of the Deputy Prime Minister 2006):

*“Social exclusion happens when people or places suffer from a series of problems such as unemployment, discrimination, poor skills, low incomes, poor housing, high crime, ill health and family breakdown. When such problems combine they can create a vicious cycle.”*

*(<http://archive.cabinetoffice.gov.uk/seu/pageac0b.html?id=96&pld=27&url=page.asp?id=213>)*

Productivity was often limited to paid employment, reflecting a particular understanding of social inclusion, the ‘social integrationist discourse’ (Levitas 1998). In this understanding, people become included via paid employment, generating wealth which then enables them to be included in other aspects of social life. Other understandings of social inclusion have been concerned with citizenship and occupational justice, valuing all types of work, paid and unpaid (Levitas 1998, Townsend and Wilcock 2004). Another perspective puts the blame on those who are socially excluded, for their failure to meet their responsibilities of being a productive member of society (Levitas 1998).

Social exclusion as a concept emerged from the work of Lenoir in the 1970s (Curran et al 2007, Morgan et al 2007), which identified people marginalised by society and who did not receive effective state help. In the UK in the 1980s, there was a shift from debate about poverty to social exclusion (Byrne 2005). It was believed that transforming the socially excluded into productive members of society would benefit all, creating wealth (Barry and Hallett 1998). However, Byrne (2005) claimed that a ‘weak’ sense of social exclusion shaped policy in the UK. In this sense, there was a focus on transforming the individual rather than the context, to overcome exclusion. Hence in mental health policy there has been tension between the two visions of social inclusion: firstly, with service users included through their own efforts to maximise their own productivity; and secondly, with society becoming more tolerant and including service users because of their potential to be productive. Locally, the first vision generated government-funded projects to create opportunities for individuals to return to paid employment or take up volunteering (Office of the Deputy Prime Minister 2004). The second

vision was less clearly supported by government funding, but generated critical responses to the first, raising questions about how possible it was in practice for people with mental health problems to take up the opportunities created by reform (Morgan et al 2007).

For example, Morgan et al (2007) suggested that no consideration was being given to why people deliberately socially excluded themselves, which in the context of mental health could be for multiple reasons. Thornicroft (2006) emphasised that where possible, people made a choice about whether to disclose their mental health problems. For some, their way of doing things prevented them from making this choice, with obvious and visible differences such as the symptoms caused by the side effects of drugs, exposing them to prejudiced and even violent responses from others. Their way of doing things, their behaviour, or occupational engagement and performance, is influenced by multiple factors (Repper and Perkins 2003, Townsend and Polatyko 2007) and can be indicated in the difficulties encountered by mental health service users in securing meaningful, well-paid, permanent employment with a sympathetic employer (Byrne 2005, Thornicroft 2006).

So, in relation to mental health, the concept of social exclusion and social inclusion is complex and problematic (Beresford 2005a, Curran et al 2007, Morgan et al 2007). In the literature there has been confusion around the issue of the right to be socially included as a citizen, and the requirement to act as a responsible and productive citizen in order to gain that right (Curran et al 2007). This is a particularly sensitive issue for mental health service users. The Social Exclusion Unit report on social inclusion and mental health (Office of the Deputy Prime Minister 2004) recognised that there were many ways for day services to promote social inclusion, but, reflecting the current political agenda, emphasised individual pathways to productivity through employment and volunteering. This may have reflected one of the two consultation exercises which preceded the report, which emphasised paid employment. The other

considered access to mainstream services, influencing recommendations about social networking as a focus for day services (Office of the Deputy Prime Minister 2003).

### **Social networking**

The incorporation of social networking in the social exclusion debate signalled an acknowledgement of social perspectives (Tew 2005) and also created a particular focus on place, with significant consequences for mental health day services. Social contact has been viewed as an important preventative factor in mental health as well as a way of promoting recovery (Bryant 1995, Gale and Grove 2005). Repper and Perkins (2003) highlighted the benefits of relationships with people who have a caring role, people with a shared experience and reciprocal relationships. The multi-faceted benefits of social life affect both individuals and communities. Rogers and Pilgrim (2003) also suggested that one outcome of social networking is improved use of services by service users.

Social networking has been analysed as a complex phenomenon, considering first the dynamic of networking and then its social aspect (Capra 2002). Networking in living organisms, such as social networks, has been perceived as a process of continual renewal – structures change slowly in a process of development, but the network is in a constant state of change. In terms of social networks, Capra sees the constant change being driven by human action, which is constrained and/or encouraged by existing power structures. However, this is not the whole story, for complexity theory is fundamentally non-linear. There is another dimension, of personal meaning, which is equally significant (Capra 2002).

Thus it is not possible to locate a person in a social network: it is something that they, by their own action inspired by a sense of meaning and purpose, create for themselves. Capra (2002) emphasises the difficulty in detecting networks from structures designed to promote or

regulate them. Because networks are constantly renewing themselves, associated structures are only an indication of their existence. The *existence* of social networks is only half of the phenomenon, which has to exist alongside the question of whether they are *happening* or renewing or alive, from the service users' perspective. Repper and Perkins (2003) show some recognition of this issue from a practical perspective in their reference to the need to support the maintenance of relationships, not just for the individual service user but for the others in their networks. People need to be supported in this role, which in practical terms might mean education and information sharing. This would help understanding of the meaning of experiences which arise from having a mental health problem.

Capra (2002) suggests that social networks continually renew themselves through a ongoing dialogue about shared meanings, shared knowledge, ground rules and identity. The boundary of the network is similarly negotiated on an ongoing basis. This offers opportunities to people with mental health problems – there is always the possibility of access as this can be negotiated. But this depends on whether the perceived purpose of the network is resonant with the individual's own ideas or, more significantly, if the individual believes it is possible to negotiate with other members of the network over whether they can be included. Perceiving the ground rules of the network may be particularly problematic, as these rules are often tacit (Capra 2002).

Social networking has been seen as an indicator of social capital (Field 2003, Morgan et al 2007). This idea has formed the basis for assessing the social health of communities and societies, generating qualitative and quantitative measures. Social capital encompasses both possession of social resources and access to them at individual and community level (Rogers and Pilgrim 2003). Where social capital is high, people are thought to be more resilient, able to withstand challenges and recover from setbacks more quickly (Adger 2000). Hall (1999) suggested that the

resilience of social capital in the UK was associated with government policy, particularly in relation to education. From Europe, Bourdieu conceived of social capital as an explanation for inequalities in society, comparing those with access to high levels of shared social resources and those without, emphasising membership and elitism (Field 2003). In contrast, from the United States, Putnam argued that individuals and communities possessing high levels of social capital are healthier and more productive, overcoming factors which undermine social capital such as pressure on time, living in urban areas and television watching (Field 2003). Almedom (2005) analysed Putnam's concepts of bonding and bridging social capital in relation to mental health. Bonding has been associated with social cohesion, creating social networks, whereas bridging resonates with the concept of day services in the 'bridge builder' role, focusing on how social networks are used to access community and collective resources (Office of Deputy Prime Minister 2004, Almedom 2005, Morgan et al 2007). However, Almedom places the bonding type of social capital at micro level, which might explain some of the difficulties in conceptualising social networks as a means of fostering mental health from an organisational perspective. However, one interesting idea associated with social capital is that bonding enables people to survive, and bridging enables people to develop (Almedom 2005). This mirrors complexity theory with its parallel processes of sustaining and developing life (Capra 2002). Favouring the development of people over and above their survival, for example by giving priority to employment initiatives within day services, could have a negative impact on service users.

Webber (2005) pointed out that close, cohesive communities, with a high priority placed on bonding social capital, tend to be less tolerant of diversity. In order to raise bridging social capital, tolerance of diversity needs to be high. Webber proposed that social capital can provide a more sophisticated understanding of social processes which contribute to, sustain or are a consequence of mental health problems. He emphasised that Bourdieu's concept of social capital, rather than Putnam,



could be helpful in this respect (Webber 2005). Putnam's concept has been strongly associated with economics and productivity, whereas Bourdieu recognised power relations, hierarchies and status (Field 2003). From this perspective, the exchange of resources and information is extremely important to sustain social capital through networks. Webber (2005) emphasised the absence of reciprocal relationships in statutory mental health service settings. One mental health setting where it has been possible for service users to build reciprocal relationships has been day services (Bryant et al 2005, Bates 2007).

### **Implications for the modernisation of day services**

The Social Exclusion Unit report (Office of the Deputy Prime Minister 2004) had a significant impact on the local day services in this research and elsewhere. There was a whole section devoted to day services and community participation. The 'key facts' were based on discussions by the report authors with service users, indicating that service users were consulted. However, the nature and method of that consultation was not made clear in the document itself. Similarly, comments about the low uptake of direct payments ignored the fact that this scheme was not widely promoted to mental health service users until after the report was published. Day services were not defined, and the information given often combined day and vocational services, which was confusing. The political agenda of engaging people with employment opportunities was present, although details of how to engage people or support them were not given. Where day services were specifically mentioned, this was in the context of encouraging use of mainstream community resources (Office of the Deputy Prime Minister 2004).

Following the Social Exclusion Unit report, the green paper 'Independence, Well-Being and Choice' set out a plan for adult social care services (Department of Health 2005). Although people with mental health problems are just one of the many service user groups in contact with social care services, there was recognition of their particular needs.

Direct payments scheme were to be promoted specifically to people with mental health problems, to improve take-up. This scheme enabled people to take control of some of the resources available and has recently become more significant in the overall drive to personalise social services (Leadbetter et al 2008). Some of the problems encountered in implementing this scheme with people with physical and sensory impairments were acknowledged, and personal choice was emphasised (Department of Health 2005). However, there were no additional resources available and it has to be questioned how services could be extended when resources were already challenged.

However the biggest implication for day services was in relation to location (Bates 2007). Social exclusion has been defined in terms of being located in specific communities experiencing social and occupational deprivation (Whiteford 2005, Cameron 2006). For people in those places designated as socially exclusive, the expectation has been that they will change, through retraining, relocation or refocusing their lives. Cameron (2006) argued that a consequence of this is that efforts to transform people are given priority over efforts to transform places. But the people in these locations do not always recognise them as socially excluding. He also argued that often locations viewed as socially excluding were those which did not require people to compete with each other for work, or to organise their lives around consumption of material goods (Cameron 2006). Although Cameron's work was a geographer's perspective on social inclusion, there are parallels with day services. They are often located in designated buildings and like many institutions associated with mental health services, are generally not concerned with competitiveness or consumption in a commercial sense.

The difficulties associated with designated buildings has been summarised by Cheetham and Fuller (1998): a particular location will bring excluded people together, providing opportunities and a safe place to be. However, the building may be a symbol of exclusion in itself, as

mental health-associated buildings often are, increasing the sense of exclusion. Stigma associated with attendance at a day centre cannot be underestimated (Repper and Perkins 2003). It is also possible that the safety of a place may foster dependence, excluding the possibility of using other places to gain social contact. However, this was not the case in the situation described by Wollenberg (2001). Here the recovery model was the guiding framework within a mental health centre. Wollenberg claimed that a 'community atmosphere' co-existed with individualised approaches to securing recovery, through contact with other service users, access to resources and information, and professional support. However, it has to be argued that the occupational therapy service Wollenberg describes is typical rather than innovative, especially in the context of the client-centred approach embedded in the Code of Professional Conduct (College of Occupational Therapists 2005). It should be noted that Wollenberg's article is based on a personal experience as a novice occupational therapist (Wollenberg 2001).

### **Conclusion**

It has been recognised that service users benefit from contact with other service users and that social networking is a means of promoting social inclusion (Wollenberg 2001, Bates 2007, Repper and Perkins 2003, Bryant et al 2004, Office of the Deputy Prime Minister 2004, Bryant et al 2005). Day services have had to face the challenge of facilitating opportunities for social networking while dismantling the apparently institutional places where service users could meet each other. As already stated, service users have to make a choice in mainstream settings as to whether it is safe to disclose their mental health problems (Thornicroft 2006), yet without disclosure it might not be possible for them to know each other. While Bates (2007) emphasised that designated places still have a place in day services, the unfortunate term of 'red light' services was interpreted by some as being undesirable and therefore inferior to 'green light' services located in mainstream venues in the community (Bates 2005).

The other problem for the modernisation of day services has been the rejection of collective approaches to the needs of people with mental health problems. The emphasis on personal adaptation and change associated with not only the social inclusion agenda (Cameron 2006) but also the recovery model (Repper and Perkins 2003) has meant that bringing service users together has appeared undesirable. This could be because of fears about the negative effects of institutional approaches to service provision (Illich 1973); although it could be argued that these institutional approaches have not diminished but reformed, for example within the prison system and forensic units (Carpenter 2000, Mind 2006). Leighton (2003) has challenged the emphasis on individualised approaches, giving details of the varied collective approaches to mental health care and their benefits. Illich (1973), while being critical of institutions such as large hospitals, prisons and military camps which manipulated people to fit, recognised the need for 'convivial' institutions, which tended to be oriented around networks rather than hierarchies. However access and use was still regulated, which in the case of mental health services, would promote safety. This issue was important for this research and is discussed further in relation to the findings.

Modernising day services has been shaped by the social inclusion agenda, which in turn has been driven by political imperatives. Interpretations of social exclusion have been influenced by political agendas, particularly in relation to productivity and consumption. Thus there has been an emphasis on paid work and relocation of services to mainstream community venues. However, in relation to mental health, this has raised particular problems. It could be argued that the emphasis on social inclusion has polarised services, with those service users with the potential to be included pushed towards individualised programmes aiming for them to become productive members of society. For those who do not co-operate, for whatever reason, issues about risk and vulnerability come into play. The difficulty with this polarisation is that

service users experience both personal risks and opportunities on a daily basis, regardless of where they are located. This research was designed to explore service users' experiences, involving them in every aspect of the research and contributing to service development. This has reflected a perspective on user involvement emphasising democratic participation and citizenship. There are many ways in which mental health day service users have been perceived over time; the next chapter is concerned with the history of day services.

## **Chapter Two**

### **A history of mental health day services**

#### **Introduction**

The day services in this research were provided by a combination of statutory and non-statutory organisations. This mixed provision, from health services, social services and the voluntary sector, reflects the history of mental health day services. Knowledge of the history behind the local configuration facilitated understanding of service user and staff responses to the modernisation agenda. This section considers this history, exploring key themes relevant to this research. These themes are broadly concerned with the evolving nature of day services; the shifting balance between occupational, medical, social and psychological approaches; and predominant beliefs about the people who attended the services. The methods used to evaluate day services have been compared and it is significant that service users do not appear to have determined the agenda for evaluation until 1993 (Rogers et al 1993). Over time, the needs of people with mental health problems have been addressed by society according to contemporary perceptions of causes of mental illness and more general attitudes to welfare provision (McIntosh 1998, Foucault 2001, Porter 2002). Such perceptions are intrinsically related to beliefs about human rights (Smith 2005).

For example, McIntosh (1998) described how in the late sixteenth century a small town in Suffolk organised care for all residents in need, regardless of cause. Assistance was given in the form of shelter, money and/or occupation, for as long as the person required it. Some families received support over many years. The small town was able to do this not only because of wealth generated by the wool trade but also because of a predominant belief that this was a good thing to do. No distinction was made based on causal factors, although the 'idle' were offered occupational opportunities rather than money (McIntosh 1998).

Segregation of people with mental health problems appears to have arisen with greater state involvement in how support should be provided, and emerging beliefs about mental health, associated with the growth of the medical profession, and psychiatry (Foucault 2001, Porter 2002). Engstrom (2006) suggested that the history of psychiatry is currently opening up to a more inclusive view of the past, less concerned with using the failings of the past to justify present approaches and more concerned with understanding the complex historical drivers for contemporary practice. For example, Suzuki (2006) pointed out that in the eighteenth century the medical profession was heavily dependent on lay understandings of mental health, encouraging family members and the community to diagnose, treat and care for people according to their own beliefs and culture. He called this 'domestic psychiatry' (Suzuki 2006). Domestic psychiatry was centred on distrust of doctors, physical treatments and institutional segregation, and belief in key relationships as to 'best communicate with, pacify and control' the family or community member in question. This person could be a family member or recruited as a servant or 'keeper'.

These examples of community care resonate with current efforts to support individuals in their home environment and draw on community resources to support and sustain recovery. This puts day services in an interesting position. Are day services to be regarded as a community resource? Or as an outpost of institutional and/or medical intervention? The history of day services suggests a complex picture. To gather the material presented here, the terms day hospital, day care, resource centres, day centres, day services and social clubs were all used to locate literature on what day services were made available to service users, and on what basis. In particular, it seemed important to explore the origins of the distinction between day hospitals and day centres. Each decade has had its particular focus: this review will briefly consider services before the NHS was established in 1948 and end with the response to the NHS and Community Care Act in 1990.

### **Before 1948: from therapeutic social club to day hospital**

In the published history of mental health services there is an emphasis on institutional care, rather than community care (Bartlett and Wright 1999). There are many reasons for this, summarised by Bartlett and Wright as being a reflection of the dominance of medical publications and research, the accessibility of hospital records and the legislative focus on hospital care, especially in relation to compulsory treatment. However, community care co-existed with hospital care, probably for the majority of mental health service users and based on the informal efforts of the family and neighbourhood and charities (Jones 1972, Bartlett and Wright 1999, Welshman 1999). There was consistent recognition that the community was a better place for most than hospital and energies were directed to facilitating this (Boardman 2005). Hospitals were widely perceived as inhumane, and as psychological, social and occupational approaches to mental health problems developed, formal certification for inpatient treatment was considered undesirable and avoidable (Jones 1972). Formal certification had been a requirement until the 1930 Mental Treatment Act, although the private sector had accepted voluntary patients since 1862. This Act built on years of dissatisfaction and provided the basis for out-patient treatment and aftercare (Smith 2005). It was in this context that the first day hospital in the UK came into being in 1946 (Bierer 1951, Farndale 1961, Boardman 2005).

This day hospital, the Marlborough Day Hospital, appears to be a development of earlier work by Bierer to establish therapeutic social clubs within the large asylums. According to Blair (1948), Bierer first presented this work in 1938. Blair himself seemed particularly struck by the potential of therapeutic social clubs to provide a context for social contact and increase involvement in 'communal activities.' While these clubs were contrasted by Blair with occupational therapy, it appears that occupational therapists were involved from the outset (Thompson 1942, 1948). Thompson focuses on the fact that a therapeutic social club was where:



*“... the patients could be their own masters, could use and develop their own initiative and could prepare themselves actively for normal life.” Page 7*

Thompson (1942), Blair (1948) and Bierer (1948) all observed that these clubs offered specific occupational opportunities for individuals as well as more general benefits for those attending, and Thompson’s account (1942) suggests that many people moved on from the club as they recovered. In the local area studied in this research, during this period inpatients were cared for in a large Victorian hospital about ten miles away which had a therapeutic social club following Bierer’s initiative.

Bierer’s primary theoretical influence was the work of Adler, in particular valuing community life and integration for mental health, and so it seems to have been inevitable that he would extend the therapeutic social clubs initiative to foster the development of a day hospital (Bierer 1951). He believed psychoanalysis was limited and appeared also to reject the division between physical and psychological approaches to mental health problems. The day hospital he set up sought to offer a holistic range of approaches, with emphasis on providing meaningful occupation and structure to the day in a non-stigmatising environment. He particularly valued occupation:

*“... in all cases where patients are unable to follow their usual occupation, they are left all day long with time on their hands in which to dwell upon the hopelessness of their situation; they spend all their time in the same environment, and this is often a contributory cause – sometimes even the main cause – of their final breakdown.” (Bierer 1951, page 10)*

Thus occupational therapy was central to the initiative, not just in terms of providing something meaningful to do but also in relation to the ideas of Adler. According to Bierer, in the day hospital context this translated into attending to people’s experiences of occupations and the social environment (Bierer 1951). Stories of recovery emphasise the extraordinarily diverse needs, ages and issues of the people who attended. It seems unsurprising that the idea of working with people as

day patients would be attractive to many involved in mental health services at the time.

### **1948 – 1959: formalising the movement**

From a historical perspective of day services, it could be argued that the formation of the National Health Service in 1948 merely drew together what little provision existed at the time. The National Assistance Act of 1948 provided general legislative support for welfare services (Tunncliffe et al 1993) but with no specific mention of mental health day services in any form. It has been commonly believed that the use of major tranquilisers in the 1950s was a catalyst for community care and the proliferation of day hospitals during the 1950s could support this view. Farndale's research (1961), which is explored in greater detail below, suggested that if this were the case then the developments in psychopharmacology and day hospitals were more likely parallel than causative. He reported that political as well as clinical energy was directed to developing day services on a national scale from as early as 1951 (Farndale 1961). This would not have been possible prior to the National Health Service. Thus political and economic considerations were as influential as any clinical factors. Carpenter (2000) also pointed to the social democratic influences on policy in the postwar period, and to the increasing influence of psychological theories about mental health and illness. This may have facilitated the separation of accommodation services from clinical issues, which evolved alongside day services (Bartlett and Wright 1999).

In 1955, a distinction was formally drawn between day hospitals and social clubs, followed by the recognition that day hospitals could offer outpatient treatment, supervision and occupation (Farndale 1961). Welshman (1999) points to a steady but small stream of initiatives leading to the report of the Royal Commission on Mental Health in 1957, which called for local authorities to become involved in the provision of mental health care in the community setting.

From 1958-9 Farndale undertook a comprehensive review of day services, categorising, comparing and contrasting the many initiatives across England, Scotland and Wales (Farndale 1961). This work also covered day services for older people and people with learning disabilities, but was dominated by mental health services. Thirty-eight day hospitals and four psychiatric after-care centres were visited by Farndale, who categorised them primarily according to location in relation to other psychiatric services, for example, a detached day hospital which existed in the grounds of a large hospital or an independent hospital which was in a town centre. This was probably because of his interest not just in treatment but in “administrative, economic and social aspects”. Farndale had a background in law and administration, and at an early stage in his account makes reference to the need to investigate the potential economic and humanitarian benefits of expanding day services. Categorising services by location was probably also a pragmatic decision, given the reported overlaps in terms of treatment, support and care. He also sought to distinguish between services where people could attend an in-patient ward as a day patient, which he claimed was an established practice for many years.

Farndale observed that the only common feature of the services he studied were that those who attended spent their evenings and weekends in the community. From the outset the emphasis on reinstating or encouraging good work habits meant that daily attendance for full days throughout the week was important. On further analysis, however, it seems there was another common feature which Farndale repeatedly observes yet draws no conclusions from. Of the thirty-eight day hospitals, all but four identified occupational therapy as a primary emphasis, even in eight places where there were no occupational therapists in post. Of the remaining four, three did not specify an emphasis and the other was described as a therapeutic community. All four after-care centres emphasised occupational therapy. Medical treatments such as electro-convulsive therapy were also priorities at thirty of the day hospitals, with

psychotherapy at twenty-eight places and social/recreational activities at twenty-six (Farndale 1961).

It was not clear whether these approaches successfully prevented or reduced duration of admission or readmission. Farndale suspected that some units actually increased demand for services, by successfully meeting the needs of a group not previously addressed otherwise. There was recognition of the diverse needs of people attending the services, from those who were likely to make a full recovery to those who had an ongoing need for support and care. No mention is made of mental health day services being offered by non-statutory organisations, although this may reflect Farndale's remit rather than their absence. However he did investigate non-statutory day services for other service user groups, so it could be possible that there were none in existence for people with mental health problems.

Finally, Farndale recognised that the services he had investigated were likely to be a phase in the development of community services. He was slightly dismissive of the economic advantages, highlighting the improvements in treatment and care offered, the reduced stigma and significant respite for carers. He attributed the diverse nature of the services he studied to a combination of individual visions and initiatives, predominant beliefs and economic resources. The detail in Farndale's report, illustrated with photographs, makes it easy to visualise the varied settings he investigated. It is clear that at this stage of day services development, service users were seen as recipients of treatment and care and, if they had the opportunity to take the lead either as individuals or a group, it was not reported.

### **1960 – 1975: an era of expansion**

In 1962, the success of developing community care was such that the Hospital Plan of that year proposed reductions in beds, anticipating further development in partnership with local authorities, which finally became a possibility with the Local Authority (Social Services) Act in

1970 and the introduction of Joint Consultative Committees (Welshman 1999, Smith 2005). There are accounts of practice in day services throughout this period, with indications of the complex pattern of provision which characterises current provision. Locally, service users have suggested that it was at this time that day service provision moved from the large Victorian asylum ten miles away to a unit based on the local general day hospital site, along with two wards. Nearby, a social services day centre was established on a former residential care home site.

Woddis (1963) gave an account of a user-led initiative, where the activities, finances, cleaning, a magazine and audits were undertaken by those involved. This social club involved ex-service users, “relatives, friends and voluntary bodies”, alongside service users, although it was not specified to what extent these people got involved. What Woddis did identify was that being involved was complex and raised many issues for staff (Woddis 1963). A later example was given of another day centre, with an emphasis on returning to work, although there was scope for long-term attendance too (Back 1967). Alongside the enthusiasm there were some doubts. Abramczuk et al (1968, based on a paper given in 1964) described challenging issues around selection of suitable patients, resistance and a lack of motivation of those who were selected, and the ongoing struggle to secure adequate resources. Although the study was based in Poland, the multidisciplinary approach reflected British initiatives. Abramczuk et al were dismissive of simple industrial work in day centres, mirroring new developments in the learning disability field.

At this time, the concept of normalisation was emerging in relation to work with people with learning disabilities (Stalker 2001). In this field, day care had taken the form of Adult Training Centres, with an occupational emphasis on industrial work. Normalisation challenged this segregation of people with learning disabilities, placing emphasis on the use of community resources accessible to everyone. The concept of day services, rather than centres, was thus slowly introduced from this point

onwards (Stalker 2001), eventually emerging into adult mental health services in the 1990s.

The account of the growth of rehabilitation and community care services by Clark (1996) at this time suggested a pragmatic approach, balancing available resources with emerging need. The day services he described initially started in 1957 in an old occupational therapy building in the grounds of Fulbourn Hospital, Cambridge. Clark observed that after an initial exodus following the introduction of a 'Work for All' programme in the 1950s, there were many people remaining in the hospital who were unable or reluctant to leave. Initially set up as a base for male patients working within and beyond the hospital, as the rehabilitation services grew the base became a Day Centre and eventually moved to a church hall in 1977, becoming a Day Clinic.

Morrice (1973) made reference to Clark's work in his account of a day hospital in Aberdeen. This day hospital was next door to an occupational therapy department which appeared to have close links. Morrice raised issues of referral criteria, having found that the day hospital often received referrals for people who had exhausted all other alternatives, although 'social crisis' was the most frequent reason for referral. It was suggested that a model of acute service provision based on day hospitals with few beds would be beneficial.

According to Jones (1972), a policy document in 1971 "Hospital Services for the Mentally Ill," proposed closing all the large hospitals, with all inpatient treatment being provided on general hospital sites. Day services were included in this vision. This document preceded the publication of the White Paper "Better Services for the Mentally Ill" in 1975, which included specific requirements for the development of local authority day care.

## **1975 – 1990: community care and consumerism**

Alongside social day care, day hospitals were expected to emphasise treatment, occupation and rehabilitation (Carter 1981). The 1975 paper “Better Services for the Mentally Ill” unfortunately coincided with a serious recession, undermining the proposed changes with insufficient resources (Clark 1996, Smith 2005). A survey by Carter (1981) found little difference between day hospitals and day centres. This survey involved three hundred and eighty-five day ‘units’, offering fifteen hundred places. A day ‘unit’ was defined as:

*“... a non-profit making personal service which offers communal care and which has care-givers present in a non-domiciliary and non-residential setting for at least three days a week and which is open at least four to five hours each day.” (Carter 1981, page 2)*

This definition suggested that day services were still very much based in specific, designated buildings and operating during working hours. What Carter found was that there was great variation across the UK in day services provision, with some areas having hospitals and others having centres, and just a few having both. This was a possible explanation for the similarities, although it was also observed that just because day centres tended to focus on those with long-term needs, this did not mean those people were less likely to have acute difficulties or crises, meaning that needs of service users in either setting were likely to be quite similar. Carter was struck by the difficulties in categorising day services because of their broad remit, describing them as an “untidy set of services”. This could explain organisational and political reluctance to focus on day services as community care expanded and the market-focused reforms began to gain favour. However, Carter did analyse the features of more successful day units (while acknowledging that defining success was not easy) and identified a common characteristic of a focus on the therapeutic environment. Key to this was:

*“expanding the status of users from relatively passive recipients to that of active participants in their own and other users’ therapy.” (Carter 1981: 245)*

To facilitate this, staff had to promote a sense of community within the day services, share the decision-making process and create choices and confront problems as they arose.

In the United States, development of what was termed 'partial hospitalization' had followed innovations in the UK, Canada and Russia (Linn et al 1979). In a study of ten day centres over four years in the United States, Linn et al sought to capture how services had evolved there, focusing on how people with schizophrenia were supported in different centres. The study found that social functioning improved regardless of approach, but symptom reduction was only found in more successful centres. These centres had some features in common, most notably less psychotherapy and more occupational therapy, and less interviewing rooms and more contact overall between staff and service users. The conclusion from this study was that occupational and recreational aspects of day treatment were undervalued.

Funding issues dominated the development of day services in the United States: Edwards (1982) placed emphasis on distinguishing between day hospital or very acute care, day treatment offering time-limited programmes in transitional phases and day care for long-term support. Edwards observed that these distinctions were arbitrary and had the effect of focusing resources on the acute day services, whereas in reality day care centres for people with long-term needs were potentially the most successful as part of community care provision. Success in this case was viewed not only in terms of prevention of admission but also acceptability to service users, especially in relation to stigma and community integration. Edwards observed that funding was precarious, access was not always easy and crises could not always be contained successfully in day services and proposed that increased funding was essential to develop community care.



A UK study by Holloway (1988) indicated that the distinction between day hospitals and day centres persisted, with day hospitals being orientated to resettlement and day centres to 'practical services' and craftwork. However, the study indicated that social contact between service users was the most frequent activity in either setting (Holloway 1988). Day services were observed to be more practical in urban areas, where access was easier (Morrice 1973). An innovative response for more rural and remote areas was to create 'travelling day hospitals' (Hawes 1982). This term might be slightly misleading, as it was the staff who travelled to a local base, rather than the hospital itself. Hawes' example was of a day unit operating from a village hall for two weekly sessions, staffed by a nurse, social worker and occupational therapist and jointly funded by health and social care. This unit provided all the well established functions of day services from a social, medical and occupational perspective. These functions were fulfilled not only in the day unit sessions but also in service users' own homes. A detailed account of the typical functions of day services at the time is given by Weiner (1985), who described a wide-ranging programme which appeared to be aimed at attending to all but the shelter needs of those who attended. Many of the day service users in this account were residents of hostels, expected to leave the hostels during the day, and so the day services became an important place of shelter and opportunity. Individual sessions and an emphasis on reintegration was highly valued. Close attention was given to interpersonal aspects of team work and working with the service users, and Weiner explored the use of family therapy and problem-solving as effective approaches to the issues (Weiner 1984, Weiner 1985).

Interest in families and their role in supporting people with mental health problems grew in the 1980s, which in turn generated more complex understandings of social networks in relation to support and rehabilitation (Bennett and Morris 1983, Birley and Hudson 1983). In this context, day centres and hospitals were beginning to be more strongly associated with

institutional rather than community care, especially through their association with industrial therapy (Bennett and Morris 1983).

Bender and Pilling (1985) suggested that the emphasis on verbal therapies alienated “less intelligent and articulate” people, explaining why people dropped out. They noted that the majority of people staying with day hospitals in their study were satisfied with the service and care provided. The most valued aspect was the opportunity to meet people, followed by the activities on offer. This study did include centres with an emphasis on work, which might have skewed the preference for activities, and it is not clear how the sample was defined and recruited – it appears to be based on the perspectives of long-term service users but this is not explicitly stated. However, their conclusion that day care offered a viable work substitute seems significant, especially given that it was made in an era of mass unemployment and degeneration of traditional manufacturing industries.

There is some evidence of consultation of service users during this period. Turner-Smith and Thomson (1979) sought opinions of people who had been discharged from their psychiatric day hospital since it was set up in 1974. This study seems to be a very honest attempt to gather opinions about very specific aspects of the service, comparing interventions and professional effectiveness. Postal questionnaires were used, and many non-responders were visited, to obtain a very high response rate. The method used in this study could be questioned in hindsight, particularly the degree to which service users felt obliged to rate the service positively, as the researchers were staff members. However, what is interesting is that the vast majority of ex-service users (90%) considered themselves to be well, and as the authors point out, this was a much higher proportion than would be expected from this population. Psychotherapy was less popular than occupationally-based approaches, and formal sessions less popular than informal sessions. Another interesting aspect of this study is that Turner-Smith and

Thomson believed that innovations in health care inevitably reflected professional perspectives, yet in developing services it is only by consulting service users that effective aspects can be identified.

Another study based on recently discharged service users' perspectives was conducted by a social worker and occupational therapist (Vaughan and Prechner 1986), who interviewed people at home. The focus of this study was on whether a structured approach was preferred to an informal one by service users, and if the organised aspects of the programme were preferred to the 'incidental' aspects. This study is truly a product of its time, with the focus on comparing individual components of a service from a consumer perspective. Midgely (2001) termed this an 'atomistic' approach, contrasting it with a holistic approach. The 'incidental' aspects were all the other aspects of attendance, defined by service users, other than formal treatment sessions. Most participants appeared to struggle with this comparison, although many welcomed the possibility of attending only sessionally rather than for a whole day. But most participants felt attendance was significant in their recovery, and that a structured approach helped them engage with the day hospital, have a sense of purpose for attending and a sense of progress from attending. The same study is reported elsewhere by the authors, this time with an emphasis on the comparison of different formal interventions (Vaughan and Prechner 1985). Once again, psychotherapy was regarded as less helpful than practical and social activities, and the authors were surprised to discover the popularity of printing. It seemed that occupationally-based interventions in particular were most successful at initially engaging people and sustaining their participation (Vaughan and Prechner 1985).

The day unit in this study had been described earlier by Prechner and Perry (1982). Set up in the grounds of a general hospital in 1979, it bridged the gap between the limited community services and the large psychiatric hospital thirty miles away. There was a programme of activities designed to enable people to maintain skills and social contacts,

and another programme aimed at developing specific skills and addressing problems. There was involvement from family members and other carers, adult education for basic skills and the Red Cross organised health and beauty care sessions.

Gudeman and Shore (1984) suggested that day services, whether hospitals or centres, facilitated transition between hospital and community for people with long-term problems. This was supported by Bouras and Kember (1985), who conducted an audit of referral and discharge patterns for one day hospital. However they indicated that it was difficult to determine which people were most likely to benefit from day hospital attendance, and that the use of the day hospital for crisis management and admission prevention was not supported by psychiatrists. Interestingly, 40% of people in their audit were discharged to out-patients and no details were given of what the day hospital offered to those attending.

Many of the studies explored so far have been descriptive insider accounts or surveys based on organisational records. Formal interview-based studies were just emerging. In contrast, there is one report of a controlled trial of day hospital effectiveness for people who had been attending for more than six months (Tantam and McGrath 1989). The experimental group were allocated to a rehabilitation team for individual-based work in addition to day hospital attendance. A matched control group continued to attend the day hospital as before. Outcomes at four month intervals for one year were measured, using standardised tools. The study appeared to indicate that there was a danger of institutionalisation associated with prolonged day hospital attendance, although there was not a significant difference in discharge rates between the two groups. Tantam and McGrath (1989) made frequent references to the lack of resources, of staff in the day hospital and of day centre places. This was viewed as being particularly important for those with long-term needs.

Health and social care reform was strongly driven in this period by a belief in market forces, aiming for services shaped by consumer need and preference (Tunncliffe et al 1993). However this aim was not always evident in practice, and economic considerations often over-ruled humanitarian concerns (Smith 2005). This reflected the political impact of the New Right, at this time dominated by the leadership of the Prime Minister Margaret Thatcher. Her speeches proposed that communities would benefit from reduced state involvement in welfare, and the promotion of competition between individuals, within private companies and organisations (Hayes 1994). The report by Griffiths in 1988, "Community Care: Agenda for Action" argued that both economic and humanitarian aspects could be met by health services operating like a market, emphasising both choice and efficiency (Smith 2005). This report preceded the NHS and Community Care Act of 1990, which formalised a split between purchasers and providers. The purchaser role was allocated to social services, and day services were viewed as a provision, usually on a bulk contractual basis. However, the Care Programme Approach formalised the concept of 'purchasing' day services for individuals.

### **1990: towards integration and inclusion**

In a report in 1991, Tomlinson suggested that community care had a long way to go, observing:

*"... the aloneness in the community of a significant proportion of service recipients, and their relative lack of opportunity for giving and receiving mutual support."* (Tomlinson 1991, page 163)

He observed that emphasis on individual packages of care in the community had undermined opportunities for collective approaches, resulting in an emphasis on accommodation and supervision rather than occupation and social contact. Deinstitutionalisation had required community mental health services to shift their attentions to people with severe mental illness (Pittman et al 1990) and, rather than seeking to reintegrate people into communities known to them, it was necessary to

reconsider the community from the perspective of people with a long history of institutional living. Tomlinson (1991) suggested that community development work was the way forward rather than expecting long-term service users to demonstrate integration by visiting one-off community events such as “festivals and fetes”.

At this time the concept of day services as an umbrella term first emerged in relation to community mental health services. Prior to this, day services had been a term used generally within social care. The NHS and Community Care Act (1990) requirement for local authorities to commission community mental health services may have been a factor in the increased use of the term to describe all forms of day treatment and care for people with mental health problems. Locally, during this period three resource centres were created to replace the day hospital and social services day centre, jointly funded and commissioned.

Some issues persisted. Holloway (1991) continued the investigation of differences between day hospitals and day centres, again concluding that they were serving people with very similar needs. This may have reflected the number of people being resettled from the large hospitals at the time. Holloway pointed out that the division of acute and long-term, or medical and social care, was not meaningful or helpful in the context of severe mental illness. Thus he was critical of the policy to give local authorities the lead in community care, arguing that this would endanger those with severe mental illness whose needs might not be met or even recognised due to the lack of expertise of social care staff. It may have been that at the time it was very difficult to visualise how community care would work. This would not be surprising given the complexity of the mental health services which have evolved since. Later, Shepherd et al (1993) wrote about the particular challenge for staff in day services, in engaging with people with severe mental illness in an informal setting. Knowing and understanding the difficulties meant that staff could be realistic and informed, but they also had to resist taking over decision-

making. Shepherd et al (1993) suggested a 'mixed economy', with staff taking the lead in some aspects of day services, and service users taking the lead in other aspects. The question was whether this could be achieved under the same roof, or whether separate services would have to evolve.

There appears to be greater evidence of consultation with service users, albeit with an emphasis on consumer satisfaction rather than possible service user agendas (Garvey 1991, Sexton 1992, Nelson 1993, Firby 1994, Ricketts and Kirshbaum 1994, Brabbins et al 1995). Garvey (1991) investigated the differences between people who attended and people who dropped out of a day unit, using interviews. This study suggested that it was important for people to know who their key worker was, to value the day unit as a means of meeting their own goals and to have adequate information about the day unit. Sexton (1992) referred to the difficulty in getting meaningful responses about the quality of services from people with long-term mental health problems, discovering that using an independent interviewer not known to participants enabled people to give negative as well as positive perspectives. The group investigated was chosen because of its success in engaging people over time, although no specific details are given of the strategies used. There was an emphasis on social contact, recovery, support, user involvement, occupation and the reduction of home visits. All these elements were thought to have been achieved successfully by both current and past service users.

Nelson's study (1993) used long, informal interviews, to give service users a chance to fully express their views. These views, gathered from eight people from four different units, suggested that social contact was more important than the activities offered at the day units. Ricketts and Kirshbaum (1994) used a Delphi study approach to gather service user perspective on day services, interviewing each participant initially and then using the findings on treatment experiences to generate a hierarchy

of how helpful these experiences were. The emphasis was placed on helpfulness rather than satisfaction as this was believed to be more meaningful to service users, who had all recently been discharged from day services. A parallel study was undertaken for the staff group. One-to-one counselling sessions were thought to be the most helpful aspect of the service. However, there were contrasts in perspectives of service users and staff, especially in relation to just attending and getting away from the outside world, valued by service users but not staff.

Firby (1994) interviewed service users of a day hospital, again seeking to find out what was helpful for them. There were more details given of this setting, creating an impression of a building-based service offering sessional therapies, social contact, food and individual work. The service users in this study indicated that they valued attendance because of learning opportunities, social opportunities and respite at difficult times. Firby also explored the issue of dependence on the day hospital, given its successful and lack of obvious alternatives, and concluded that for some people dependence was inevitable and a preferable alternative to being a long-term inpatient.

The study by Brabbins et al (1994) was based on interviewing people known to the community mental health services, of whom just under a third attended the local day centres. Half of this sample never attended, but the reasons were not reported. More than half of the participants wanted day services and the authors speculated about the reasons why there were people who wanted day services but did not attend those that were available. They suggested that diverse needs and interests were difficult to accommodate, although there were twenty-one different facilities available. The Community Group Network described by Brewer et al (1994) was an innovative attempt to address diverse needs, emphasising social networks in a range of community settings. Working sessionally in partnership with volunteers and staff in the community settings reduced the stigma associated with building-based services.



Service users also had more opportunity to take on specific roles which might have otherwise been undertaken by staff in traditional day hospitals and centres.

Occupational therapists were the predominant professional group, echoed in my study of social contact groups, which had developed along similar lines (Bryant 1995). This study evolved from personal observations that the expectation that future development of day services should be informed by particular beliefs about their purpose, particularly in relation to working with long-term users of mental health services. There was a vision of fostering user-led sessional groups, in mainstream community venues, oriented to social contact. It seemed important to examine to what extent this was a shared vision between group leaders, and how it was viewed by service users. Multiple methods were used. The social contact groups studied were valued by service users and preferred to other forms of day services, but only those currently involved were consulted (Bryant 1995). There were variations between the groups, but all were small-scale with a social and occupational focus. At the time, it seemed quite possible that these groups could facilitate social inclusion.

It seems that at this time a more sophisticated understanding of day services was developing as community mental health services became more established. Clark, writing about the development of all forms of day care, across different service user groups, suggested a spectrum from residential care to “occasional support in the community for independent living” (Clark 2001). Between the two extremes of this spectrum there were many possibilities and forms of day services across all service user groups. From this perspective, day services were less oriented to building-based services and more concerned with addressing service user needs during the day. As previously stated, in the learning disability field this view had been evolving for some time. Seed et al (1989) gave an example of day services using a multi-purpose mainstream community building, sharing responsibilities between all involved, emphasising

individual and group goal setting, and integrating effectively with other community care and mainstream resources.

Ward (2007) suggests that day services in general were slower to respond to the normalisation and social inclusion agenda because service users were perceived to be less vulnerable to organisational constraints, compared with those in residential or in-patient settings. As such they were less likely to be consulted for their views on services. However, Carson et al (1993) indicated other difficulties with the concept of normalisation, specific to community mental health services. Firstly, it was difficult to define what 'normal' or 'ordinary' actually meant. Secondly, management of risks associated with the symptoms of severe mental illness appeared to be ignored. They observed that "physical integration is much easier to achieve than social integration" (Carson et al 1993, page 272). Discussion of these issues has continued in relation to the concept of social inclusion and exclusion.

An example of day services which acknowledged the normalisation agenda was given by Shepherd et al (1993). The day services described were provided within complex partnerships with other organisations and embraced social, occupational and shelter roles. Occupation in this sense related to employment, time use and meaningful activity, and this emphasis may have reflected the work already undertaken locally where social and occupational rehabilitation had been developed since the the 1950s (Clark 1996). Shepherd et al's account also analysed the difficulties which arose. These included the selection of the right person for the right sort of day service, getting people engaged, balancing opportunities for social interaction with spaces for refuge and privacy, and ensuring that occupations were meaningful.

Shepherd et al (1993) made particularly insightful and useful remarks about the issue of dependency and institutionalisation. They linked some incidences of the appearance of institutionalisation to the negative

symptoms of schizophrenia: social withdrawal was not just caused by having lived in an institution but by the experience of psychosis in itself. They warned against expecting full integration for every individual and argued that “some degree of dependency is probably inevitable”. Within the day services they described, it was believed to be important to identify which sources of support a person could depend on, on an individual basis, recognising that this would change over time. They made particular comments about drop-in services and dependency, recognising that the potentially unstructured and undemanding nature of a drop-in could foster dependency. Their response to this possibility was to impose structures on drop-ins to facilitate user involvement in information exchange, decision-making and recreational activity (Shepherd et al 1993).

As before, themes from the past persisted within day services. In Scotland, a survey of six day services observed that while the services were highly valued by service users, there were ongoing difficulties with resources, with poor staffing levels and inadequate premises (Social Work Services Inspectorate for Scotland 1995). The services surveyed offered the usual range of day services, with embryonic initiatives in user involvement. It seemed that services did not really know how to involve service users meaningfully, although the survey itself gathered users' views. There was concern about crisis management, weekend and evening provision, access and a lack of provision for those who found social contact challenging. The recommendations were wide-ranging, with suggestions to improve what was offered, target particular service user groups and promote user involvement. The challenging nature of the work was recognised, with a recommendation for regular supervision of staff (Social Work Services Inspectorate for Scotland 1995).

Hinshelwood (1998) analysed the impact of the political belief in a market-based organisation of health services, suggesting that the drive for efficiency ignored the fact that mental health services were already largely very efficient, having survived for many years on very limited

resources. Critical to his argument was that ignoring the emotional component of the task of providing services significantly undermined efficiency of staff. Caring for their emotional well-being, in order that they in turn could be responsive to the emotional needs of service users, was seen as an essential component of efficient and effective services (Hinselwood 1998).

In all the studies examined so far, the agenda used in consulting service users had been determined by professionals. The survey reported by Rogers et al (1993) was very different, in that service users determined the topics covered and the questions asked. This survey was undertaken in collaboration with Mind and was a comprehensive examination of all aspects of mental health services. In relation to day services, it was suggested that locating services on district general hospital sites had fostered an institutional and clinical atmosphere, rather than forging links with the community. There was a lack of meaningful activity, an inflexible approach and issues about access. Social contact and meaningful activities were the most valued aspect of day services. Service users in this survey suggested services could be improved with a greater integration with the community, more choice and better collaborative working with staff. This contributed to the view that there was a:

*“need for a new model of working between those using day services and those providing it.” (Rogers et al 1993: 77)*

But there was also great concern that day services had been cut.

## **Conclusion**

It has been suggested that day services do not receive sufficient attention given their significant role in supporting many people (Clark 2001). However the history captured here suggests that this has not always been the case. As indicated in Chapter One, currently political and professional interest has shifted once again to the role of day services in the recovery and support of people with mental health problems. Resettlement is now less of an issue and there appears to be a more

sophisticated understanding of community mental health care. It seems that day services could have a more defined role once again. In particular, the introduction of crisis resolution and home treatment teams potentially offers an important resource for day services in supporting people in crisis, with the focus on resolving interpersonal difficulties and having a gatekeeper role for other services (Hoult 2006). Curiously, social and shelter/self care needs are recognised, but a broader occupational focus is absent in community mental health services (McGlynn and Flowers 2006). This may present an opportunity for day services to refocus on occupation.

## **Chapter Three**

### **An occupational perspective**

#### **Introduction**

This chapter analyses the occupational perspective brought to the research, which influenced choices at every stage, including the topic and the design. This perspective is focused on how human life is driven and shaped by engagement in occupation, or the things we do. This contrasts with other perspectives which emphasise particular aspects of human life, for example arising from biology, psychology or social science (Wilcock 2006). The occupational perspective is not an alternative to these perspectives but a synthesis of them. It could be argued that it resembles the biopsychosocial perspective on health (biology-psychology-social), promoted by the World Health Organisation in relation to the International Classification of Function (ICF) (2001a). The ICF has been welcomed by occupational therapists in particular because of the parallels with the occupational perspective, and the central importance placed on activity and participation in relation to health, along with capacities arising from the body function and structure (College of Occupational Therapists 2004, Wilcock 2006, Hocking and Nicholson 2007).

However, the biopsychosocial perspective on health still sees activity or participation as a component of a healthy life (World Health Organisation 2001a). In contrast, the occupational perspective has been claimed to be an advance on the biopsychosocial perspective (Hocking and Nicholson 2007), by emphasising the central place of occupation (or participation and activity) in relation to the other components, and claiming that occupation underpins every aspect of human life (Wilcock 2006). Knowledge of occupation is derived from everyday experiences, across all cultures and history, from individual to population levels (Molineux and Whiteford 2006, Wilcock 2006). People understand occupation and its significance, knowing that to be active is to be alive and well (Rebeiro 1998, Caulton and Dickson 2007). Thus occupation is not just another component of human life to be considered but a foundation, not only for

understanding human life but also for transforming it (Townsend 1997, Duncan and Watson 2004).

The occupational perspective sees human life through this lens, embracing other perspectives (Wilcock 2006). However it could be argued that other perspectives are equally necessary because of the complexity of occupation. By taking different perspectives on what people do, it is possible to understand the impact of occupation in a manageable way. These understandings of occupation have emerged from occupational science, an academic discipline which has been concerned with studying “*the form, function and meaning of human occupation*” (Zemke and Clark 1996). Occupational science, and the development of an occupational perspective on health, has been developed primarily by occupational therapists (Yerxa 2000, Molineux 2004, Molineux and Whiteford 2006, Hocking and Nicholson 2007). Wilcock (1998a, 2006) suggested that the dominance of other perspectives, for example the medical and sociological views of health, has inhibited development of the occupational perspective, despite its long history reaching back to antiquity. Interest in occupation beyond occupational therapy has been predominantly associated with paid employment rather than everything people do. Occupational science has been developed by occupational therapists to broaden critical debate about occupation and health, although it is not clear to what extent this has occurred beyond the profession of occupational therapy (Wilcock 2006).

These statements must be explained, explored and justified further in relation to this research, and so this chapter is focused on the occupational perspective. Initially, the nature of occupation and participation is analysed. The belief that occupation is fundamentally important for survival and health is also addressed. This involves acknowledgement of the complex nature of occupation, in terms of its forms, functions and meanings, which informed the analysis of the findings of this research. Factors influencing participation in meaningful

occupation are briefly considered in relation to the research setting of mental health day services. Finally there is an exploration of the use of occupation as a tool for, and focus of, transformation or change.

### **Search strategy**

The literature reviewed here was located from a range of sources. The study of occupation by occupational therapists and occupational scientists was marked initially by theoretical articles from 1988 onwards (Molke et al 2004), which have since been synthesised into chapters and books. The approach therefore has been to examine and compare the most recent synthesised accounts, the majority of which were published since 2002 (for example Hasselkus 2002, Christiansen and Townsend 2004, Molineux 2004, Christiansen et al 2005, Watson and Swartz 2005, Whiteford and Wright St Clair 2005, Molineux and Whiteford 2006, Wilcock 2006, Hocking and Nicholson 2007). Key original papers and books have also been reviewed (Nelson 1988, Yerxa et al 1990, Wilcock 1993, Zemke and Clark 1996, Townsend 1996, 1997, 1998, Wilcock 1998a, 1998b). This review also involved a search for recent relevant publications, a key word search of databases such as AMED, CINAHL, Medline, Academic Search Premier and Google Scholar. The key words used in combination are listed in Table 1.

**Table 1: Key words used in literature search**

occupation	participation	health	well-being
form	function	meaning	purpose
transformation	justice	injustice	
marginalisation	alienation	deprivation	imbalance

For the purposes of this review, there is emphasis on concepts, theories and ideas rather than research methods and findings. This is because, for this research, the occupational perspective has been understood primarily as a synthesis of ideas rather than a product of empirical research.



## **Recognising and valuing participation in occupation**

Wilcock (2003, page 176) issued a challenge, underlining the importance, in her view, of the occupational perspective on health.

*“The first task is to try to develop an occupational perspective [...] Rethinking social structures or political or education policies from an occupational perspective”*

One of the difficulties with developing this perspective is that occupation is an ambiguous term. According to Royeen (2002), one major problem with defining occupation is that it is evident both as a process and as a product. It is simultaneously the means to achieve something and an end in itself. The process of doing this research was characterised by a variety of activities or occupations, but there was also a widely shared perception of the research as a separate occupation in contrast to other things that were happening in peoples' lives. Royeen perceived that occupational therapists did not have a problem with this but suggested that others might. This tension, between means and ends, or process and outcome, was significant to this research, especially in terms of getting people involved and engaged with the project. However other perspectives on occupation were equally important, especially when communicating with those involved about occupation (Appendix A).

### ***Defining occupation***

In recent times, occupation has been primarily associated with paid employment (Christiansen and Townsend 2004, Jarman 2004, Unruh 2004). The occupations classified in the international standard classification of occupations are exclusively those for which people get paid (Jarman 2004). This situation has been interpreted as a consequence of the Industrial Revolution, when people became employees rather than being self-employed and so were forced to make a more rigid distinction between time spent on paid occupations and time spent on unpaid occupation (Marx 1975, Wilcock 1998b).

In contrast, occupation has been defined in various ways by occupational scientists and therapists (Royeen 2002). All these definitions broaden the

scope of occupation beyond paid work. Creek (2003) distinguished between occupation, activity, tasks and skills, suggesting a hierarchy of complexity. In relation to this research, this understanding was useful at times when thinking about people's skills, what tasks they might undertake as part of the research activities, and how these activities related to their overall sense of engagement with the occupation of doing research. Christiansen and Townsend (2004) also argued for a distinction between occupation and activity, suggesting that occupation is a more complex concept, including broad contextual aspects as well as personal capabilities. They also suggested that the universal experience and everyday nature of occupation has meant less interest from the academic world in general. However, occupational scientists have stated an aim to use and develop the findings of other disciplines, such as sociology and anthropology, claiming that there is a rich resource yet to be used (Yerxa et al 1990, Yerxa 2000).

Wilcock (2006, page 343) suggested that occupation is "*all that people need, want, or are obliged to do*". This broad definition challenged the tendency to place more value on some occupations over others, and how activities, tasks and skills are understood in relation to occupation. If everything a person does is considered to be an occupation, then the implications for this research would be complex but also inclusive. Contributions to the doing of the research could be varied in every aspect – in terms of time taken and products and outcomes. For example, the act of putting a name on a mailing list could be considered an occupation, and a contribution, by expressing interest and support for the research. This understanding of occupation was important when designing this research and analysing the findings. However, defining occupation in terms of everything a person does also potentially creates complexities and misunderstandings. Royeen (2002) suggested that one way of overcoming the ambiguity between occupation as process and as product is to define occupation as the "*process of doing with meaning*" and to define the outcome of this doing not as occupation, but as activity and

participation. But Wilcock (2006) suggested that occupation was essentially a combination of activity and participation. For many stages of this research, it was enough to emphasise the value given to what people do, rather than the terminology used (Appendix A, publicity slides for research).

This value, placed on what people do, is in essence what an occupational perspective is about. It has been proposed primarily for understanding what response can be made to problems in human health and well-being (Yerxa et al 1990, Wilcock 1993, 2006). Making occupation a central focus simultaneously grounds the occupational perspective in everyday concerns and also embraces many other perspectives. For example, the occupational perspective on the experience of psychosis would consider it in terms of the impact on what the person does in their life. This would involve acknowledging how the internal experience of psychosis alters how and what people do, requiring an understanding of psychosis in terms of body and mind, of physiological, neurological, cognitive and other psychological processes. Thus medical, psychiatric and psychological perspectives are incorporated into an occupational perspective (Wilcock 2006). Understanding these other perspectives enables predictions and interpretations to be made, enhancing understanding of the meaning and purpose of what a person does. However, external responses to the actions of a person experiencing psychosis are equally important, recognising the social and cultural contexts and how these shape what people do (Rebeiro 1998, Christiansen and Townsend 2004).

Conceptual models of occupation seek to show this relationship between occupations, the person and their environment (Law et al 1996, Christiansen et al 2005). In principle, this research was structured along these dimensions, with Strand A being concerned with the *environment* of day services, Strand B with the *occupations* of social networking and recreation, and Strand C with the roles played by *people* in user-led

groups. Here, the environment involves not just the physical space, but also the social, political, institutional and cultural environments which shape occupations (Law et al 1996). However, while there might be a focus on which dimension (person, environment or occupation) could be developed, each could not be separated entirely from the other. So in this research, while there might be prevalent beliefs about which environments were desirable in terms of social inclusion, meaningful plans for development could only be identified by also taking into account the people using day services and the things they needed to do.

Yerxa (2000) highlighted the importance of studying occupation without thinking about therapy. She argued that this would facilitate a greater understanding of how occupation contributes to health and well-being, benefiting everyone and not just people in contact with occupational therapists. Hocking (2000) has stated that key components of the study of occupation, or occupational science, should be concerned with understanding occupation itself, the processes and outcomes of being occupied, and the relationship between occupation, health and other issues.

Occupational science first emerged in the USA where occupational therapists were disillusioned by dependence on medical and psychological explanations for ill-health (Zemke & Clark 1996, Yerxa 2000). That is, explaining ill-health in terms of occupation. The occupational perspective on health was also core to Wilcock's work (1993, 1998b, 2006) and has been the subject of continued debate amongst occupational therapists (Molineux and Whiteford 2006, Hocking and Nicholson 2007). There is no doubt that this development echoed broader shifts beyond occupational therapy, influenced by postmodernist perspectives on health and well-being (Creek 1997, Whiteford et al 2000). Wilcock's work was based on a history of ideas, examining how an occupational perspective on health had evolved since antiquity (Wilcock 1993, 1998b, 2001a, 2002, 2006). She drew on many examples to

support her argument. For example, common directives on how to live the good life, such as the Regimen Sanitatis, gave very specific advice on what to do to stay healthy in terms of everyday occupations (Wilcock 2006).

An occupational perspective on health, then, requires consideration of internal and external influences, as expressed through what people do. There is recognition that the things that people do are not only a response to changes in their internal or external situations, but also are personal efforts to initiate and sustain changes (Townsend 1998). In these terms, health is indicated by active participation in occupations which enhance health or wellbeing (Wilcock 2006). This is not to assume that the ability to participate is solely dependent on having specific personal capacities (Blaxter 2004). An occupational perspective fully acknowledges the environmental or external determinants of occupation (Wilcock 2006). But the belief that people are also actors, or agents, in determining their own lives, is central (Blaxter 2004). However, an interest or focus on everything people do potentially leads to an unfocused, subjective and unmanageably complex situation, possibly also intrusive and/or mundane, being concerned with everyday actions. The notion of participation can be helpful in containing the occupational perspective.

### ***Participation and occupation***

Participation is another term used widely, both within the occupational science and therapy literature, and beyond the health and social care context. The limitations and difficulties in encouraging participation to inform development are recognised (Cooke and Kothari 2001), especially in relation to gaining consensus on issues and representativeness (Kothari 2001). This relates to the discussion in Chapter One about citizenship and direct democracy. Participation is not just expressed through casting votes and contributing to public debate. Eligibility to participate in society is judged on the basis of what people choose to do.

For those who are not considered eligible to participate, occupational choices are restricted, for example asylum seekers, prisoners and people with mental health problems detained for the safety of themselves and others (Polgar and Landry 2004, Whiteford 2004).

Participation is viewed by occupational scientists and therapists as being intrinsically related to occupation (Polgar and Landry 2004, Hocking and Nicholson 2007). Borell et al (2006) investigated how service users with an experience of chronic pain understood participation, and argued that it was a much more sophisticated concept that might be assumed from the definition in the International Classification of Function (ICF). Participation has been placed alongside activity and body functions/structures in the ICF and defined as "*involvement in a life situation*" (World Health Organisation 2001a). Borell et al (2006) found that service users offered a more detailed view, with participation involving activity and social aspects. Being active implied physical actions and being social included not only doing things with other people, but doing things for other people. There was also a sense of agency, which in this context was about taking control of occupations.

However, Hocking and Nicholson (2007) have suggested that the ICF's emphasis on participation has precipitated a shift in attention within the health professions. It must be recognised in turn that the ICF was a response to the efforts associated with the advocates of the social model of disability (World Health Organisation 2001), who viewed participation as more important than cure or elimination of symptoms at all costs. So far, participation has been seen as a good thing. In contrast, Polgar and Landry (2004) recognised that participation is not always out of choice and user control is not guaranteed. This is echoed in debates about user involvement which have already been discussed in Chapter One. Their understanding of participation in relation to occupation emphasises the need to:

*“engage the whole person – their body, mind and soul – either on an individual basis or as a group.” (Polgar and Landry 2004, page 199)*

This understanding of participation was important to this research – people as individuals were viewed as participants if there was a sense of this engagement of the whole person. Equally, groups of people were viewed as participating, even if it appeared as if individuals might not be able to engage as a whole person all of the time. Hence signing up to be on the mailing list was seen as entering into the spirit, or soul, of the research, even if it involved minimal bodily activity.

Perhaps the act of signing up signalled a promise of greater participation to come. Watson and Lagerdien (2004, page 109) suggested that:

*“Participation has a strong immediate influence but also informs and enables other actions that follow.”*

This promise could be seen as a signal of intention to participate. Occupational scientists have suggested that people are primarily oriented to do things that are meaningful and purposeful (Christiansen and Townsend 2004, Christiansen et al 2005, Wilcock 2006). One of the common themes in this work is that human physiology, especially the brain, is primarily designed for action or occupation, in order to secure survival and health (Wilcock 1993, 2006). Thus our occupations meet not only our social and economic needs but also our physiological needs (Wilcock 2003). Wilcock’s studies of the history of health and occupation (2001a, 2001b, 2002) led to the claim that utopian visions were centred around occupation, ensuring that not only would all citizens have something to do, but that it would be based on their individual needs and capacities as much any collective requirements.

For this research, understandings of participation were informed by these utopian ideas. It was believed that participation is primarily expressed through occupation. People were considered to be participating in the research if they were doing something related to it. It was also seen as a focus of the research, in that participation could be achieved by paying

attention to what people wanted and needed to do. Aspects of doing (or participation or occupation) were carefully attended to for their potential to involve service users at many different levels in many different ways. This seemed ethically appropriate given the nature of their difficulties as people with long-term mental health problems. The simultaneous attention to what they were doing and what could be done is reminiscent of the ambiguous nature of occupation, referred to at the beginning of this chapter. Complexity theory was helpful in understanding this consequence of taking an occupational perspective on the research.

### **Recognising complexity: Form, function and meaning**

Occupational form has been analysed as an expression of culture by Caulton and Dickson (2007), who argued that culture is central to occupation, *“not just something to take into account”* (page 112). The culture of mental health day services, along with the urban location and the academic research culture brought to the services, all shaped the form of the occupations undertaken as part of the research, which in turn were interpreted for their function and meaning by those involved. Caulton and Dickson (2007, page 95) claimed that *“knowing what to do is precisely the problem”*. Based on their work with community programmes in South Africa, they suggested that because it was very important to consider what people were participating in, and what they were doing, the facilitators (or therapists) had to become participants themselves, in order to understand what was possible. They also recognised that when possibilities were transformed into realities, the journey to create these possibilities was not always remembered. Tacit knowledge is integral part of this (Polanyi 1966). Once again, there is a question of process and outcome, means and ends.

In a definition of occupational therapy as a complex intervention, Creek (2003) suggested it was because of its complex nature that occupation could be both the means and the focus simultaneously. So for this research, it was possible to focus on the occupations associated with



doing the research, and also those associated with the research topic, at the same time. It was also recognised that these aspects would interact not only with each other, but with other things going on, for individuals, groups and organisations. Whiteford et al (2005) highlighted implications of complexity theory for occupational therapists, and these are summarised in Table 2.

**Table 2:**  
**Implications of complexity theory (Whiteford et al 2005)**

Recognising diversity  
Recognising interactive processes  
Recognising qualitative processes  
Recognising multiple explanations  
Simulation rather than simple models  
Coping with unpredictability  
Limitations of logical, deductive reasoning  
Exploring patterns and relationships

Rather than try to simplify and control a situation, complexity theory proposes a direct engagement with its multidimensional, dynamic nature, accepting unpredictability as part of life (Plsek & Greenhalgh 2001, Brown 2006). There is some debate about complexity theory and occupational therapy in terms of interventions (Creek et al 2005, Duncan et al 2007), but this research was not concerned with therapist-controlled interventions, being more interested in collaboration and service development in a setting committed to change. As discussed in Chapter One, the phenomenon of complexity has implications for understanding life processes at every level, from a cell to an organisation (Capra 2002). The concurrent processes of development and renewal are strongly aligned with the issue of means and ends in relation to occupation. In Capra's view, these processes are directed by human action, which is in turn invested with personal meaning. Personal meaning is important in relation to occupation, too, along with occupational form and function.

From an occupational perspective, considering the form, function and meaning of an occupation involves paying attention to the way things are done (the occupational form), the purpose for the action (the function) and the significance (the meaning) (Kielhofner 2002, Larson et al 2003, Nelson and Jephson-Thomas 2003, Nelson 2005). In this research, these aspects were consistently important as considerations and have been used in the final analysis. While there is disagreement between theorists on the finer details of what constitutes occupational form, function and meaning, there is agreement that the occupational form can be observed but only understood in terms of functions and meanings, which may be diverse, numerous and inevitably are subjective and individual (Hasselkus 2002, Kielhofner 2002, Larson et al 2003, Nelson and Jephson-Thomas 2003, Polgar and Landry 2004, Baum and Christiansen 2005, Moyers 2005, Nelson 2005).

Distinguishing between function and meaning was important in relation to this research – Nelson (1988) provided a helpful distinction, suggesting that function (or purpose) is concerned with prediction, whereas reflection is required to reveal meaning. Creek (2003) suggested that an occupation might not be always perceived as meaningful at the outset, but meaning would be created as participation evolved. This understanding has been echoed by Rapport (2003), an anthropologist, in an analysis of what makes individuals powerful. This analysis suggested that less emphasis needed to be placed on why people do things in terms of external drivers, or 'because motives'. As a balance to this emphasis, renewed focus is required on why people do things in terms of what their intentions are, or 'in order to motives' (Rapport 2003). In terms of this research, both 'in order to' and 'because' motives were meaningful – as a response to the context for the research and in recognition of how people sought to be engaged with it.

Form, function and meaning, as three dimensions of understanding the products of human activity, are found in linguistic theory (Hamers 2000, Macey 2001), art and sculpture (Wittkower 1977, Van der Meer and Sudjic 1997) and anthropology (Rapport and Overing 2000). The relationship between form and function was first expressed in linguistic theory, emphasising the interactive and dynamic aspects of language which can be captured by considering its form (or words, accents, technologies), its function and many different meanings (Hamers 2000). In architecture, debates have been provoked by the modernist proposal that architectural form, or buildings, are best when primary consideration is given to their function, ignoring the potential meanings that might be associated with aesthetic or symbolic features (Van der Meer and Sudjic 1997). These debates were triggered by the claim by Louis Henri Sullivan that form follows function (Knowles 1999). Anthropology is concerned with the diverse forms of human activity and understanding the meanings behind each form. Rapport and Overing (2000) suggest that cultural forms are subject to simultaneous processes, of estrangement from their origins and re-creation as old forms become redundant. In becoming estranged from their origins, cultural forms are shared and become increasingly meaningless to individuals, who are then driven to generate new forms which are subject to the same process. This was evident in mental health day services, as expectations changed within and beyond the services, occupations shifted and changed, raising new questions and challenges.

There are post-structuralist arguments against imposing a framework of form, function and meaning onto human occupation, for example from Deleuze and Guattari (Fox 1993). These arguments are considered in the discussion of the final analysis.

### **Factors influencing participation in occupation**

So far, it has been suggested that the occupational perspective is associated with an understanding of the complexity of occupation and its

central importance for human survival and health. Wilcock (2006, page 209) suggested that:

*“Doing, being, becoming and belonging are the means to survival and health.”*

In other words, survival and health can be attained through specific occupational forms (doing) which reflect personal meaning and identity (being), are oriented to particular functions or purposes (becoming) and acknowledge the social nature of individuals (belonging). This section briefly considers the reasons why people are not able to do this. In this research it was important to recognise how the setting of mental health day services constantly impacted on people’s occupational choices. Rebeiro (1999) suggested that some community mental health services restricted participation, with the emphasis on individual problems which in turn created a “*labyrinth*”, affecting accessibility and inclusion. People got stuck trying to navigate formal services to meet their own needs to the extent that it became impossible to see beyond the services to other occupational opportunities and sources of support for recovery.

Occupational perspectives on choice, access and inclusion are drawn together in the theory of occupational justice, proposed by Townsend and Wilcock (2004). A distinction is drawn between occupational justice and social justice to highlight the importance of individual occupational potential and personal meanings (Townsend and Wilcock 2004, Townsend and Whiteford 2005). It is therefore important to acknowledge what people are able to do but also what is meaningful to them and meets their ‘becoming’ needs, or intentions. This derives from the definition of occupation as being everything people do (Wilcock 1998a). If everyone is to have the opportunity to do the things they need to do to secure their health and survival, there are major implications for the distribution of resources and the value attributed to different occupations. Different economies, policies and cultural values all impact on occupations, leading to occupational justice and injustice (Townsend and Wilcock 2004).

The outcomes of occupational injustice have been identified as occupational risk factors, originally identified by Wilcock (1998a) as occupational imbalance, occupational deprivation and occupational alienation. These risk factors describe situations where people have too much or too little to do (imbalance), are prevented from participating in occupations (deprivation) or participate in occupations that are meaningless to them (alienation) (Wilcock 1998a, Townsend and Wilcock 2004, Whiteford 2004, Wilcock 2006). The study preceding this research generated an interest in occupational alienation in mental health day services, which has since evolved (Bryant et al 2004, Bryant 2008). Other occupational risk factors have been identified such as occupational apartheid (Kronenberg and Pollard 2005).

It has to be questioned whether there is an advantage in prefixing terms such as apartheid, marginalisation and alienation with the word 'occupational'. Yet it has been possible to distinguish between occupational, social and intrapersonal alienation (Bryant 2008). The occupational perspective embodies an assumption that it is possible to transform situations not only by shifting how people think and relate to each other, but also by changing what they do and how they do it. The next and final section briefly considers transformation and occupation.

### **Occupation and transformation**

Evidence of change or transformation can be attributed to shifts in attitude but more often it is the way things are done which indicates that sustainable change has taken place. Townsend's research in mental health day services, an institutional ethnography, enabled her to contrast situations where transformations or changes were possible, and where they were inhibited by power relations and institutional practices (Townsend 1998). Occupations in real-life, as opposed to simulated, environments were an important factor. For this research, it was

important to engage the participants in the whole process of the research and all its associated occupations.

Watson and Lagerdien (2004, page 112) stated that

*“Transformation is about how what we do now differs from the past, and partly as an awakening of understanding about how to change things for the better.”*

Simulated environments, because they are not controlled by the participants, limit how much sustainable transformation is possible and how much reflection is required. This is interesting in relation to equipping service users for participation in research by facilitating access to training courses in research methods. While there is no doubt that these courses provide a valuable opportunity to learn, it seems appropriate to argue that there has to also be an opportunity to participate in research that is actually happening. The “*awakening of understanding*” suggested by Watson and Lagerdien (2004, page 112) will surely be more readily provoked by tangible experience, or occupation. In a passionate call for occupational therapists to use emancipatory approaches to facilitate transformation, Duncan and Watson (2004) argued that action (or occupation) framed by reflection was the most effective tool for transformation.

## **Conclusion**

For this research, occupation, action and participation have been understood as being different ways of explaining the same phenomenon. The literature on participatory action research, discussed in the next chapter, gave insights on how to conduct a project and what could be achieved. Action was understood as a contrast with reflection, giving something to reflect on and building a shared occupational history within the research process. Using an occupational perspective gave access to an increasingly rich professional and academic source of knowledge about occupation. In particular, it facilitated a more sophisticated understanding of action and participation. This was particularly in relation

to the meanings of actions, occupations and participation; the potential for transformation through actions, occupations and participation; and the equal value given to every participatory act or occupation within a framework of occupational justice.

So the occupational perspective intersected with the whole process of this research. So much of life is concerned with the process of doing, or what we do, with inactivity associated with ill health and a lack of life. This core belief infiltrated each stage, emphasising not only action, but reflection on action and transformation through action. Occupation embodies not just doing, but thinking about doing and changing through doing. This depth and complexity of the occupational perspective has offered language and conceptual frameworks for both the focus and the design of the research.

## Chapter Four

### Methodology

#### Overview

The methods chosen for this research reflected its basis in participatory action research and critical ethnography. The principle of involving service users in every aspect of the research reflected a core belief of participatory action research, which is discussed here. The research took place alongside the overall development work fostered by the Day Service Forum, which is described in more detail in Chapter Five. The research design evolved from consultation within the forum and other meetings, leading to the three specific strands which offered an opportunity for service users to become more involved in the research itself. The strands had specific methodological issues, which are discussed in Part Two.

The day services modernisation project, the emphasis on social inclusion and my own interest in occupation were all powerful external influences on the design and the implementation of the research. A critical approach was essential to ensure that the research design gave scope for service users to analyse these influences in relation to their own direct experience of services. As an outsider, it was easier for me to be critical without threatening existing relationships. Yet there were still challenges associated with being critical. The literature on critical ethnography was particularly helpful in understanding how to manage these challenges, for example to engage people in research which could impact on the services they received.

The use of both critical ethnography and participatory action research also reflected the dual task of engaging with the local setting and studying the process for formal academic purposes. In this chapter, participatory action research is discussed first. Following an analysis of the principles of this approach, examples from mental health research and occupational therapy research are reviewed. Critical ethnography is then described



and analysed. In conclusion, strategies which brought the two approaches together and enhanced reflexivity are identified.

## **Participatory action research**

The design of this research was primarily guided by principles of participatory action research, as one of the primary intentions was to explore how service users could participate in gathering information to influence the services they were receiving (Robson 2002).

### ***Definition of participatory action research***

It might seem that the term 'participatory action research' is self-explanatory. *Participatory* could indicate a social and political context, being associated with democracy and citizenship (Cornwall and Jewkes 1995). *Action* could suggest that this is a situation where human action is valued and a central focus, and *research* is usually associated with work towards change and knowledge generation. Koch and Kralik (2006) discussed the use of the term participatory action research, stating a preference for 'collaborative inquiry' although this term is only used sparingly in their text on participatory action research. However their definition of participatory action research provides a starting point:

*"Participatory action research is a process in which 'we', researchers and participants, systematically work together in cycles to explore concerns, claims or issues that impact upon or disrupt people's lives." (Koch and Kralik 2006, page 27)*

Key terms in this definition resonated with this research, where the collaborative nature of each stage of the research offered opportunities for participants to develop research skills and thus become researchers. The issues arising in day services had a direct impact on the lives of both service users and staff, and a systematic approach enabled these issues to be explored in a number of ways. What this definition does not seem to indicate is the creativity involved in developing and sustaining collaborative relationships, and the many ways in which 'concerns, claims and issues' can be explored. The systematic 'work' that takes place is not detailed.

However, the cycle of 'look, think, act', based on action research, is suggested elsewhere as a core structure (Koch and Kralik 2006). This cycle is mirrored in other process models such as Kolb's learning cycle (Kolb 1984) and, significant for this research, the occupational therapy process (Creek 2003). Both these models incorporate stages of assessment or looking, reflecting or thinking and intervening or acting. Familiarity with these models in practice helped understanding that the cycles within participatory action research are not necessary distinct and consecutive, but overlapping and concurrent.

An alternative definition is offered by Nelson et al (1998, page 885):

*"a research approach that consists of the maximum participation of stakeholders, those whose lives are affected by the problem under study, in the systematic collection and analysis of information for the purpose of taking action and making change."*

This definition does not overtly indicate the involvement of participants at every phase, nor the characteristic cycle. However the use of the words 'maximum participation' suggests an emphasis on this aspect of the research. Koch and Kralik (2006) place emphasis on stories as a central resource for reflection and analysis. In this research, it was recognised that storytelling does not just have to be a verbal exchange. Meaningful occupations could generate new shared stories and provide new perspectives on stories still unfolding (Mattingly 1998, Clouston 2003).

### **Origins**

There appear to be two main influences for the emergence of participatory action research, stemming from the work of Lewin and Freire (Khanlou and Peter 2005). The belief, that useful knowledge can be generated in partnership with those who know the topic, underpins action research and originates from the work of Lewin. A similar but more political belief underpins influence of Freire. Here the process of engaging with those who know the topic of inquiry is recognised as being empowering (Khanlou and Peter 2005).

Lewin's work was oriented to mapping processes of human life, and has been used by occupational therapists (Law et al 1996) as a theoretical reference point for the person-environment-occupation model which has since evolved into the Canadian model of occupational performance (Canadian Association of Occupational Therapists 1997, Townsend and Polatajko 2007). Lewin's research examined the interplay between the social environment and production in factories (Coring 2001, Young 2006). It was believed that users of the technology could generate useful insights into how the system worked. Lewin (1952) proposed action research as a means of exploring the processes and structures of social life. His emphasis on process led to the cycles of reflection, planning and action which characterise action research (Schwandt 2001). Lewin also recognised that knowledge gained through experience was valuable, leading to the particular value placed on participants' knowledge in participatory action research projects (Krimerman 2001) and the implicit challenge to the status of detached, objective, professional experts (Baum et al 2006).

An equally significant influence on the development of participatory action research was Freire (1970) who made a detailed analysis of the process of empowerment through education. Of particular relevance to this research was his emphasis on those in leadership roles facilitating empowerment through dialogue. The responsibility for naming experiences and ideas should be shared, in this research illustrated by events such as naming the poster produced in Strand B "Getting better by going out" and large group discussions about what day services were actually designed to do. An issue for the design of this research was whether Freire's notion of dialogue was exclusively verbal and oriented to abstract ideas, or whether it could be rooted in occupation. The emphasis on dialogue suggested a verbal emphasis; however Freire suggested that words are created by the interplay of reflection and action (Freire 1970). The naming of the poster produced in Strand B was a simple example of this – for without the action of producing the poster there would have

been nothing to name, and without collective reflection on the action of producing the poster, a name could not have been identified.

The emphasis on empowerment indicates one of the major differences between action research and participatory action research, although the distinction is not always clear. Participatory action research is often regarded as one approach of many within the category of action research (Schwandt 2001). It could be that the processes of action research and participatory action research appear broadly the same, with more emphasis on empowerment in the latter. However, this difference is significant. Lewin valued the knowledge held by participants as useful resource, whereas Freire valued the process of making people aware of the knowledge they had. Koch and Kralik (2006) suggest that one of the key differences between action research and participatory action research is the influence of feminist theories, where equality and the significance of the everyday are significant. Potentially, everybody can be involved in every phase of the research in a variety of ways. This was important for this research, which involved collaborative work from the very first meetings through to identifying how the findings could be taken forward.

### ***Key features of participatory action research***

Participatory action research is focused on political, social and educational knowledge (Young 2006). Schwandt (2001) suggested that participatory action research is about working to change practice rather than generate theory. One of the most exciting aspects of participatory action research is the potential for a mutually beneficial relationship between researchers, paid workers and users of the research setting, oriented to change which benefits those within the setting (Corring 2001, Baum et al 2006). This addresses some of the ethical barriers to conducting research with marginalised communities (Young 2006): meaningful participation offers the potential for all participants to shape the research to reflect their key agendas. In a participatory action research project, there is an emphasis on participation at every stage,

based on the belief that everyone can contribute and that the outcomes should be useful as well as empowering. There is an inherent recognition of how power can be shared and negotiated within the process of change, actively addressing inequalities which prevent people being involved (Baum et al 2006, Young 2006).

Koch and Kralik (2006) indicate two main dimensions to the process of participatory action research. The democratic dimension underpins the relationship between the participants and the overall approach of the research, being primarily concerned with a positive engagement with human resources and issues. The cyclical dimension suggests the shape of the process, emphasising that not only is action involved, but also reflection on action and the generation of new understandings (Koch and Kralik 2006). The level of involvement can be compromised by organisational barriers and pressures. Power inequalities can undermine participation and action, and thus efforts to conduct research (David 2002, Hodge 2005). For this research, it was important to reflect on the barriers to participation and to question them. Sustaining this approach over time was challenging in this setting, as at times the involvement of service users was affected by other difficulties, often associated with their long-term mental health problems.

Criticisms of participatory action research have centred on the focus on empowerment rather than the creation of new universal truths, suggesting that participatory action research cannot contribute to scientific progress (Krimerman 2001). Krimerman examined the philosophical objections to participatory action research, highlighting the difficulties associated with knowingly involving participants in a process which they might not be familiar, yet focusing on a topic about which they might well have strong feelings. Neutrality seems remote in this scenario. However, emotional investment is valued in participatory action research, as a means of securing the engagement of people who would usually be excluded from other forms of research or subjected to a narrowly focused inquiry which might ignore the socio-political context (Koch and Kralik 2006). It would

seem that Krimerman deliberately polarised his argument, placing participatory action research at the opposite pole to scientific research, despite his own admission that conventional methods of social science, such as surveys, have been used within participatory action research projects.

Rapport (2003) drew on Nietzsche's suggestion that both non-scientific and scientific endeavour are required to advance knowledge and understanding. Without science, there can be an absence of structure and accountability. Without 'non-science', there can be an absence of passion and inspiration (Rapport 2003). Participatory action research requires passion and inspiration to fuel participation, but successful action requires a structured and accountable approach. This is essentially the conclusion that Krimerman (2001) came to, although he used the terms 'partisan' and 'value neutrality'. By being partisan, relevant topics can be identified and explored in meaningful ways. Value neutrality is required to ensure that the process of identification and exploration is accessible, understandable and democratic. A similar analysis was conducted by Wadsworth (2005), a sociologist, examining the contrasts between the positivist tradition and critical constructivism. She concluded that the growth of popularity of participatory action research within and beyond sociology offered an opportunity to bridge the two extremes.

Other identified disadvantages to conducting participatory action research were concerned with the unpredictable and time-consuming nature of a typical project and, for academics, the low status given to the achievements of projects (Baum et al 2006). The strategy adopted in this research, of being based in a setting already committed to change, had some advantages. It secured organisational commitment to the research while offering an opportunity for participants to influence and direct the details of initiatives. The cyclical nature of participatory action research gave scope for developments to be built on reflection and action. Within occupational therapy it has been recognised that participatory action research is strongly resonant with the core values of the profession

(Kronenberg et al 2005) and the issue of status was therefore less significant.

Participatory action research is not a method in itself, but a point of reference for making a choice of methods (Khanlou and Peter 2005). The exact methods used to gather information, provoke reflection and structure action vary from project to project (Koch and Kralik 2006). In this research particular attention was given to using contrasting methods, as a means of engaging different people in different ways. This reflected principles of occupational justice (Townsend and Wilcock 2004): it was not enough just to create an opportunity for participation; but varied opportunities were required to reflect the individuality of occupational choices (Townsend and Wilcock 2004). What suited one person might not suit or be meaningful to another. To understand how research could generate different opportunities, it would be necessary to consider each of the occupations associated with the research.

Another challenging aspect to participatory action research is getting people involved. Cornwall and Jewkes (1995) suggest that the concept of participation may not be welcomed by a community, challenging both recruitment and issues of representation. For this research, perceptions of participation were varied for a number of reasons. It was recognised that participation was ultimately controlled by mental health professionals who determined service users' status within the organisation. This status could range from compulsory inpatient treatment under a section of the Mental Health Act to discharge and exclusion from participation all together. One participant did experience compulsory admission during the research but it was possible to remain in contact. This is discussed further in Chapter Seven. What was more challenging was engaging service users who were being actively discouraged from attending day services. An ongoing dialogue with the staff was important to understand what was happening. In one instance a service user was excluded from day services because of involvement in criminal activity. Because of the serious nature of this situation, it was not felt to be appropriate to

encourage continued involvement in the research, although an active part had been taken in the early consultative phases.

These considerations were in some ways specific to the mental health setting. Examples from the literature emphasised the importance of skills in group facilitation and the benefits to service users in participation (Khanlou and Peter 2005, Knightbridge et al 2006, Koch and Kralik 2006). There have been consistent efforts to secure service user participation in mental health service development (World Health Organisation 2001b, Crawford et al 2003, Hodge 2005) but the use of participatory action research has not been widely reported in academic literature. Community participation has been particularly valued in a general sense (World Health Organisation 2001a, Cameron et al 2003, National Social Inclusion Programme 2006) and Corring (2001) suggested that the emergence of participatory approaches to research has reflected how energy has been redirected to involve patients or service users in decision-making on an everyday basis. There are specific examples from the mental health setting such as Knightbridge et al's study (2006) which mirrored this research with a focus group study as a basis. However, that study is research in progress and the outcomes of the proposed community advisory groups and consultative forums have yet to be reported.

Kralik and Koch (2005) reported on a completed participatory action research project with people living in supported accommodation and experiencing continence problems, convening a series of group meetings in collaboration with the Continence Nurse Advisor. This approach is echoed in the design of the first two strands of this research, where specific groups were established to explore a particular topic. Kralik and Koch (2005) observed that experience of group facilitation was particularly important and recognised the role of the facilitator in protecting the boundaries of the group. However there was no recognition of the differences between small and large group dynamics which was equally important (Bion 1961, Finlay 1993, Cole 2005).



This research required an understanding of both small and large group dynamics, encompassing both. It was recognised throughout that large group meetings in particular would present a challenge for equal and respectful participation, and so regular opportunities were created for participation in small groups or informal, unstructured times, to promote interaction. These opportunities were created before and after many meetings, giving individuals an opportunity to make informal approaches to express interest in the research, ask questions or just make informal social contact. Participatory action research is inevitably associated with group work (Koch and Kralik 2006); by its nature bringing people together to work on shared issues. It was felt to be an appropriate research methodology to use in the mental health day service setting, where a sophisticated understanding of the power of group work had been established for many years (Shepherd et al 1993).

Another example of participatory action research in mental health (Khanlou and Peter 2005) highlighted the benefits to participants, for example the acquisition of leadership skills and increased self-awareness. The aim of participatory action research has been claimed to facilitate change (Baum et al 2006) and it could be argued that seeking to do this within statutory mental health services was over-ambitious. Indeed it was not the intention of this research to initiate change but rather to work with the change process that had already been initiated, securing opportunities for people to become involved with the ongoing process in a meaningful way. Developing services was not the only change in process, as staff and service users inevitably were engaged in personal transitions of their own.

### ***Participatory action research and occupational therapy***

The final consideration in relation to participatory action research was in relation to occupational therapy. Participatory action research has received attention from two separate schools of thought in occupational therapy in recent years. The first is in relation to scholarship of practice

(Forsyth et al 2005, Suarez-Balcazar et al 2005), although there is a greater emphasis on action research rather than participatory action research. This would seem appropriate, given that scholarship of practice has the improvement of professional practice as a central concern (Forsyth et al 2005). The second school of thought is informed by occupational justice, which has been discussed in Chapter Three (Townsend and Wilcock 2004). It has been proposed that participatory action research has a natural affinity with further inquiry into occupational justice (Kronenberg et al 2005, Wilcock 2006). This research was strongly influenced by this belief.

Examples of participatory action research undertaken by occupational therapists include a study by Taylor (2003), which was focused on how a participatory approach could be used to develop a group programme for people experiencing chronic fatigue syndrome. A focus group was used initially to determine issues to be addressed within the programme and identify personal goals. The data were used as the basis for eight subsequent group meetings. This study was interesting in that the programme had overt therapeutic aims yet drew on consultative strategies used in participatory action research. It has been suggested that participatory action research and client-centred practice have much in common (Townsend et al 2000, Taylor 2003).

For this research, it was observed that staff beliefs and understanding of client-centred practice influenced their ability and enthusiasm for engaging service users in participatory action research. For example the co-facilitator staff member for Strand A was very anxious that her presence should be a beneficial factor to the group, and open discussions about confidentiality enabled her to negotiate with the service user members, for example about what should happen should they wish to criticise her colleagues. She also used her prior knowledge of service users to identify appropriate opportunities for involvement. Townsend et al (2000) identified that research is an occupation, and thus to an extent the aims of occupational therapy mirrored the aims of participatory action

research. For both, there is an emphasis on facilitating meaningful involvement to improve the lived experience of participants. However, occupational therapists have traditionally worked on an individual basis to this end and within organisational constraints, unlike participatory action research where a collective approach is fundamental, and organisational constraints are challenged.

Suarez-Balcazar (2005) reported on a participatory action research project where an occupational therapist was involved in many elements of the project, which aimed to work with a community group with emphasis on facilitating access to technology as a tool for community participation. Her analysis suggested a role for occupational therapists, based on professional knowledge of the community, skills in collaborative working with other professionals and service users, and skills in analysing and facilitating occupational development for participants.

Most relevant for this research was the study led by Elizabeth Townsend (Townsend et al 2000), consisting of twenty-five separate projects involving service user members of a mental health club house over a two year period, building on an institutional ethnography which had commenced six years earlier (Townsend 1998). These projects resembled the strands in this research, although on a much larger scale. The projects were carefully categorised according to the components of data analysis, education and action. All projects involved some sort of data collection but varied in other respects. Townsend linked the study with the principles of occupational justice and called for occupational therapists to be client-centred in research as well as in practice.

The occupational perspective framing this research provided a sophisticated understanding of participation, and this perspective enabled diverse contributions to the research to be recognised. Along with the modernisation project and the emphasis on social inclusion, this perspective required a critical approach to the setting. While participatory action research was the principal reference point to inform this research,

critical ethnography also played a key role, clarifying and informing the role of insider and outsider, and leadership in particular.

### **Critical ethnography**

It was during the consultative phase of this research that critical ethnography was investigated in relation to this research. The investigation grew in significance as the potential of critical ethnography became clear. I was particularly sensitive to metaphors, jargon and terminology, seeking clarification on terms which seemed to be in common use in particular ways within the organisation. Understanding the details of the setting in this way reflected an ethnographic approach (Hammersley and Atkinson 2007). Thomas (1993) suggested a contrast between taking an ethnographic approach to a setting, in order to understand what it is all about, and a critical ethnographic approach, in which the researcher explores what it could be, rather than what it is. Critical ethnography is an attempt to uncover the agendas which support the status quo. In other words, it is not thinking about a future idealised situation which could be worked towards, but what assumptions are currently operating covertly. Thomas defined critical ethnography as:

*“the reflective process of choosing between conceptual alternatives and making value-laden judgements of meaning and method to challenge research, policy and other forms of human activity.” (Thomas 1993, page 4)*

This definition strongly linked reflection and questioning. It could be argued that I had to adopt the role of a critical ethnographer in order to achieve my goal of exploring how service users could become involved in the development of day services. I was concerned with understanding what was happening in order to construct a meaningful and useful research study.

Madison (2005) claimed that the origins of critical ethnography lie in social anthropology and the work of John Dewey. In contrast to participatory action research, in critical ethnography there is an emphasis on issues of representation and interpretation. Both approaches are

embedded in a belief that research can have an empowering effect on participants. In participatory action research, the focus is on enabling participation within the wider context for the research, perhaps indicating its origins in action research. In critical ethnography there is greater emphasis on the responsibility of the researcher to engage with the participants in their culture and world (Madison 2005), perhaps reflecting influences from social anthropology.

It is in relation to the leadership of participatory action research that critical ethnography appears to be most helpful. Madison (2005) suggested that a person leading research with marginalised people has to actively consider issues of interpretation and representation. This requires awareness of the leader's personal agendas. In this research, this awareness was explored through the use of a number of tools of reflection, from diaries to informal and planned discussions with a range of people. The service users involved in the research, as they evolved into co-researchers, became particularly valuable partners in reflection. The contrasts in perspectives on the research constantly challenged me to consider where my perspective derived from.

Thomas (1993) emphasised resistance, and how it helped clarify predominant interpretations. Each of the three research strands was designed to explore particular beliefs which were encountering resistance from different places. Strand A focused on the use of social lounges for social networking, which was being discouraged by staff in favour of integration into mainstream community settings, despite strong service user resistance. I was particularly interested in questioning what would constitute an equivalent to the social lounges in the 'mainstream' community. Strand B focused on the belief that there were many things to do in the community which were accessible to people with mental health problems, which would benefit service users. I was interested in exploring to what extent these activities acted as a substitute for building-based, informal day services. Strand C focused on the belief that service users could support themselves in groups without involving mental health

professionals. I was interested in how the service users perceived this task. Each of these beliefs were strongly influential both in the local agenda for development and in the national agenda for the modernisation of day services.

Baum et al (2006) suggest that a 'critical edge is central' to participatory action research. Working with change in a setting with multiple agendas and shifting power relations requires a critical examination of actions and motives in the present and the past. Freire's writing on oppressors and the oppressed (1970) was a trigger for ongoing personal critical reflection and texts on critical ethnography (Thomas 1993, Madison 2005) were used to inform this process. My status as PhD student and academic indicated an independence from the organisational division between staff and service user.

From a distance it could be assumed that the staff were the oppressors and the service users the oppressed, and as a consequence my task would be to focus on the oppressed, the service users, and challenge the oppressor. There were times when this did happen. However the study preceding this one (Bryant et al 2005) indicated that a designated role did not in itself indicate the role of oppressor or oppressed, with staff working in the day services feeling oppressed by other staff groups and managers, and service users feeling empowered by some strategies used by staff. Freire's analysis of the relationship, beliefs and behaviours of both oppressors and oppressed led him to conclude that meaningful involvement could only be achieved through people working together, trusting each other and aiming to re-create knowledge and understandings which reflected everyone's views (Freire 1970). Everyone had the potential to be oppressor or oppressed. Meaningful involvement required ongoing attention to these issues, as an integral part of the process of change.

Familiarity with Freire's ideas from an early phase in this research led to value being placed on critical explorations of my role, especially in terms

of being a facilitator for the research. The 2002 study (Bryant et al 2005) required active consideration of the differences between working as an occupational therapist as a therapist, and working as a researcher. In this research, these differences were revisited in the light of the collaboration required with service users and staff, and the long duration of the project which extended over years, not weeks. I could have made use of the practical examples and precedents established within participatory action research, but I was conscious that in addition to facilitating the reflections and actions of others, a very active, critical and personal reflective process was taking place. This was particularly evident in the evolution of my role within the Day Services Forum, a meeting which occurred every eight weeks to oversee developments of the day services. From an early stage, I was drawn to share my critical reflections and questions, not just to promote this process in others but also to share and evoke different perspectives. In doing this it seemed possible that I was seeking to control and shape the situation in a way which might not have authenticity for the participants, and yet it seemed necessary in order to raise awareness of not only the issues but the possibilities and the conflicts. I was surprised to discover how my own personal history as an activist was increasingly important in this setting.

David (2002) reflected on the conflicts inherent in participatory action research and how they impacted on an academic researcher. He suggested that rather than try and advocate particular agendas and risk alienating other potential participants or stakeholders, the academic researcher should maintain 'a degree of critical distance.' How achievable this is in long-term studies is questionable. In this research, my overt aim was to conduct doctoral studies, and there was no issue of being accountable to funding agencies as there were no funds available. However, ongoing discussion was required regarding the outcomes of the research. It seemed important to generate tangible products, in this case the photographs, reports and poster, which could be owned by the participants and used independently from the research. Likewise it was

recognised that my ultimate motivation was to produce a thesis which would have significance beyond the local setting.

### ***Precedents***

There are not many published critical ethnographies by health and social care professionals, and none by occupational therapists. Hodge (2005) gave an account of a study of a service user forum established by a statutory organisation anxious to increase service user involvement. An ethnographic approach was used to uncover the power relations in operation in dialogues between service users and officials at the forum. However, this study did not seem to constitute a critical ethnography, as there was no evidence given of sharing interpretations or perceptions with the forum, with a view to empowering the participants. For this research, there was an option of progressing in this way, taking a purely ethnographic approach. But the prevailing emphasis on modernisation prompted questioning dialogues between Day Service Forum members.

Cook (2005) suggested that it is not always clear what the distinction is between critical ethnography and participatory action research. She made reference to a study by Travers (1997, cited in Cook 2005) which combined the two, much in the way that this research has done. She suggested that the participants are regarded differently in the two approaches: in participatory action research the aim is for the participants to become co-researchers, as equals. In critical ethnography, the researcher retains control of the research at specific stages. The use of Carspecken's five stage approach (Cook 2005, Hardcastle et al 2006) clarifies this. The first stage of Carspecken's approach is to engage with the setting in order to understand the issues. Rather than engage the participants from the outset in a dialogue about the issues, the critical ethnographer seeks to create a 'thick' description or understanding of the setting from an outsider's view. This mirrors the beginning of the consultative stage of this research, where it was not clear who the participants were going to be or which issues were going to be the focus.



The second stage of Carspecken's approach is called the interview stage and the three remaining stages are concerned with analysis (Cook 2005). The purpose of the second stage is to engage participants in questioning the critical ethnographer's description or understanding of their setting. The end of the consultative phase in this research had echoes of this process, although consultation was more focused on the design and topics of the three strands. The three strands in this research marked the shift from critical ethnography to participatory action research, although there was not a distinct break from one to the other.

## **Conclusion**

Combining critical ethnography and participatory action research facilitated a critical and active engagement with the setting. This approach was innovative for day services, mental health services and occupational therapy. The interplay between the theoretical aspects and what was practically possible was essential to create a study which was both credible and feasible. The theories used and the beliefs about what could be achieved were influenced by experience of, and reflection on, the setting. Reflection in this case meant more than thinking over experiences and resolving how to act in the future. McFadden and McCamley (2003) used the metaphor of loosening knots to describe reflexivity in their participatory action research project. This metaphor resonated with the ongoing, process-oriented nature of being reflexive in this research. Reflexivity has been defined by Finlay (2002, page 533) as an analytical process, engaging with an *"immediate, continuing, dynamic, and subjective self-awareness."*

Thinking and questioning pervaded the research, within the setting and beyond. Conversations, discussions and debriefing enclosed and underpinned critical incidents and planned events. The dynamic aspect of being reflexive involved not only questioning my own responses, but listening carefully to the questions and responses of others. There was constant movement between consideration of my own perspectives, and

those of others (Finlay 2002). Conference presentations in particular gave an opportunity to explore where the research fitted in the wider world. Regular academic and operational supervision facilitated this process and continued throughout the phases of the research, which are detailed in the next chapter.

## Chapter Five

### Method

#### Overview

Practical aspects of the planning and implementation of the design are discussed here. Broadly, the research fell into three phases, with collaborative work throughout. There was a consultative phase, an active phase and an evaluative phase (Table 3, Phases of the research). In the active phase, there were three distinct strands which are introduced in this chapter and detailed in chapters six, seven and eight. The findings from these strands were analysed alongside the findings from the collaborative work, and the strategy for analysis is explained in this chapter.

The practical strategies are described in detail here for several purposes. It is necessary to explain what was planned and what happened, to demonstrate that a systematic approach was taken both in planning and in responding to issues as they arose. Prior to accounting for the phases of the research and collaborative work, details of the setting, media and participants are given and ethical considerations accounted for. For clarity, the research has been divided into three main phases (Table 3, Phases of the research), although it should be remembered that these phases were not consecutive but overlapping and running parallel to each other. Ongoing collaborative work underpinned each of these phases.

	2003	2004	2005	2006	2007
<b><i>Consultative phase</i></b>	■				
<b><i>Active phase</i></b>			■		
<b><i>Evaluative phase</i></b>					■
<b><i>Collaborative work</i></b>	■				

## Setting

The research was based in an outer London Borough, an urban area divided into three areas for delivery of community mental health services. A local demographic profile (2007) stated that the population consisted of 243,006 people in 2001, based within forty-two square miles. There was a lower population density than other areas of London, because of the green spaces within the borough. About one fifth of the population were people from ethnic minorities and 41% were aged under thirty in the 2001 census. There was a higher level of unemployment than average recorded in 2006, running at 9.7%. In relation to mental health, during the time of the research it was estimated that over two hundred people regularly accessed day services across the Borough.

The setting is illustrated in the Map on page 15. Each of the three areas had a resource centre and two teams, a day services team and a community mental health team. Each resource centre had facilities for small and large group work, a cafeteria and/or coffee lounge and outdoor areas accessible to service users. Historically one resource centre was funded by the Borough, one by health and one jointly. Some occupational therapists worked in both day services and the community mental health teams, unlike other staff such as nurses and support workers. The day services were managed by a development manager, assisted by two coordinators. Other statutory services which interfaced with the day services were the acute services, based in the centre of the Borough, the Home Treatment Teams and the Crisis Response Team.

There were close links with a non-statutory organisation, the Oak Foundation, allied to a national mental health charity which provided day services in addition to befriending, accommodation and other supportive services. The Oak Foundation had a centre in the middle of the Borough and hosted weekend services at the other resource centres. One paid member of staff for this organisation, Maneesha, was responsible for coordinating services for ethnic minorities and collaborated with this

research as opportunities arose. Next door to the centre owned by the Oak Foundation was a large church, St Peter's, whose rooms were used for meetings. For this research, the large hall was used for the second social networks day and one of the smaller rooms was used by the Plane Tree group studied in Strand C. Across the road was a long-established unit for supported work, the Lumos Workshop. The group of service users at the Lumos Workshop were active locally, and evolved into the Plane Tree Group.

Other changes occurred within the setting as the research progressed. The most significant were related to personnel changes, strategic reorganisation and funding issues. Victoria, the director of the Oak Foundation retired during the consultative phase of the research which impacted on the partnership with that organisation. The statutory services provided by the local primary care trust were taken over by a large London mental health trust during the active phase of the research. Finally, during the active and evaluative phases of the research, major funding problems for both the local primary care trust and the Borough had a dramatic effect on day services, forcing cuts justified on an economic basis.

## **Participants**

While the emphasis of this research was on service user involvement, it was recognised that in this setting it was not possible to involve service users meaningfully without effective partnerships with staff and others involved. These partnerships were invaluable for facilitating access to the service users, venues for meetings, and information for safe and effective consultation. Many day services staff supported service users in making decisions about the research, advised them as issues arose and supported those who chose to take an active part in the research. This involved actions as simple as suggesting that appointments with other staff be renegotiated to avoid clashing commitments. There were many

members of staff involved, and the key people are in the list of pseudonyms on page 12.

This list also gives details of service users who played a key role. There were many more involved in the consultative and active phases: final analysis indicated there were eighty-five events involving service users. These events ranged from individual discussions to the social networks days, the first of which involved more than sixty people. Throughout the research, the inclusion criteria for service user participants were that they should be adults who were currently or recently using statutory and/or voluntary mental health day services in the area, or involved in the development of the services as a local user representative. To use the day services, people had to have an enduring mental health problem. There were specific recruitment strategies for each strand of the active phase of the research, and these are detailed in later chapters. Ground rules were agreed for strands A and B, and in the event of service users persistently breaking these rules, exclusion from the research was the ultimate sanction, for the benefit of others involved. This did not arise during the research. Other ethical issues are discussed further below.

### **Tools and media for information gathering and analysis**

A variety of ways were used to gather information and communicate with participants. Analysis of the information gathered involved assembling records and using NVivo 7, a data analysis software package, to ensure a systematic and comprehensive analysis. In the process of the research, communication involved emails, letters, and telephone calls which were recorded with written field notes where appropriate. Meetings generated field notes, agendas, flyers, records of discussions and formal documents. The three strands involved specific media such as photographs for Strand A, checklists for Strand B, and interview recordings and transcripts for Strand C. Field notes and audio-recordings of discussions strands A and B were made and transcribed where required, for further analysis and reflection by the research groups.

Throughout the research, reflective journals were kept and used to record personal and shared reflections. Additionally, audio recordings were made of personal reflections in strands A and B, immediately after each group meeting. Finally, regular searches were conducted for relevant literature, depending on the focus of each phase of the research.

## **Ethics**

Formal ethical approval was given by the Brunel University Research Ethics Committee and the Primary Care Trust Local Research Ethics Committee (Appendices B and C). Khanlou and Peter (2005) suggested that participatory action research cannot begin until formal ethical approval is gained. Yet the point at which this research began cannot be clearly identified. There was a long period of consultation prior to finalising the design of the three strands (June 2003 – March 2005). In this period issues were identified and explored, and familiarity was gained with the setting. A small number of people were consistently involved through this phase, but many others came and went. Such is the nature of day services. The final proposal reflected this prolonged process – it could be justly claimed that it reflected not only the ideas generated through the consultation, but also that it was practical and achievable. Khanlou and Peter (2005) argued that the emphasis on action in participatory action research is problematic for formal ethical approval processes. For this reason it was felt to be appropriate to submit the three formal strands for approval, as there would be a clear plan for each strand, justified in the context of the research as a whole. The strands acted as a focus for my actions, and a reference point for the development of the day services. The strands also acted as a focus for recruitment – while the Day Services Forum invited membership, the strands invited participation in a more active sense.

The formal processes for ethical approval were essential to indicate to everyone involved that serious consideration had been given to the research. However, serious consideration was also an ongoing process

throughout, identified as 'ethical reasoning' for this research. There has been a distinction between ethical decisions based on abstract rules, and ethical decisions based on perceived consequences (Birch et al 2002). But the context has to be considered in each situation where a decision is made (Seedhouse 1998, Birch et al 2002):

*"Thus ethics become part of our relationships, our interactions and our shared values" (Birch et al 2002, page 6).*

Singer (1993) suggested that it was possible to live ethically by engaging in active reasoning, which he believed meant creating a distance from personal perspectives to gain broader perspectives. Then a sense of duty could also be broadened, from the limited view of a personal contract with other individuals, to a sense of duty emerging from all life experiences. Midgely (1994) argued that people have complex roles which imply multiple duties as well as having a duty to oneself and to the non-human world. With all these different factors, judgements and decisions should reflect a continuous process of ethical reasoning.

This continuous process of ethical reasoning has implications for participatory action research. Seedhouse (1998) believed that autonomy had central importance for ethical practice within the healthcare setting, although it was not the only consideration. Birch and Miller (2002) questioned how autonomy could be facilitated in participatory projects and argued that it was better to seek a covenant with participants rather than a contract. This could give more scope for negotiating what participation involved as a project evolved, rather than defining it from the outset and seeking commitment within a formal contract. This raises issues about consent, however, and Miller and Bell (2002, page 53), in the same text, argued that:

*"... 'consent' should be ongoing and renegotiated between researcher and researched throughout the research process."*

Madison (2005) claimed that ethical reasoning was very significant in critical ethnography because of the core function of questioning judgements, beliefs and assumptions. The reasons for asking the question and the possible implications of raising specific issues have to



be clear and justified. Madison (2005) argued that priority had to be given to the well-being of those involved, for critical ethnography involves entering their world, learning about it and then deciding which aspects and issues of their world to focus on. This decision is an ethical one – but is not a single decision at a single point of the research. Ethical reasoning is ongoing throughout the research, demanding constant reflection on all perspectives encountered. These perspectives include those informed by professional knowledge (White 2001), much of which is tacit (Parry 2001). Reflection enables access to tacit knowledge to be expressed (Parry 2001), giving reflection a central importance in this research in relation to ethical reasoning as well as the practical and academic aspects.

As familiarity was gained with the setting and research participants, particular challenges arose. Madison (2005) drew on the work of Conquergood to highlight very specific ethical issues in critical ethnography. The issue of identity and difference could challenge efforts to be respectful if the researcher over-identified with participants, romanticising their situation in what Conquergood termed ‘ethnographer’s infatuation’ (Madison 2005). To some extent in this research, there was some protection against this from my professional experience of working in mental health services, including day services. A greater risk was ‘custodian’s rip off’, which in Conquergood’s terms meant an emphasis on ‘getting good material’ without appreciating its significance to the participants. The photographs in Strand A in particular embodied this risk, and there was ongoing dialogue about the ownership of the images. This dialogue resulted in some photographs, which would have constituted very good material, not being used because not everyone was happy to see them used. Respecting different opinions and perspectives was fundamental to the process and something that had to be raised continually, in a way that was meaningful to the participants. For example, one participant’s focus on sexuality presented ongoing challenges to other participants, and it was necessary to visit ways in which everyone could resist being drawn into this focus and shift communication to other issues. The participant was not excluded

because of this focus, but it was important to continually consider whether it generated socially unacceptable effects for everyone present.

The other dimension in Conquergood's work (Madison 2005) is detachment and commitment. Critical ethnography demands that the researcher get involved not only with the subjective realities of the participants, but of her own subjectivity in response to the project. Being detached is not desirable in this situation because subjective responses are seen as key to understanding processes and interpretations. Conquergood's 'skeptic's cop-out' is thus a risk, for example at moments of insecurity about the academic credibility of the research. In presenting the research in progress, there was also a risk of succumbing to minor pressure to present astounding results, indicative of Conquergood's 'curator's exhibition' (Madison 2005), where exciting and exotic phenomena are highlighted and misinterpreted for an impressive effect.

So, for this research, ethical issues were considered in an ongoing process of ethical reasoning (Blackburn 2001). Specific guidance was drawn from professional guidelines (College of Occupational Therapists 2003) and Faulkner (2004), on involving mental health service users in research. It was recognised that the research involved vulnerable adults, being people with long-term mental health problems and particular attention had to be given to issues of potential harm, benefits, respect, decision-making, honesty, justice and confidentiality (College of Occupational Therapists 2003).

### **Harm**

Getting involved in the research generated varied new experiences for participants, which at times raised the possibility of more support being required. Being alert to this possibility was imperative but it was more important to engage in direct and honest dialogue with service users about what the nature of the additional support might be. The closed research groups in strands A and B fostered a supportive network which

built on existing networks. The existing groups in Strand C shared the decision to get involved, and those individuals who were interviewed were supported by other group members. Existing relationships with key members of staff during each strand gave easily accessible practical and emergency back-up. Faulkner (2004) suggested that service users are less concerned about potential harm: this was echoed in this research where some service users discussed the distinction between participatory action research and clinical trials of invasive medical procedures.

Particular attention was paid to the use of cameras in Strand A, to ensure that the group members could use them safely and confidently. In Strand B, emphasis was placed on service users choosing activities which they would normally consider doing in their everyday lives. Strand C, being concerned with individual interviews, presented minimal risks to participants, but there was back-up provided from staff. In addition, Ken, the interviewer, had details of the crisis team to offer interviewees if required. We debriefed in a phone call after each interview.

### ***Benefits***

The information sheets for this research (Appendices D, E, F) state that there were no specific planned benefits for participants in this research. In this sense, it meant that participants did not receive preferential treatment within or beyond the day services as a result of participating, although it was recognised that participation and the research itself generated many indirect benefits for individuals who got involved. Faulkner (2004) highlighted the many benefits of emancipatory research. Service users were interested in the benefits for themselves from the experience of being involved, the potential benefits for others if services were developed in response to the research findings, and the benefits to me from studying for a PhD.

### ***Respect***

Strategies to emphasise mutual respect included emphasis on ground rules in strands A and B, not just in deciding what the rules should be but

sticking to them. When the rules were breached, discussion took place within the groups as to how to respond, thus developing further strategies to sustain mutual respect. The groups developed their own particular culture to sustain this. This was not just an issue for service users but also for the two members of staff, Sian and Sally, who assisted in strands A and B, as the research required a shift in their role. Active support was given to them when making their role within the groups explicit. Their role was defined as primarily supporting everyone to ensure that group members were working within their capabilities, and to facilitate rapid access to support beyond the group should it be required. In Strand C Ken, the interviewer, ensured that the interviews took place in a location chosen by the interviewee, making them feel comfortable. For that reason, two of the interviews took place in a quiet corner of the pub where one of the groups met. From the start, he emphasised that the interviewee could pause, interrupt or postpone the interview at any time, for any reason which promoted their comfort or well-being.

### ***Decision-making***

Decision-making continued throughout this research: this process encompassed decisions made by individual participants, to group decisions, to my decisions and beyond. It was believed that informed decision-making was underpinned primarily by good communication. A particular issue was one of informed consent for the people involved in the strands, some of whom had difficulty using written and verbal information. Facilitating access to this information was made a priority when first seeking consent and for ongoing decisions about participation. A critical issue for this was negotiating roles in strands A and B, which depended on participants understanding and reflecting on what roles were possible within the research, and to what extent they felt able to take up these roles. Being an experienced group facilitator in clinical and educational settings was a significant resource for this research.

### **Honesty**

Where relevant, attention was drawn to the research questions not just during the recruitment process, but throughout the research in discussion and reflection. It was recognised that perspectives shifted over time and so continued dialogue was therefore required. Specific strategies were built into the structure of the research groups for strands A and B, detailed in chapters six and seven. It was also imperative to consider the possible outcomes of the research and how they could be adopted or received by the wider context (Faulkner 2004, Khanlou and Peter 2005). In this research, situating the research within the Day Services Forum meant that challenges to interpretation of policy were given a voice. However, it was questioned what power the Day Services Forum had to determine future developments and challenge prevalent interpretations of policy, especially those which were economically driven. There was a risk that participants would see the research as an opportunity to secure the developments which they as individuals particularly valued. Two aspects of the research served to counterbalance this. Firstly, it was emphasised at every point that the primary purpose of the research was for the PhD, and while the intention was to conduct research which was useful and meaningful, use of the findings beyond the PhD was dependent on the partnership between participants and the Day Services Forum. Secondly, because the research was conducted with groups of people, personal agendas could be acknowledged but then synthesised. This was evident in each of the strands.

### **Justice**

Securing equitable access to the research and building mutual respect amongst participants was a central concern of this research. One potential difficulty was the issue of paying service users for their involvement. As long-term service users, many of them were reliant on welfare benefits which also constrained them in terms of additional earnings. While the local participation fund holder was prepared to offer some funds on an ad hoc basis for expenses in relation to the research, this could only be obtained with written evidence that the activities were

contributing to service development. While this was not a problem in itself, it was decided to give priority to more tangible rewards for involvement, such as giving copies of photographs taken in Strand A to group members, a copy of the poster to each group member in Strand B, and certificates of participation for both groups.

The distinction between the strands and the research overall was helpful in creating equal opportunities for access to participation. Faulkner (2004) stressed the importance of involving service users from the outset of any research project. By defining the strands as the active phase of the research, it was possible to secure equity of access from the beginning of each strand. As already stated, inclusion criteria were determined by attendance at the local day services. This raised potential issues for service users who had moved on but chose to get involved in some of the forum's activities, and subsequently, in one case, the research. However, the clear structure of the strands made it possible for ex-service users to participate without appearing to be re-engaging with services.

One issue relating to justice was ensuring a fair representation of the findings, both locally and beyond. Participants were informed of opportunities to present the findings and their involvement was sought whenever it seemed feasible. Service users were encouraged to take an active part in presentation, working in collaboration to identify ways in which the findings could be communicated in a meaningful and representative way. Presentations relating to this research are listed in the Declaration at the very beginning of this thesis.

### ***Confidentiality***

Confidentiality was a challenging issue in this research, being based in a setting where there were many networks and communities involved. As a principle, all information gathered was stored securely away from the field. Contact details were not divulged to other participants. Details of individual contributions to the research were anonymised, although in shared verbal presentation of the findings those who were presenting

owned their own contributions at their own discretion. It was agreed at the beginning of each strand that individual contributions would not be identified unless there was evidence of an actual event or likely event of harm, and in that situation disclosure to appropriate mental health professionals would follow discussion with the individual concerned. This was not required at any point.

Discussion in the consultative phase generated debate amongst service users about the use of photography for Strand A. In response to this, there was a final selection of images to be used in reporting the research and for the personal use of the group members. For strands A and B, each group member was consulted individually and all except one wanted to be named as authors on the products of the research: the report and the poster.

Ken, the interviewer for Strand C, stored contact details and audiotapes securely during information gathering and analysis, and handed all records over for storage at the University. All contact details and research data (records on paper and digital media, photographs and audio recordings) were stored securely, requiring a key and/or a password for access.

## **Phases of the research**

Each phase of the research (Table 3) was characterised by different occupations, strategies and roles. The remainder of this chapter is concerned with the details of how these phases were implemented. The consultative and active phases are described first, followed by details of the collaborative working. The section on the evaluative phase focuses on the strategies for analysis.

### ***Consultative phase***

The first phase was the ***consultative phase***, where the partnerships were created, issues were identified and ideas discussed. This also

included reviewing literature in relation to the topic and methods. It was characterised by the following:

- Partnership building with Geraldine, the day services development manager.
- Formal ethical and organisational processes.
- Membership of the Day Services Forum.
- Social networks days.
- Consultation and partnership building with service users and staff.
- Building knowledge of the setting, literature and policy.

#### Partnership with Geraldine, the day services development manager

In the focus group study which preceded this research, a number of recommendations were made to inform the development of the services (McKay et al 2003). The organisation appointed a manager, Geraldine, to take the recommendations forward and one of her initial actions was to approach the University for further input and advice. Following discussion it was agreed that I would work in partnership with the organisation. This role was formalised by the organisation in terms of an honorary contract. My role was formalised within the University as a PhD student.

#### Formal ethical and organisational processes

The honorary contract was issued by the local primary care trust and re-issued by the mental health trust after the reorganisation of services. Most activities associated with the research were governed by two key commitments. Firstly, the honorary contract bound me to the policies of the organisation aimed at safeguarding the well-being of everyone involved. Secondly, my own professional Code of Ethics and Professional Conduct imposed clear guidelines (College of Occupational Therapists 2005). In the informal and formal activities associated with the preparation of the strands and ongoing membership of the Day Services Forum, these two formal aspects provided clear guidance for ethical decision-making and behaviour.



### The Day Services Forum

One of the recommendations of the previous study (McKay et al 2003) had been to establish a forum for consultation with service users, staff and other agencies about the purpose and development of services and Geraldine convened the first meeting soon after being appointed. I was a member of the Day Services Forum from the first meeting. The forum was open to any service user, staff member or other person interested in day services, attracting volunteers, carers, students and other visitors. It was scheduled to run for two hours on a Tuesday afternoon every eight weeks in one of the resource centres, with dates being agreed each year in advance and publicised by flyers and letters to those people who had given their contact details. The Forum was led and administered by Geraldine. In the second year of its existence, the Day Services Forum had a theme for each meeting.

In this context, participatory action research and critical ethnography emerged as being the most appropriate methodological reference points for the research, although one issue that was potentially contentious was that the participants themselves were not seeking to change services – the impetus for change was generated by national agendas. This tension became more acute with the publication of the Social Exclusion Report (Office of the Deputy Prime Minister 2004), which imposed four main areas for action - user involvement, volunteering, employment and social networking. At this point, consultation with service users and staff suggested that a major concern was how social networking was going to be developed within the services, given that many opportunities for social networking had been removed as a response to the demand to create socially inclusive and non-institutional services. This became the focus for the research and it was agreed that a whole day event, a social networks day, could be hosted to take this forward. The success of this day led to a second event, sixteen months later.

### Social Networks Days

The first social networks day took place in the consultative phase of the research in July 2004 and the second just before the active phase of the research began in November 2005. Both days attracted service users who did not usually attend the Day Services Forum, and were planned in partnership with service user representatives and other agencies who were involved or seeking to be involved in day services. Lunch was provided. My role included creating, distributing and analysing evaluation forms for a report for the service user newsletter (Appendix G, evaluation form and Appendix H, report).

The first social networks day involved:

- Opportunities for service users to create and recreate social networks through a speed networking exercise, shared lunch and refreshments and group work.
- Identifying local social and recreational activities through a large group mapping exercise.
- Increasing awareness of the barriers to social networking by discussing “Ten top tips for going out” in small groups
- Agreeing priorities for action and ideals to influence future development of services.

This social networks day resulted in the creation of the BITRA (Borough Index to Recreational Activities), which formed the basis for work in Strand B. I led parts of the day, including a shared reflective session after lunch. This provided me with an opportunity to explain my role in relation to the services and the research, and gather names of people interested in being involved or receiving further information. Evaluation of this day was reported in the service user newsletter (Appendix H).

By the second social networks day in November 2005, ethical approval had been gained for the three research strands. Information about the research was displayed on the day (Appendix A). In addition to this, the second social networks day offered those attending an opportunity to

learn about what was happening in the Borough, in particular new developments such as Capital Volunteering and the Green Gym. I arranged for Lou, a service user from another area, to come along. She was leading a social and recreational project which had been running for many years, and a subgroup discussed user-led social groups with her. I also led an activity designed to increase awareness of diversity of need in relation to social networking. This day was also evaluated using feedback forms which also gave those attending an opportunity to seek further information about opportunities, including getting involved in the research, which enabled revision of the mailing list which had been created following the first social networks day.

#### Consultation and partnership building with service users and staff

From the first social networks day, I set up a meeting to discuss the research. This was attended by three service users and involved a preliminary exploration of possible topics and methods. Of the three people attending this meeting, one person (Eleanor) subsequently became involved in Strand A and another (Andrew) sustained contact with me throughout, although did not get actively involved in any of the strands. From here various means were used to consult with people about the research, including attending user/staff business meetings and the service user group meeting. The topics and methods of the three strands of the research were based on these consultations, exploring key issues and practical aspects where appropriate.

#### Building knowledge

The consultative phase also involved increasing my knowledge and understanding of the relevant literature, national policies and local policies impacting on the setting.

#### **Active phase**

The second phase was the **active phase** of the research, primarily involving the three strands of investigation. Each strand involved phases of promotion, recruitment, information gathering and analysis, synthesis

and dissemination of findings. In this phase, service users were actively involved in all aspects, supported by staff and other stakeholders, such as non-statutory organisations. Practical aspects of the research were coordinated as part of my leadership role. This phase ended with the analysis of the data from Strand C.

As well as the theoretical reasons for designing three strands, there were practical reasons. Consultation had generated a number of suggestions and a limit had to be placed to ensure the research was feasible. It was felt that three strands gave scope for comparison between the strands and made contingency research work possible if one strand proved problematic. Most importantly, there was the possibility of increased accessibility for service users who wanted to get involved. Each strand was allied with one of the main resource centres, although service users from anywhere in the Borough could join, and several did. Strands B and C involved users from each of the three resource centres. I was keen to find a clear way of communicating the theoretical perspective on occupation and so three strands focused on three elements associated with occupation: the person, the environment and the occupation itself (Law et al 1996). The three strands clearly defined the active phase of the research, so that those who got involved knew from the start of each strand what the timescale was for their involvement, and those who followed the research through all three strands had an understanding of both the limitations and possibilities associated with it. Each strand is described briefly here: more detail is given in subsequent chapters.

#### Strand A: "The Social Lounge and beyond"

This strand was concerned with the environmental issues in relation to the occupation of social networking, focusing on the social lounge at Elm Lodge. This focus was developed in response to consultation with service users there as well as in response to the views of service users using similar spaces at the other resource centres. Views about drop-ins and informal networking shared in the previous study also influenced the focus of this strand (McKay et al 2003, Bryant et al 2004, Bryant et al

2005). In the broader context, the focus on the building as a resource was in response to the modernisation agenda for day services already discussed in Chapter One. This agenda emphasised the use of 'mainstream' community resources rather than segregated, institutional buildings. The research was based on this question and aims:

Are social networks being formed and sustained in the Social Lounge?

#### Research Aims

1. To gather information on how the Social Lounge is currently used.
2. To generate themes to stimulate further discussion and development.

Photography was used to gather data in Elm Lodge, to explore how the Social Lounge was used, and all the images were analysed by the research group. This process was repeated until saturation (Lincoln and Guba 1985, Holloway and Wheeler 2002). This meant that it was agreed by the group that the photographs taken offered a sufficiently comprehensive account for their responses to the research question and aims, and that they had explored this responses to the extent that they could not identify any further variations or issues. The risk that identities could be revealed without consent was addressed by setting up a closed group to undertake the research at a designated time at the resource centre. Visual information was believed to be more accessible to a range of users, especially where literacy and cognitive difficulties might compromise access to written information. This applied to the presentation of the final findings, which was illustrated with some of the photographs, increasing accessibility to the research findings and fostering further debate about the implications of the research. The focus of the research was on the media, rather than the participants themselves, which helped with participation at many levels (Rapport 2004).

### Strand B: “Getting better by going out”

The first social networks day resulted in some service users working together to produce the BITRA (Borough Index to Recreational Activities) in a paper version and distributing it to the resource centres and to members of the non-statutory organisation. At the launch it was suggested that further development could include how accessible the activities were, and whether they could be recommended to other service users. This resonated with other service users’ views gained in the consultative phase, and so Strand B focused on the development of the BITRA, based on this research question and aims:

How accessible are local social and recreational activities to people with enduring mental health problems?

#### Research Aims

1. To gather information on the accessibility of local social and recreational activities.
2. To summarise the information to support existing information resources.

Service users engaged in or reflected on chosen activities, using a checklist (Appendix J). This checklist was designed and piloted by service users participating in Strand B. They chose the activities to be studied, defined the components of the checklist and gathered the data. As for Strand A, an eight week, closed research group was established. The group agreed to involve other service users to fill out checklists and the results were collated and analysed within the group meetings. A final account of the research was organised in a poster (Appendix K), with copies being given to each of the resource centres for display in an area accessible to service users and staff. In relation to the theoretical orientation for this research, this strand related to the ‘occupation’ part of the person-environment-occupation model.

### Strand C: "A state of flux"

This strand was different to the previous two in that it involved investigating groups already in existence rather than setting up a new group. This strand was in response to the belief that user-led social groups provided a valid alternative to statutory day services, and sought to explore the experience of being in such a group. For this strand, user-led groups were defined as those where service users were responsible for the leadership, recruitment and organising the group. Staff were not present at group meetings, although they might play a part in supporting the user-leaders. Analysis revealed issues and themes related to self-help and support groups. Thus the strand was oriented around the roles people play, or the person aspect of the occupational perspective. An independent interviewer, Ken, conducted individual interviews to explore experiences of the group and to develop a narrative of the groups as a whole, based on the following research question and aims:

What do people do to initiate and sustain a user-led social group?

#### Research Aims

1. To explore the story of a user-led group from the members' perspectives.
2. To identify themes to inform how these groups are initiated and supported.

It was proposed that one possible outcome of Strand C could be a play, as this was believed to be a useful way of portraying roles within a story and conveying some of the research findings without revealing identities. This was not considered to be a part of the research, but as Ken, the independent interviewer, was a playwright, it was possible that this idea could be taken forward, if feasible, after the research was finished.

### **Collaborative work**

To facilitate the consultative and active phases, collaborative work took place. Three aspects are discussed here: the partnership with the day services development manager, the work with service users and staff and being a member of the Day Services Forum.

#### Partnership with Day Services Development Manager

The role of Geraldine, the day services development manager, expanded within the organisation during the research but she maintained a core commitment to the development of day services. She acted as an initiator and central source of information, not just within the local setting but also in the broader context of modernisation of day services in London. Duggan et al (2002), in their paper on modernising the social model for mental health, were critical of a simplistic approach to partnerships, as in health and social care this rarely meant a partnership between just two parties. However, there was a formal aspect to the partnership with the day service development manager: under the terms of the honorary contract, I was accountable to her.

This partnership was developed and sustained through regular communication and joint working, especially in relation to the Day Services Forum. Geraldine included me in planning meetings relating to the forum and increasingly requested that I led discussions and activities in the forum meetings. Field notes and recorded reflections were kept in relation to this. As the partnership evolved, there were regular meetings and telephone discussions between us. This usually involved firstly updating each other on service developments and the progress of the research. Our collaborative work involved sharing ideas and thoughts on how to meaningfully involve others in future developments, including the Day Services Forum. Usually this involved designing programmes and activities to facilitate involvement in the service development, or identifying actions required within the research. Through this partnership, the research was embedded in the service development: as findings emerged, they were shared and incorporated in development activities.



### Working with service users and staff

The consultative and active phases of this research generated many opportunities to consult with and work with service users and staff. My presence in the setting lasted from 2002 when the previous project started, to the end of active involvement in 2007, and so I was a familiar face to many people. Throughout the consultative and active phases of the research, a mailing list was maintained of people who were interested in the research so postal updates could be sent to them. The Day Services Forum and social networks days gave opportunities to meet informally with people and discuss the progress of the research. This was useful for those who were interested but did not want to get actively involved, or those who were supporting others who were more actively involved. After the consultative phase, for strands A and B, meetings were held with staff and service users at the resource centres to recruit for the research and make practical arrangements. For Strand A, because it was so focused on Elm Lodge, the findings were initially presented at the user/staff business meeting.

Working with service users required communication primarily in face-to-face meetings, letters and telephone calls. Only one service user was keen to use email as a means of communicating. Often telephone contact was most successful in the evening, as many service users were out in the day and did not use mobile telephones. At times persistence was necessary to successfully respond to service users' communications. When my working base was relocated to the local area in 2006, this had an immediate beneficial effect as service users were able to access me more easily, for example coming to the University for planning meetings about formal presentations.

Two meetings were held at the Oak Foundation with the user group, following invitations for me to report on the research as it progressed. This group was service user led and influential locally, having been set up on the basis that it was advantageous for service users to work together

to respond to issues and consultation, rather than have lone service users working as representatives on formal committees, although some service users, such as Andrew, worked in that way too. These meetings were valuable, being an opportunity to test the usefulness and meaningfulness of the research beyond the day service setting with people familiar with the local services.

#### Membership of the Day Services Forum

The Day Services Forum was central to the collaborative work undertaken for this research which evolved in consultation with the forum, and provided a focus and reference point for many of the discussions within the forum. The forum was consulted to explore what support there was for the research in progress, and as the findings emerged, to present them to influence future developments.

Returning to the role of critical ethnographer, Madison (2005) highlighted an ongoing tension between being a researcher and being an advocate. Engaging with marginalised people can lead to the role of advocate, especially where there is a personal history of activism as was the case in this research. Madison (2005) suggested that this was an integral part of critical ethnography. I was most aware of this issue in presenting the findings of the strands locally. While seeking to involve the participants or co-researchers in presentations, this was not always a predictable process. In addition the consultative phase enabled me to make contact with people who were very interested in the research but did not want to actively participate. Some of these people were also active in engaging with the findings. At times it was necessary to emphasise aspects of the findings that were being overlooked in an enthusiasm for a particular interpretation. It was also necessary to push the focus towards what actions could be made to take the findings forward, rather than focusing on the fact that consultation had taken place. Thomas's idea of 'living signposts' (1993) was useful in this respect, suggesting that there were directions which could be followed, but that these would develop as the day services continued to change.

Although the forum sought to foster service user involvement, this was constrained by a number of factors. The staff present at the forum were day services staff, meaning the degree of involvement of service users was to some extent dependent on the relationship they had with staff members. The non-statutory organisations represented had a different relationship with service users but funding issues meant there was a dependence on the statutory organisation which also had implications for what questions could be asked.

### ***Evaluative phase***

The third, ***evaluative phase*** involved evaluation of the first two phases by conducting a systematic analysis of all the material gathered. At this point I ended my active role within the Day Services Forum but retained some contact with those who had been actively involved in the research.

This phase was characterised by the following:

- Ending of active involvement in setting, including Day Services Forum
- Overall data analysis
- Presentation of emerging findings

### **Ending of active involvement**

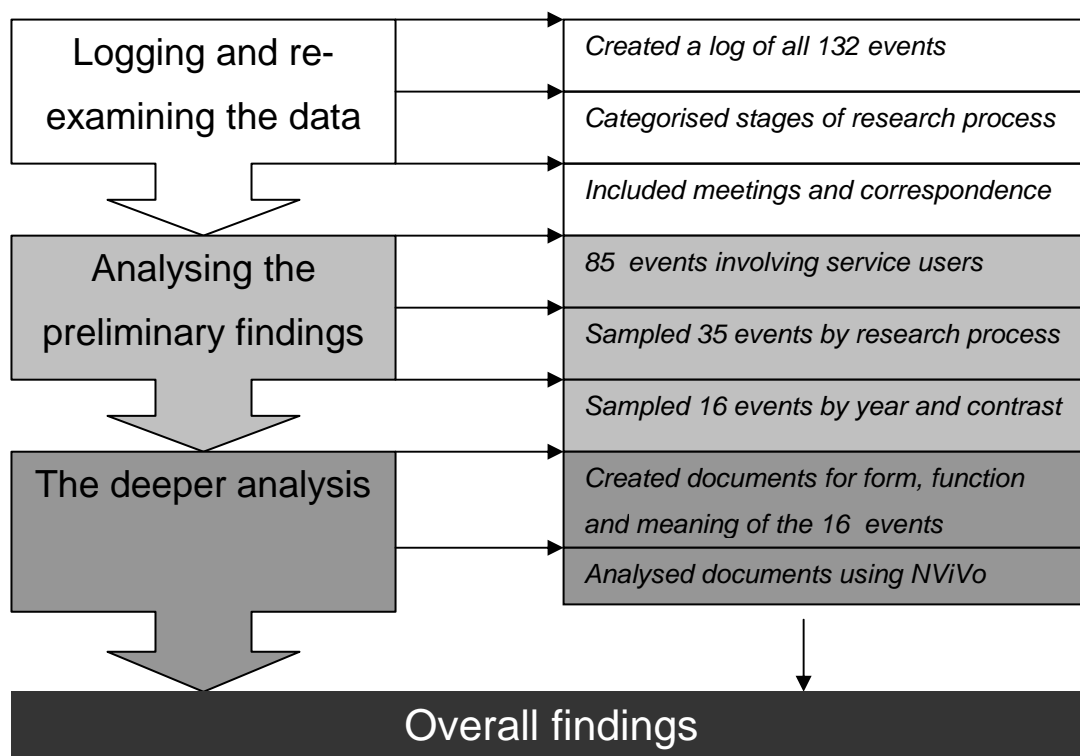
Particular attention was paid to the process of ending the research, especially as a number of service users and staff had become very actively involved and interested in the research. It was important to anticipate how the ending of the project could be managed. The three strands had each had their beginnings and endings, mirroring the project as a whole. Northway (2000) suggested that one issue to be considered is the nature of the contact, if any, between researcher and participants once the project is completed. She suggested it is important for the participants to determine whether or not they wish to maintain contact, recognising that people will have different views about this. In this research, potentially realistic ways of maintaining contact after the

research were identified, within the university context. It seemed that those service users and staff who had engaged with the project throughout much of its duration were primarily interested in the process of research and the opportunity to become involved in aspects of university life. It seemed appropriate to set up an opportunity to formalise these activities, as the University was very much concerned with involving the local community in teaching and research partnerships. However, it was important to distinguish this as a follow-up activity from the research.

The beginning of the evaluative phase was signalled in the Day Services Forum, with a meeting dedicated to reviewing the earlier phases of the research. This meeting was structured to include an informal discussion and an opportunity to give feedback on a evaluation form (Appendix L), which was developed in consultation with service users who had become very involved in the research. Their responses were included in the final analysis, which is detailed below.

### **Analysis of findings**

The ongoing cycles of action and reflection, central to participatory action research, and critical ethnography required an analytical approach throughout the research, rather than constituting a very separate phase. Analysis in this sense was a dynamic process, occurring in dialogue with participants and resulting from individual or shared reflections. Each of the strands also involved analysis of the specific findings. In strands A and B, the analysis was conducted by the research groups, whereas in Strand C, a constant comparative analysis was conducted using the interview transcripts. Once the active phase came to an end and the three strands were completely analysed, a final stage of analysis took place. The analysis was conducted in stages, illustrated in the flowchart in Figure 1.



**Figure 1: Overview of stages of analysis**

In the first stage all the data which had been gathered were logged and reviewed. Then specific events were sampled for a deeper analysis in relation to the research question. The findings from the deeper analysis are reported in Part Three of this thesis.

#### Logging and re-examining the data

Re-examining all the data was a process which was not conducted in isolation, for there was continued contact with a number of service users and staff at events where the research was presented or discussed. However, these discussions were often focused on particular aspects of the research. To ensure that equal consideration was given to all the phases of the research, this final analysis was initiated. This began by gathering together everything relating to the research and creating a log, using a spreadsheet. Each item was given a number along with details of the date, who was involved, where it took place (for meetings) or what type of communication, and what part it played in the research process.

For this purpose the research process was categorised in five overlapping stages:

- **Notifying:** *where information about the research was given*
- **Shaping:** *where there was a contribution to the design of the research*
- **Doing:** *activity focused on the research topic*
- **Reflecting:** *on the outcome of the 'doing' stage, or on the research topic*
- **Reporting:** *where the outcome(s) were reported*

This process could have been categorised into only two stages – the action and reflection cycle associated with action research (Koch and Kralik 2006). But this seemed to imply a continuous cycle without acknowledging the beginning, middle and end stages. These terms (notifying, shaping, doing, reflecting and reporting) were chosen to capture the single, overall cycle of the research. However, it was recognised that events in the research often involved more than one aspect of the process and it was decided that each item could be put into more than one category.

#### Which data?

Another key issue was to decide how data could be grouped in relation to specific events. Some events such as the social networks days had generated a mass of related items, whereas other aspects were recorded in much less detail. Many informal conversations occurred within the Day Services Forum which were not recorded at all. As a result, a decision was made to think in terms of meetings or correspondence and gather all items relating to particular events together. Two spreadsheets were created. The meeting items were coded with a number prefixed by 'M', and included every documented event where I was present and the research was discussed, apart from supervision meetings. The correspondence items were coded with a number prefixed by 'C' and included every instance of recorded communication about the research. An example of the spreadsheet recording communication is in Appendix M. Documents, fieldnotes and reflective accounts were grouped together

under one 'C' code. As each item was examined, a note was also made of where it was stored and whether it related to a key event or not. Key events were particular milestones – when decisions were made or when something new arose. This was a reflexive process, reviewing the events while examining the evidence.

The varied evidence of communication also required some decision-making. Emails were used extensively to communicate with the day services manager and staff about arrangements for the strands, and while some of these were significant, many were merely confirming times and venues, and so were excluded from the logs. Communication with service users involved much informal contact, telephone calls and letters, and not all of these were recorded or logged. Again, it was necessary to reflect on what evidence was available and consider it in relation to what took place and with whom. Often the appearance of a name on a mailing list or in a newsletter was enough to highlight individual contributions to the research, and further evidence was sought out and logged where possible.

### **Analysis**

The two spreadsheets, one for meetings and one for communication, contained 132 entries. Meetings accounted for 81 events, and communication for 51 events. In this instance, an 'event' is a coded entry on the spreadsheet and may be represented by multiple sources of data. The events were grouped according to year of occurrence, to get a sense of how they changed over time in relation to involving users and the research process. While there were limitations in taking this broad overview, this stage of analysis did reveal that user involvement was evident throughout the research process. Table 4 illustrates this observation:

Table 4: Involvement of users in logged events						
	2003	2004	2005	2006	2007	Total
<i>Total logged events</i>	6	17	45	54	10	<b>132</b>
<i>Number of logged events involving users</i>	3	8	35	33	6	<b>85</b>

It should be noted that 2003 involved six months of active participation in the research, and 2007 involved four months of active participation, as the research drew to a close. In the first two years of the research, there was greater contact with the day services manager alone – as this tailed off the involvement of service users increased. For example, in 2003, the day services manager was involved in all 6 (100%) logged events, whereas in 2006 she was involved in only 18 (33%).

Service users were involved in 64% (n=85) of all events, and this was broken down further into involvement in meetings and correspondence, shown in Table 5. In reading this table it must be remembered that the numbers refer to the number of events, not number of service users involved, and that the years 2003 and 2007 involved less active participation time.



Table 5: Further details of service users' involvement by number of events						
Events \ Year	2003	2004	2005	2006	2007	Total
<i>All meetings</i>	5	13	21	38	4	<b>81</b>
<i>All meetings involving users</i>	3	6	15	27	3	<b>54</b>
<i>User-only meetings</i>	0	1	2	5	2	<b>10</b>
<i>All correspondence</i>	1	4	24	16	6	<b>51</b>
<i>All correspondence involving users</i>	0	2	20	6	3	<b>31</b>
<i>User-only correspondence</i>	0	1	17	6	3	<b>27</b>

The meetings involving only service users were significant in that they tended to be events when there was a full focus on the research, in contrast to Day Service Forum meetings, when other items were on the agenda. It took time to build the connections with service users to enable this to take place. Correspondence involving only service users included mail to and from me, and this peaked in 2005, when the finer details of the research were being shaped, ethical approval was gained and recruitment began for Strand A. The correspondence analysed was primarily via fieldnotes from telephone calls and mail.

Events not involving service users were not considered for this analysis. There were 85 events involving service users and Table 6 shows how they were coded by stage in the research process. The research process was reflected in how the categories were represented each year, with more notifying and shaping events in the earlier years, and more doing, reflecting and reporting events in the later years.

Table 6: Events involving users coded by stage in research process						
Year	2003	2004	2005	2006	2007	Total*
Events						
Notifying	0	1	17	10	0	<b>28</b>
Shaping	3	6	20	14	1	<b>44</b>
Doing	0	1	2	17	2	<b>22</b>
Reflecting	0	0	2	12	4	<b>18</b>
Reporting	0	1	0	9	1	<b>11</b>
Total*	3	8	35	33	6	<b>85*</b>

***\*The total number of events are not a sum of the columns or rows, because many events involved more than one stage in the research process.***

These events were analysed further to explore service user involvement over the whole research cycle. The aim was to focus on events which contrasted how service users were involved, and which represented different stages of the research process. This strategy was derived from knowledge of the constant comparative method of analysis (Silverman 2000, 2006), where differences between data segments are explored to generate new understandings. Events which incorporated multiple stages were also singled out. In considering each of these events, only the code numbers were used at this stage. This was to try and give each event equal consideration and be open to the possibility of changing perceptions of the significance of each event. For example, it would have been easy to skim over the significance of some of the correspondence in favour of the higher profile events such as the social networks days, but reducing each to a code made equal consideration more likely. This process also helped in considering the Day Services Forum meetings, which were frequent yet not always making a major contribution to the progress of the research.

In summary, this stage of the final analysis involved a systematic approach to the data. Events were identified from each year, equally from meeting events and correspondence events, and across the research

process stages. This reduced the 85 events to 35 events, which were grouped and compared again, but this time they were identified by name and date in order to further reduce the number of similar events. Reflection and reconsideration of each event was central to this process of analysis. Immersion in the data in this way was essential for several reasons. It was important to ensure that the overall findings were drawn from as many different aspects of the research as possible, to safeguard meaningfulness and authenticity. It was also believed that it was important to generate useful findings which indicated the varied ways in which user involvement could be understood in relation to the setting and the occupational perspective. Contrasting examples and thorough analysis was required. These considerations, of meaningfulness, authenticity and usefulness, were proposed by Lincoln and Guba (2000) as being as important in qualitative research as the more widely used concepts of trustworthiness and rigour (Holloway and Wheeler 2002).

#### Preparing for deeper analysis

By this stage, the criteria used for sampling and analysis had considered what part each event played in the research, who was involved and when it happened. User involvement and the setting had been the focus so far and the emphasis had been on sampling for difference to capture the varied elements which enabled people to be involved. From this systematic and rigorous approach, sixteen events were selected for deeper analysis. To sustain this approach and facilitate analysis using NVivo 7, a qualitative data analysis software programme, it was decided to create documents to bring the evidence together. At this point, it was necessary to bring in the occupational perspective, to ensure that the research question was fully utilised for the analysis. A recognised and established theoretical framework for an occupational perspective was used to structure the new documents. Three dimensions of an occupational perspective, of form, function and meaning (already discussed in Chapter Three) were chosen for this stage because they were believed to be fundamental building blocks for designing occupations, in this case associated with participatory action research.

The research questions used at this stage were:

**What factors shaped user involvement in this research?**

- a. How did the form or design of the research facilitate user involvement?
- b. How did the purpose (function) of the research facilitate user involvement?
- c. How did the significance (meaning) of the research facilitate user involvement?

Firstly, the occupational form of the event was recorded. For example, for a meeting, there were often details of how many people were present, the topics discussed and the location. Some contextual or background information was also added. Many of these details were taken from fieldnotes alongside agendas and correspondence. Secondly, the function of the event was distilled from the description of the occupational form in single sentences, for example, for a letter from a service user the function was to shape the research topic. Thirdly, another document was created for the meaning of each event. This involved drawing on reflections at the time from reflective logs and audio recordings. For example, the audio recordings of the final meetings of the groups for Strand A and Strand B were listened to, and key statements transcribed for this purpose. Finally, in this document, a new reflective section was written, capturing thoughts which had occurred during this period of analysis.

To facilitate this process a metaphor was chosen and explained for each event. Choosing a metaphor was informed by the work of Bolton (2000), who demonstrated how metaphors can facilitate reflection. Where possible, metaphors taken directly from the field were chosen, using the words of the participants, or my own words from the time. For example, a service user newsletter produced after the first social networks day was associated with the metaphor of turning over a pebble. This had been proposed by a service user in discussions before the day and emerged again in the newsletter which followed. It also seemed to link with the newsletter in the sense of uncovering service user perspectives in a low-

key but significant way. When this was not possible, a metaphor had to be chosen which seemed to fit the form, function and meaning. For one of the meetings with the service user group for all the mental health services, I chose the metaphor of accepting a gift, because at that time the group gave me extremely useful feedback on the proposals for the strands. Inevitably many of these metaphors had an occupational sense to them, being concerned with doing, reflecting the action of the research, the emphasis on participation and the occupational perspective. Other metaphors reflected the stages of the research process, for example, 'passing the baton' for the letter sent to inform the review of Day Services in 2007, at the end of the active phase of the research. These metaphors helped in thinking about the meanings of each event as analysis progressed. The events selected are listed in Table 7.

Table 7: List of sampled events for final analysis		
Event date	Event code	Event name
14/10/03	M3	Day service forum meeting
06/07/04	M12	Social networks day
31/08/04	C19	Newsletter
13/12/04	C8	Letter to service users
25/01/05	M18	Meetings with service users at Alder House and Elm Lodge
7/03/05	C22	Letter from Andrew, service user
15/06/05	M24	Meeting with service user group
01/11/05	M41	Social networks day
8/2/06	M60	Research group meeting, Strand A
28/06/06	M68	Meeting with Oasis group
11/07/06	M71	Research group meeting, Strand B
21/11/06	M37	Day Services Forum
20/12/06	C3	Letter from Adam, service user
10/1/07	C51	Telephone call to Gabrielle, service user
20/03/07	M45	Day Services Forum
24/4/07	C45	Letter for Day Services Review

At the end of this process there were three documents for each of the sixteen events, a total of forty-eight, created for further analysis using NVivo 7. At this stage of the analysis, themes and categories were emerging in relation to each dimension. A 'tree node' was created in NVivo to capture these themes and categories, and expanded as analysis progressed. So, in addition to nodes on the form, function and meaning of the research, new nodes were added: the service users' perspectives, day services, and the insider view as a researcher. 'Free' nodes were also created for data which seemed very significant or did not appear to fit other nodes initially. At the end, the free nodes were reviewed and it was possible to integrate them into the other nodes. Finally, the nodes were reviewed in relation to the literature, for discussion, and organised into the themes of this thesis: the occupational perspective, user involvement and day services. These three themes are addressed in Part Three. The insider view node was felt to be significant in drawing the themes together, and so was used to synthesise conclusions about this research.

### **Conclusion**

This chapter has described the design, ethical and practical considerations, and the implementation, of the research as a whole. The research has been conceptualised for this purpose in phases of consultation, action and evaluation. The next part of the thesis focuses on the active phase of the research, characterised by the three strands, which are described in detail in chapters six, seven and eight.

## **Introduction to Part Two**

### **The strands**

The active phase of the research was mainly concerned with the three research strands, although collaborative work continued. This part of the thesis has one chapter for each strand. For each strand, relevant literature has been reviewed, the method described and the findings presented and discussed. Strand A, in Chapter Six, was focused on the social lounge at Elm Lodge, which was identified by service users as a place where social networking took place. The significance of place was analysed, informed by human geography and occupational therapy literature. In addition, there was a review of literature on using photography as a means of gathering qualitative data. Photographs taken by service users in the Strand A research group are used to illustrate the findings, which emphasised the importance of a safe space within day services. The title of Chapter Six, 'The Social Lounge and beyond', is the title given by the research group to the final report, which was produced to inform local service development.

Strand B, detailed in Chapter Seven, was based at Alder House and focused on access to social and recreational activities beyond the day services. The literature on these activities, including leisure, is reviewed. Equally significant for this strand were the strategies used for empowering the members of the research group. The principles associated with empowerment are introduced and discussed in relation to the findings, which detail the group process and the outcomes of the group's work. The service users distinguished between places they could visit occasionally and those they visited regularly, which had greater implications about whether to disclose mental health issues or not. The title of Chapter Seven, 'Getting Better by Going Out', was originally created by the group for the poster, which presented the findings locally.

Strand C contrasted with the other strands in that it involved individual interviews rather than a closed research group. In Chapter Eight, the

literature on user-led groups is reviewed, considering self-help as well as aspects of groupwork. The findings have been organised into themes which include narratives of each of the groups studied. The title of this chapter, 'A state of flux', is related to these findings, which indicated that the user-led groups were in a constant state of flux with implications for the leaders, members and staff recommending the groups to potential new members.

In this part of the thesis the three strands are very separate: they are brought together again in Part Three for the final analysis and discussion. There were many people, places and groups involved which are listed on page 12. Appendix A shows the slides used to promote the three strands in meetings with service users and at the second social networks day.



## Chapter Six

### Strand A: The social lounge and beyond

#### Overview

Strand A focused on service users' perspectives on the use of the social lounge, the dining room and the garden at Elm Lodge for social networking. A research group was set up there, taking and analysing photographs as a source of data (Figure 2). This chapter gives an account of the strand, its methods and findings. As an introduction, two specific aspects are explored in relation to the literature. First is the significance of place in mental health services, drawing on literature from human geography. The second aspect is the use of photography as a tool in qualitative research, tracing the development from its beginnings in anthropology to recent studies in health and social care. Following specific details of the strand itself, the chapter concludes with a discussion of the findings.



**Figure 2: Anu and Wendy at Elm Lodge, seen through the garden door.**

## Place and mental health services

At the time of the research, places such as the social lounge within the statutory sector were under review as part of a national drive to combat social exclusion and promote integration into mainstream community life (Office of the Deputy Prime Minister 2004, Bates 2005, Taylor 2007). This issue has been analysed and discussed in Chapter One. This drive seemed to be strongly associated with the view that designated places for mental health services were associated with dependency and institutionalisation, especially when attendance was prolonged over many years. The literature reviewed here offered another perspective on designated places in mental health services, especially in relation to the idea of asylum, or place of safety. This perspective has been largely developed by human geographers who recognised that specific places are identified by people in relation to health, not only for safety but also as places where health and well-being are actively promoted. These places have been called ‘therapeutic landscapes’ (Williams 1999, Parr 1999). This section will give an overview of these ideas in relation to mental health.

The social lounge and associated spaces at Elm Lodge had not been identified as a therapeutic landscape. Ongoing review meant their therapeutic value was being actively questioned. However, in the preparatory phases of the research as a whole and in the previous study (Bryant et 2005), service users consistently identified therapeutic benefits of the three resource centres in the area as places to go to. This perspective seemed to fit with this definition of therapeutic landscapes:

*“Therapeutic landscapes are those changing places, settings, situations, locales, and milieus that encompass the physical, psychological and social environments associated with treatment or healing...” (Williams 1999, page 2)*

Geographers have become interested in developing a more complex understanding of places beyond capturing the physical aspects, generating an interest in the impact of human activity on places and what makes a place significant to human life (Williams 1999, Cresswell 2004).

The term ‘therapeutic landscape’ was first used by Gesler in the early 1990s to identify those places which are specifically and consistently associated with healing, for example, Lourdes (Smyth 2005). Since then, the term has been used more broadly to identify the perceived health benefits of other landscapes and places (Williams 1999, Andrews 2002, Smyth 2005). For example, national forests, national parks and summer camps for children (Bell 1999, Palka 1999, Thurber and Malinowski 1999). Palka’s study of a national park in Alaska suggested that it was not the inherent physical properties of the park which contributed to the therapeutic experience but the way people were supported to access and use the park safely. It seems that it is not enough to assume that the existence or aesthetics of a particular landscape will make it therapeutic. People have to feel that it is practical, meaningful and safe for them to access it (Palka 1999). This is echoed in an analysis of how private mental hospitals are marketed as places of retreat, healing and safety (Moon et al 2006).

Smyth (2005) argued that ideas of what constitutes a therapeutic landscape are dependent on contemporary assumptions about health and well-being, and that interest in different settings has evolved as assumptions have changed. She pointed out that in the past fresh air was valued as a healing factor, and so hospitals were designed to bring fresh air into or closer the hospital (Smyth 2005). The history of healing specifically associated with mental health problems has been characterised by particular places such as asylums created to confine and contain people with severe mental health problems (Foucault 2001, Porter 2002). These asylums varied in approaches to insanity, ranging from physical restraint to encouraging self-control (Foucault 2001). Porter (2002) suggested that bringing people together in one place encouraged the development of knowledge and fostered the development of psychiatry, alongside the more general impact of the Enlightenment. In particular, occupation was used to foster self-control, with people taking on responsibilities for particular aspects of asylum life, for example

working on the asylum farm, or in the laundry (Porter 2002). With the rise of psychological and social explanations for mental health problems, occupational approaches were less favoured, and attention turned to how asylums as social environments exacerbated psychological problems, giving rise to community care but not solving the issue of segregation in relation to mental health problems (Porter 2002, Pilgrim 2005a).

Smyth (2005) proposed that therapeutic 'networks' were currently more prevalent, reflecting changing views which emphasise multiple sources of assistance with health problems. However, mental health services are still often clustered together, recognised as 'post-asylum geographies' (Philo 2005, Andrews 2002). The social lounge in this strand was in a building which housed the day services and the community mental health team, and was next door to a supported housing scheme for people with mental health problems. Previously the building was a children's home and was located adjacent to fields, slightly away from the local public transport and shops. The whole site had been a safe space for different groups of people at different times.

The work of Parr and Philo (Parr and Philo 2003, Parr et al 2003, Parr et al 2004) was partly based on the perception that discourse around community care tended to assume an urban setting. Their study of remote rural locations gave useful insights in contemporary assumptions around inclusion and integration. In the Scottish Highlands, mental health problems were potentially highly visible. This could be a simple matter of everyone in the locality knowing what the community psychiatric nurse's car looked like. This visibility was associated with the risk of social exclusion. In contrast, those who had personal experience of the asylum for the area, regarded it as a significant place in therapeutic terms (Parr et al 2003). 'Spatial proximity' to others with similar experiences enabled people to access caring relationships and a sense of being included. Specific places, which accepted and included people in varying states of

mental health, were perceived as therapeutic in many of these studies (Parr 1999, Pinfold 2000, Parr and Philo 2003, Parr et al 2003).

What is striking about these geographical analyses of place and mental health is how focusing on the places themselves has meaning for staff and service users, being focused on everyday experience. Place, from the perspective of human geography, is the product of an interplay between an actual physical spaces, and human efforts to control what happens there, based on perceived and constantly changing meanings (Cresswell 2004). Because the view of the social lounge at Elm Lodge as a place of potential exclusion was associated with the concept of social exclusion, the meaning of the social lounge was challenged at the time of the research. Resistance to this imposed and preferred meaning was an ongoing process, evident in this research. Thus Cresswell (2004) argued that places are continually recreated through everyday routines and habits, yet also responsive to bigger shifts in power relations and perceived meanings.

With the significance of power relations, Foucault's work has been used as a theoretical reference point for human geographers studying mental health services (Parr 1999, Parr et al 2003). There is some evidence that clinical theories about healing and therapy are also used, such as psychoanalysis (Parr and Philo 2003, Andrews 2004). Conradson (2003) used the work of Carl Rogers as a reference point in his study of a drop-in centre, suggesting that it was important to attend to the 'shift in subjectivity', as people shifted their perceptions of themselves, others and the environment in response to particular locations. This way of understanding place is readily understandable to many occupational therapists, who often deliberately manipulate the therapeutic environment or setting to facilitate such shifts and consequently occupational performance (Rigby and Letts 2003, Stewart and Law 2003). Thus, for this strand, the service users' view that the social lounge was a significant place in terms of their recovery made sense, and their fears about not

being able to access it seemed justified. It seemed important to question what particular aspects were important and to what extent these could be replicated in mainstream community settings.

### **Gathering information using photography**

The choice of photography arose from three main considerations. Primarily, it was believed that this method of data collection would offer increased opportunities for participation, being non-verbal and a meaningful occupation for many people. This belief was derived from a preliminary informal analysis of photography as an occupation. My personal and professional experience suggested that participants would be familiar with photography and its products in many ways, a view echoed by Harrison (2002). A second influence was the recent development of the use of visual methods in healthcare research. Arts-based approaches to data collection, such as photography, appeared to be developing in both complexity and credibility (Rapport 2004). This development drew on established methods in social anthropology and sociology, where multiple methods of data collection are valued as a means of achieving a detailed representation of culture (Rapport and Overley 2000). Photography has formed part of this since the earliest investigations of anthropologists (Collier 1967). The fact that there was an established convention of using photography in social science research was a third consideration for this study.

This section explores these three influences in detail, drawing together the practical and theoretical aspects of using photography in Strand A. Beginning with photography in social science research, this section will then consider developments in recent health-based research. Emphasis will be placed on the extent to which the reported studies were participatory in nature, reflecting the overall aim of this research to involve service users.

### **Photography in social science research**

The use of photography as a means of collecting anthropological research data was pioneered by Mead in the 1940s, and Hall in the 1950s and 1960s (Collier 1967). This innovation appeared to emerge from a combination of two factors: the development of photography as a technology and arts form, and a desire to capture the complexities of social life without imposing interpretations. Photography offered a convenient means of quickly recording observations in situ, becoming a standard resource in anthropology (Harper 2002). Collier explored this further, naming the active use of photography in research as visual anthropology (Collier 1967). His work compared the use of photography with more conventional methods, and findings led him to claim that photography was a highly accurate method of measuring social interaction and behaviour, challenging existing assumptions about people (Collier 1957, Collier 1967).

However, there is a paradox in Collier's notion of accuracy, for he also recognised that the act of taking a photograph is not a neutral one (Collier 1957). There are four or more stages of subjective interpretation and judgement in taking a photograph. For example, for the photograph at the beginning of this chapter (Figure 2), the photographer made the decision to participate by taking a camera out into the garden in the first place. Then there was the decision to take a photograph through the open doorway. The group members' co-operation was required for taking the picture. Finally, in analysing the usefulness of the photograph in relation to the research, different perspectives were discussed. Thus the idea of a photograph being an accurate means of measurement is less plausible when interpretation and representation are considered. The belief that an objective representation can be created has been superseded by recognition of contextual influences on the researcher (Rapport and Overing 2000, Harrison 2002) and of power dynamics in "photovoice" projects (Wang et al 2000).

Harrison (2002) took a different perspective on the shift in emphasis in the use of photography. She claimed that, initially, photography was used by anthropologists as a 'visual map' of culture. When the subjects of investigation became involved in explaining the images, she suggested that photographs became a 'field note'. From here, a more collaborative approach evolved. Harper (2002) pointed out the collaborative potential of a conversation about an image or a photograph. The term used in this context is photo-elicitation, defined by Harper (2002) as "inserting a photograph into a research interview". In contrast, Harrison (2002) is more specific, suggesting that photo-elicitation is focused on using photographs quite deliberately to elicit responses from participants, especially where the topic under investigation is difficult to verbalise. In the context of experiences of healthcare, Harrison points to a study of pain and gender as an example.

Hurworth (2003) referred to the term 'photo interviewing' as an alternative to photo-elicitation. This method involved participants taking photographs themselves and explaining them to the researcher, driving the focus of the research. Other variations included 'reflexive photography', used to investigate cultural differences; 'photo novella', used to investigate everyday life; and finally, "photovoice", used as a basis for participatory action research (Hurworth 2003).

The work of Wang et al (2000) involves a number of studies using photography in the context of participatory action research. In their account of a project involving homeless people in Canada (Wang et al 2000), they described three key aspects of "photovoice". It is oriented to promoting health through community action, acknowledging power relations and incorporating the need for critical reflection by participants through discussion of the photographs. Wang et al (2000) rooted the method in the health promotion strategy stated in the Ottawa Charter (World Health Organisation 1986), feminist theory and the work of Freire.



The method enables people to “*amplify their place in and experience of the world*” (Booth and Booth 2003, page 432).

There is a defined structure to the process. A training session is required at the beginning, not only to share technical skills in handling cameras, but also to give an opportunity for discussions about the dynamics involved in taking photographs and being photographed. Interestingly, Booth and Booth (2003) deliberately omitted this opportunity in their study with mothers with learning difficulties, claiming that it might ‘intellectualise’ the project. However, this resulted in difficulties, which will be discussed further below.

Following the training session, the “photovoice” method (Wang et al 2000) involves a process of taking photographs and discussing them, followed by events to promote and display the findings. These events offer further opportunities for dialogue with people with power to change things. In the study with homeless people (Wang et al 2000), it is clear that the project was energised by the proposal to build a new shelter beyond the city. However, in Booth and Booth’s project (2003), it was not so clear what the researchers were seeking to change, and the participants refused to participate in events after the project. Regrettably, neither study in its published form contained photographs taken by participants.

### **Photography in health and social care research**

Photographs have been used as a means of illustrating work on the lives of people with mental health problems. Knowles (2000) used photographs to illustrate findings from a large-scale informal project, in her book on community mental health care in Canada. As illustrated in the photograph in Figure 9 on page 172, this book was used as a reference source by Alan, a member of the research group for this strand. Photographs were also used in a book of narratives of patients from Bethlem Hospital (Gale and Howard 2003) – conveying the indiscriminate nature of mental health problems and the dignity of the people experiencing it. In this book, the

photographs are an interesting contrast to the narratives, which incorporate extracts from case notes. These photographs were originally taken for a number of reasons, including attempts to categorise people by linking their diagnosis and physical appearance (Gale and Howard 2003). The motives of the authors, however, were different. They wanted to ensure that the narratives were not lost.

Photography thus has a potential to illustrate findings, which was one purpose of using it here. However, it also has the potential to involve participants in research – this is explored by Rapport (2004), who grouped photography with other arts-based methods. These methods were a means of redirecting attention from the individual to the medium, and a means of offering a richer way of capturing the experiences of individuals, beyond words.

In health and social care research, photo-elicitation and “photovoice” techniques appear to be the most common, as illustrated in the studies already discussed. There seems to be a pragmatic approach to the use of both techniques, possibly related to the desired outcomes of the research. It seems quite possible that the prospect of increasing understanding or improving the illness experience generates emphasis on possible outcomes, rather than exploring the diverse meanings of experiences.

For example, the study by Aubeeluck and Buchanan (2006) claimed to be using the “photovoice” method, but it was overtly oriented to gathering data to inform the design of a standardised measure of quality of life of the carers of people with Huntington’s Disease. In this study, the subject matter for the photographs was defined by theoretical concepts of quality of life, and participants were expected to illustrate these with their photographs. While there was some recognition of the potential of the study to give voice to the participants, there was no desire to change policy or services, a key stated aim of the “photovoice” method (Wang et

al 2000). The data analysis was undertaken solely by the researchers (Aubeeluck and Buchanan 2006). This study subsequently proceeded to use focus groups in further preparation of the measure.

In contrast, the study by Booth and Booth (2003), already mentioned above, did involve participants in the analysis of the photographs taken. There were two opportunities to do this – firstly in an individual interview, and secondly in a group setting. Interestingly, the attendance at the group session was poor, even though it was held at the same time as a previous group session known to the participants. It could be because issues of ownership and dynamics in taking photographs were not discussed in the initial session. There could have been an assumption operating that people with learning disabilities were unable to participate in this type of discussion. Despite this, the findings of the study provide an interesting insight into the personal lives of the participants. However, Booth and Booth (2003) recommended that the “photovoice” method probably worked better with shared rather than individual experiences.

A “photovoice” study involving women who had survived breast cancer took a systematic approach to their shared experiences. Rather than seeking to change policy by directly presenting experiences to policymakers, Lopez et al (2005) sought to develop a model or theory of women’s experiences using the “photovoice” method. Thus the study was conducted not as a participatory action research project, but as a grounded theory project. The justification for extending the concept of “photovoice” was based around the idea that power could continue to be shared beyond the collecting of data. The development of a theory or model could give the women a basis for negotiating strategies and developments. The women were involved in every stage of the research, which took place over seven months (Lopez et al 2005). The process, of taking photographs, analysing them and synthesising categories into themes, was central to enabling the women to feel involved.

There appears to be an emphasis on words in health and social care qualitative research, perhaps reflecting the situation in social science more generally (Harrison 2002). However, photography cannot be separated from words entirely, but potentially offers another perspective. Radley and Taylor (2003) explored this issue in some depth in their photo-elicitation study involving people receiving medical or surgical treatment as in-patients. This study was clearly designed as an ethnography, with emphasis on gaining insight into the participants' experiences of in-patient treatment. There were distinct phases to the research, balancing reflection and action, suggestive of Freire's approach to empowerment and education (Freire 1970). This was partly imposed by the setting, as cameras could not be left on the wards and the photographs could not include other patients. There were two individual interviews, one as soon after the photo-shooting session as possible, and the second after discharge.

This gap, between the photographs and the interviews, was highlighted by Radley and Taylor (2003), who also suggested that the act of taking a photograph in itself was a means of creating distance, however briefly, between the person and their immediate environment. They proposed that this distance or gap contributed to the richness of the data. Surviving an admission required immersion in the setting. The gap created by the act of taking a photograph allowed intolerable or unpleasant aspects of admission to come into focus. This aspect will be considered further in discussion of the findings.

### **Photography – an occupation**

There seems to be two aspects to using photography in research – the process of doing the photography, and the responses to the photographs as a product or outcome (Radley and Taylor 2003). Harrison (2002) categorised these two aspects into topic and resource, with a slightly different emphasis. Here the topic is the photograph, as a product, whereas the idea of photography as a resource suggests a process of accessing information via photography. Schwartz (1989) proposed two

possible responses to photography – as a work of art or as a record. Either way, responses are bound by the viewer's own interests and context, making photographs 'inherently ambiguous' (Schwartz 1989). For this reason, it is essential to contextualise photographs, giving voice to competing interpretations from those who are represented (Hirsch 2004). This in turn gives an opportunity for people to get involved, to make sure their voice is heard, in relation to the photograph.

This suggestion resonates with this research, where service user involvement in the process was a key aim. This strand was structured to give everyone the opportunity to participate in the process: choosing subjects, taking photographs, interpreting and analysing them through discussion, and making final decisions on which photographs should represent the views of the group. The issue of interpretation of images was discussed regularly.

A photograph provides a rapidly absorbed source of data – Collier (1957) described photographs as "objects of consuming curiosity". The benefits of using photography included an increased engagement with the research, by focusing on images not people, and as a means of overcoming difficulties arising with literacy problems (Collier 1967, Schwartz 1989). Harper (2002) suggested that photographs are more successful in engaging people than words because they use the visual, rather than the auditory, sensory system. He claimed that visual stimuli are processed in different ways to words, although his ideas about engaging a deeper level of human consciousness as a result seem unsubstantiated. However, it seems quite possible that photography gives an opportunity to elicit different responses, simply by engaging another sensory modality. Similarly, in a context where mental health services are focused on people as individual service users and particular aspects of their lives, photography appears to offer an opportunity to represent other, equally relevant but often ignored aspects.

Ownership of the photographs was considered for this research. Did a photograph belong to the person who took it, to the people in the picture, or to the group? This dilemma echoed issues of authorship in contemporary art. In my preparation, I was influenced by the work of Dimitrijevic (Godfrey 2005). In his project 'Casual passer-by', Dimitrijevic followed a systematic approach to creating an exhibition of his work. He took a portrait photograph of the first person he met each day, and enlarged the photographs into banners. These were then displayed in public places. An exhibition would take place at the same time as the banners were displayed. Each portrait was displayed, along with another photograph of the banner in its public space. A certificate was placed alongside these two images, capturing the date, time and location of the original meeting. This work put ordinary people, or 'casual passers-by' in prominent places and made them visible. The certificate underlined the sense of occasion (Godfrey 2005).

In relation to this research, then, the issue of authorship was considered. The work of Dimitrijevic suggested that authorship was negotiable and could be shared. There was the primary issue of consent, firstly to have a photograph taken and then for the photograph to be used to explain the research. I believed that there was an essential gap between the two aspects, between the experience of being photographed, and of the photograph being used. While the photographs in this research were not being enlarged into banners and attached to the walls of the local Town Hall, there was a strong sense that by consenting to participate, the participants would be making themselves visibly attached to the project and its outcomes. The idea of formalising that process by producing a certificate was considered very carefully, with initial photographs being presented for analysis in a certificate form. However, the volume of images prevented this from being pursued, and so the plan was split. The images were organised for rapid analysis and the participants were encouraged to choose a picture about which they wanted to make a statement. In the following week a transcript of the statement was placed

alongside the chosen photograph, for further analysis and member checking. Finally, group members chose their favourite photographs and before the group ended, they received a certificate of participation.

For this research there was also the issue of the subject matter, how a space (the Social Lounge) impacts on the people within it, especially in terms of their social life, or social networking. Could this be captured by taking photographs? Can a landscape convey a sense of human social life? Dean and Millar (2005) point out the limitations of a visual representation, using a film by Lockhart, *“Teatro Amazonas”*. This film was carefully constructed, selecting the setting as representative of a particular time, and the people as representative of a particular place. Yet the film could not convey this process of creation (Dean and Millar 2005). Similarly, this research was structured so that the photographs were a means of expression, but not the only means. The photographs were not expected to speak for themselves, but to illustrate the perspectives of the service users involved. Thus the interplay between the photographs, the photographers and the photographed was essential. This was an enduring process of interpretation and analysis. Collier (1957) described the photographs in his research as a *“language bridge”*, clarifying and giving accessible detail to participants’ experiences.

It is worth considering briefly how developing technology contributed to the design of Strand A. Collier’s research (1957) reported that participants were intrigued by images of themselves and he speculated whether they had ever seen a self-portrait before. The participants in Strand A were not in this position: collections of photographs were on the walls of the Social Lounge. Although they were not familiar with digital cameras, everyone had used a camera before. Harrison (2002) highlighted the importance of acknowledging that the use of photography in research may differ from that experienced in everyday life.

In conclusion, then, photography was chosen as the focus for gathering data in Strand A. Through the taking of photographs, service user perspectives were captured and explored. By using the cameras and owning the photographs, if they so wished, the service user participants were offered the opportunity to participate actively in the research, and to own the products. Using the products, or the photographs, as a focus for discussion, is recognised as a means of eliciting rich data. In this strand, these data served two purposes: to inform the process of change in the local area, and to gain insight into how service users could be involved in research and service development.

### **Method and procedure**

The people involved in this project wanted to make their views known, especially in relation to the use of the resource centre buildings. Those participating in this research became involved after hearing about it in various different ways. Following liaison with the day services manager, Caroline, flyers were displayed (Appendix N) and a visit was made to the user/staff business meeting at Elm Lodge. Caroline also requested a formal letter explaining the research for the other teams using the building, and there was discussion about how to distinguish this group from a therapy group. The user/staff business meeting gave service users an opportunity to ask about the research and why it was happening. The chair of the local user group, Andrew, was also present to support the research. It was emphasised that anyone currently or recently involved in day services was welcome to join the group. At a subsequent business meeting, service users questioned how confidentiality would be maintained, and ongoing liaison up to the start of the group enabled further discussion to take place. Sian, a member of staff who had attended the first social networks day and was very interested in the research, took responsibility for this liaison work and then became a member of the research group, with Caroline's approval.



The research group consisted of five service users: Adam, Alan, Eleanor, Anu and Tony. All but one of the group members (Tony) were familiar with the research from the Day Services Forum or the Social Networks Days. Sian, the staff member, acted as co-leader and provided access to facilities and in house services as required. It was agreed that the group meetings would take place on Wednesday afternoons, when there were no other groups taking place and the centre was quiet.

This strand was given ethical approval by Brunel University research ethics committee and the local Primary Care Trust ethics committee (Appendices B and C). The agreed procedure was highlighted to participants informally, as a means of keeping the group focused and ensuring they understood the safeguards for their well-being within the group. Discussions about ethical decisions took place throughout the group's existence, particularly in relation to confidentiality, the photographs and presenting the research. This was also particularly important for Sian, who was aware that her responsibilities as a member of staff were potentially in conflict with research priorities. A weekly review session after the group and regular communication between group sessions was essential to facilitate her involvement.

Each of the service users were long-term users of mental health services and raised issues at some point during the research. At times it was necessary to liaise with other staff who gave valuable advice as to how to best facilitate involvement. There were times when it was difficult to sustain the focus on the research, and this advice was essential as a source of successful strategies to keep the group functioning well. Key to these strategies was engaging the whole group when difficulties arose, so that responsibility was shared. For example, it was agreed that it was acceptable to interrupt and disagree with one group member who spoke at length and at times offended people. This agreement empowered the group as a whole and set boundaries for the member concerned,

enabling him to remain a member of the group and setting the scene for his continued active involvement in the research.

There were eight project group meetings. At the first meeting, everyone present had an opportunity to find out about the research and give their consent to participate (Appendix P). They were given a programme for the group (Table 8) and an information sheet (Appendix D). The group met in a room upstairs, the Learning Centre which was separate from the Social Lounge. A map of the social lounge in relation to the building and its surroundings is illustrated in Figure 3. The resource centre occupied a large site, and only the area used by the research group is included in the Figure. However, the garden did extend beyond this area.

<b>Table 8: Schedule for research group meetings in Strand A, December 2005 - February 2006</b>	
December 7 <sup>th</sup>	Introduction to the research, followed by break while participants give written consent. Introductions. Agreeing ground rules. Preparations for information gathering: camera skills.
December 14 <sup>th</sup>	Take photographs
January 4 <sup>th</sup>	Analyse findings, take more photographs and prepare for next session
January 11 <sup>th</sup>	Analyse findings, take more photographs and prepare for next session
January 18 <sup>th</sup>	Analyse findings from previous session. Start overall analysis
January 25 <sup>th</sup>	Analysis of all photographs
February 1 <sup>st</sup>	Prepare themes to present to User/Staff meeting this week.
February 8 <sup>th</sup>	Reflect and close.

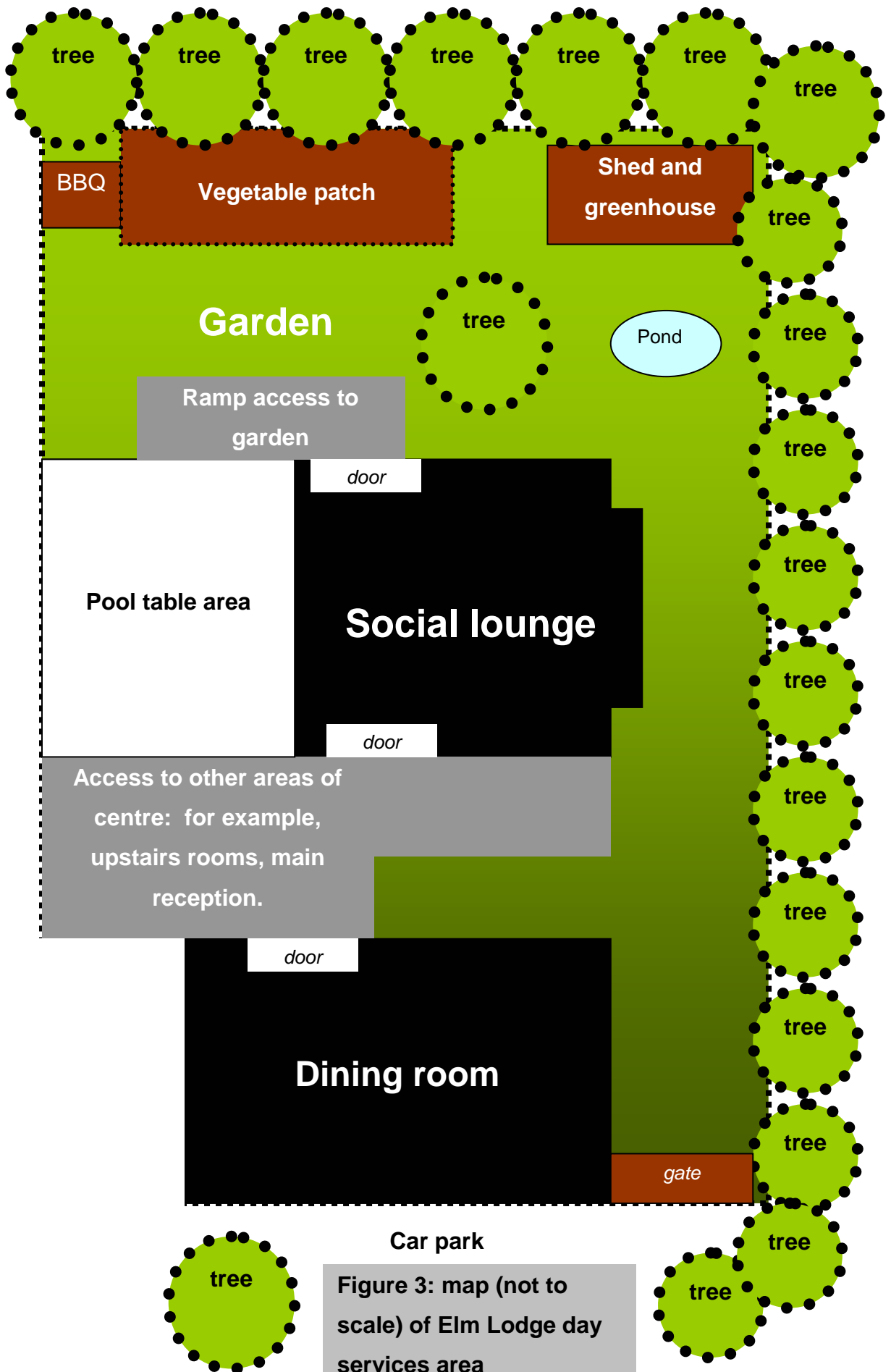


Figure 3: map (not to scale) of Elm Lodge day services area

As previously stated in Chapter Five, the question used to guide this strand was “Are social networks being formed and sustained in the Social Lounge?” and was produced as a one-sheet handout for all group members to refer to, along with the aims. These were:

- To gather information on how the Social Lounge is currently used.
- To generate themes to stimulate further discussion and development.

The question and aims were used to focus the group’s activities throughout the eight meetings. Giving people a choice about how they wanted to participate was a very important aspect of this research, and ground rules were agreed before work started. Tasks were shared between group members and priorities were negotiated each week. As a preparation for this, in the very first week, the digital cameras were passed around the group, and each person was invited to say where they preferred to be in relation to the camera. This gave immediate information about them to the whole group, for example their curiosity about the technology and willingness to be photographed.

The group meetings lasted for an hour and a half and there was always a break at some point. The breaks and the variety of activities meant there was always scope to negotiate how much to be involved as the work progressed. Negotiation also took place over the initial focus on the social lounge, leading the group to the garden and the dining room. Going outside to take photographs was combined with a break when the weather allowed. Some photographs were posed, others were spontaneous. All were taken by the group within the meetings to ensure that only people involved in the research were in the photographs. Everyone gave their signed permission to use the images here and in future presentations of the research, by signing the back of their selected photographs.

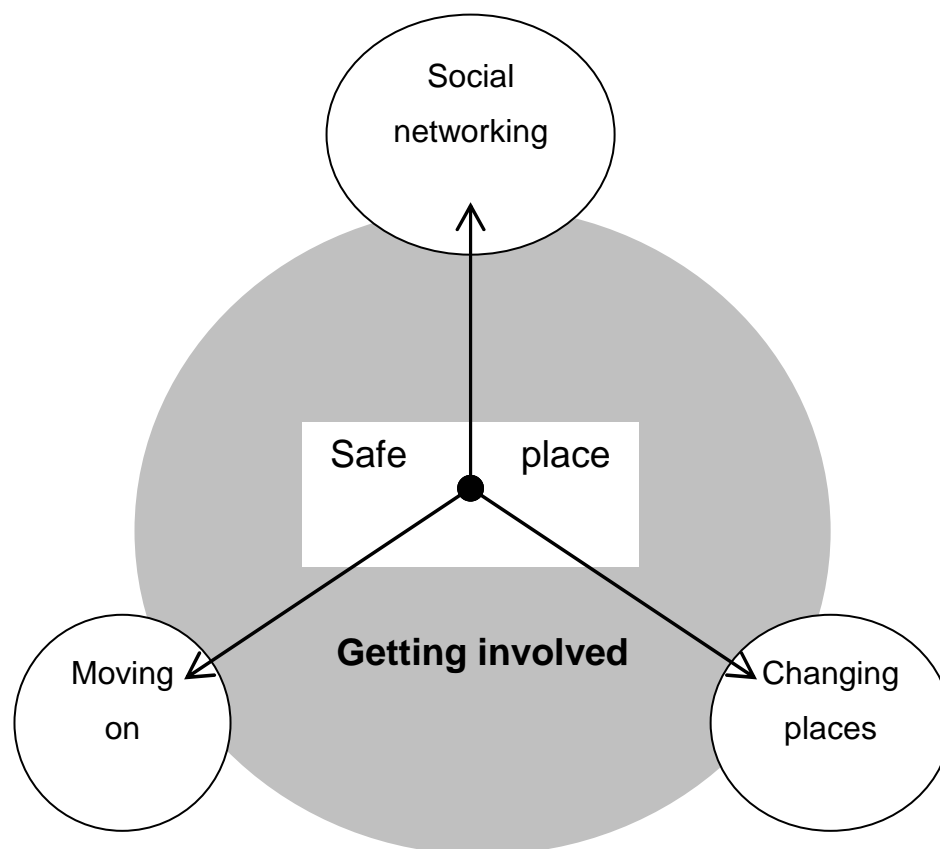
Photography is more than pressing a button on a camera: so each week there was time allocated to examine photographs previously taken and discuss them. There was a pattern of having informal discussions about the photographs, which I recorded in brief field notes. As discussions developed, digital audio recordings were made to capture everyone's ideas. This was an important way of conveying the importance of everyone's contributions, and encouraging group members to synthesise and convey their reflections. These thoughts and statements about the photographs were transcribed and presented to the group each week. Thus the group worked in a cycle of action and reflection, which enabled them to identify ideas and organise them into themes, directly linked to the photographs. As part of this process, an MP3 player was used to capture personal reflections before and after the group meeting. A fieldnotes book was also used, to record where people sat, key issues and statements, and immediate reflections afterwards with Sian.

For the sixth group meeting, there was a recorded discussion about the report on the research, using a framework to structure the discussion ('Bare bones of a report', Appendix Q). This helped to prepare for the end of the group and a tangible product (the report), as well as focusing thinking and reflecting to synthesise the findings. The final group meeting also gave an opportunity for each member to reflect on the experience of being involved, as well as finalising the themes and identifying the photographs used to illustrate them. Everyone was given a certificate (Appendix R) as evidence of their involvement, and later copies of their chosen photographs were put in albums and sent to each of them. Summarising the groups' findings and discussions, a report was drafted and sent to them for comments. With their agreement, the report was made available locally and used to support presentations of the findings. Two group members chose to be involved in these presentations. One also became involved in preparing and organising the research for an exhibition at the university. This display was subsequently given to Elm Lodge for permanent display there.

## Findings

Despite the ongoing challenges of living with long-term mental health problems and the distractions of Christmas, most people came to many of the eight meetings. In reviewing the experience of being involved in the research, they felt that there had been a high level of commitment and enthusiasm. One group member believed that it had been a means of self-help, acknowledging the serious nature of the research. Humour played a part in managing the tasks and constant visual images of the group members in the photographs. There was a shared view that being involved in the research had immediate benefits for the individuals involved which is discussed further in Chapter Eleven, on user involvement.

Towards the end of the group, Adam organised the main themes from the photographs and discussions into a model (see Figure 4 below). The first theme, central to the findings, was that day services offer a safe space to service users. From this safe space it was possible to get involved in social networking with other service users. Linked to this, and again requiring service users to be involved, was the theme of moving on as individuals. The final theme was concerned with changing times, which was a reflection on the shared experience of changes in the organisation and provision of day services. In this next section, these themes are addressed in turn, illustrated by the photographs. The section is based on the local report created by the research group, with additional material derived from a review of the audio recordings of the discussions and reflections, fieldnotes and photographs from the group.



**Figure 4: Model of themes for Strand A, created by Adam**

### **A safe place**

The initial focus for photographs in this research was the Social Lounge, a large multipurpose room on the ground floor of the building. As can be seen in Figure 3 (page 163), the room was divided into two halves, with a pool table in one half. The other half had tables and chairs, low coffee tables, bookshelves and noticeboards. There was an exit to the garden and a large bay window, making the room light. This room was the venue for the user/staff business meetings, the social group and where service users congregated when not attending other groups. The dining room was also used as a point of social contact, as was the garden. These three areas represented a key part of the day services:

*“The social lounge is part of the safety net that is [Elm Lodge]”  
(fieldnotes)*

This description was meaningful to the other group members, one of whom used a different resource centre and another who had been discharged some time ago. Safety as a theme was believed to have different components and was the subject of several discussions within the group.

The photograph of the cloudy sky and trees (Figure 5) provoked discussion about the physical environment surrounding Elm Lodge. Service users valued the natural environment, suggesting that contact with it made them feel calmer. The tree in Figure 6 was a favourite for shelter in the summer, with people sitting together under the tree. The group proposed that the whole area used by day services users was an oasis and a bolthole.

*“Oasis with a sense of community. There is no pressure to buy things. There is no pressure to talk to people. There is peace. Get away from bullying. In the oasis people get on with each other. There is time. It’s a long journey to find what to do next.”*  
(fieldnotes)

*“Bolthole. There’s choice in the bolthole. Life’s a bummer. You have the stigma which means you are refused jobs. You learn from it far too late. There’s fiction in the choices. You don’t know what’s around the corner. Many people are trapped.”* (fieldnotes)

In this sense, the bolthole offered a positive contrast to the rest of life, beyond day services. Living with mental health problems on a long-term basis presented ongoing challenges for the group, and an opportunity to escape from these challenges was highly valued.

The group members believed that being in a place where they were accepted for who they were without question was important, especially when they had time on their hands and had limited resources. One person spoke of wanting *“just to be with people”* (audio-recording) and some time was spent discussing how being with people who knew and understood mental health problems was beneficial. It was believed that despite the treatment on offer, living with long-term mental health



problems meant that there was no freedom from the illness itself. As a result, group members highlighted the importance of changing attitudes - those of the person, to their illness, and those of the people they come into contact with. The tolerance of other people and the familiarity of the resource centres made them comfort zones. One group member said that *"nobody likes to be out of their comfort zone"* (audio-recording).

Thus threats to the social lounge were taken very seriously. The group was concerned about reports in the national media of rising rates of mental health problems and that, locally, other people might not have the social lounge as a resource. The cafes which they were being encouraged to use instead seemed to offer less of a comfort zone. This comment was provoked by one photograph (which cannot be shown here because not everyone in it gave consent):

*"Independent, taking his time, doing something for him, and not feeling pressurised to be part of people's conversations at the table behind him."* (audio-recording)

Group members were of the opinion that they were more likely to experience hostility in the wider community, and so having somewhere safe to go made a difference to life. The photograph of the coats (Figure 7) was taken deliberately to capture the sense that you could hang your coat up and not worry about it. One person said *"You don't have to worry when you're somewhere like this"* (audio-recording).

Similarly, the photograph of the gate (Figure 8) was chosen as a reflection of discussions about experiences of prejudice beyond the day services. However, within the day services, being able to trust the other people, including staff, was important, and had to be established before getting involved in other aspects of the day services.



**Figure 5: Cloudy sky and trees from the garden**



**Figure 6: The tree used for shade in the garden**



**Figure 7: Coats hanging up in the pool table area**



**Figure 8: The side gate by the dining room**



**Figure 9: Alan, reading Knowles (2000), in the dining room**



**Figure 10: Wendy and Anu**



**Figure 11: Eleanor, in the social lounge**



**Figure 12: Adam, taking the photograph for Figure 24**

## Getting involved

The group agreed that a safe place was central to their experience in the social lounge and so placed it at the centre of the model (Figure 4). Getting involved in the other aspects (social networking and moving on) was dependent on this sense of a safe space. Paradoxically, the absence of imposed and unrelenting responsibility made it more possible to get involved:

*“It’s not forced upon you, that’s what I like about it. You can be yourself. You don’t have to worry when you’re in a place somewhere like this. At home, it’s different, you’ve got to, and you just want to go upstairs and curl up, and hide away.” (audio-recording)*

*“Just to talk, and then you’re arguing, and then you’re helping yourselves. Because you learn from your mistakes.” (audio-recording)*

The experience of getting involved in the research appeared to mirror the experience of getting involved at Elm Lodge. Everyone in the group got involved in this research: safety, routine and familiarity helped this process. Ground rules were discussed in the first session and often referred to after that. There was a regular place and time to meet. On the whole there were no interruptions to the work of the group and there was a routine, which allowed for break times, which were important when concentration was difficult. Everyone negotiated how much to get involved - some days some people felt good and wanted to be really involved, other days were more challenging for some. One group member brought in examples of her own creative writing which related to the research question. Alan engaged with the literature, as shown in Figure 9, preferring not to take photographs but to read relevant books and papers within and between group sessions and using his new knowledge to inform the analysis. The different ways in which people engaged with the research reflected their capacity for involvement from week to week, and the opportunities on offer.

For others, using a digital camera was a welcome challenge, demanding concentration and resulting in a sense of achievement. The photographs in Figures 10, 11 and 12 show group members taking photographs for the research. Everyone was interested in thinking about service user involvement as much as the issue of social networking in the social lounge, thinking about how the structure of the research enabled them to express and explore their ideas. The photograph in Figure 12 shows Adam taking a photograph which was a very personal expression of life with a long-term mental health problem (Figure 24).



**Figure 13: Sian, in the dining room**



**Figure 14: Wendy, Sian and Adam playing ludo in the social lounge**





**Figure 15: The 'Diana' tree**



**Figure 16: Adam, Wendy, Eleanor and Sian  
at the entrance to the dining room**

## Social networking

Getting involved often meant making social contact with the other people in the Social Lounge and the Dining Room. But there was more to it than that:

*“I have known people for a long time, I know how they tick and I can help. In 10 years of history you know more than the number of cats they have. I have helped someone avoid getting really ill – I knew what would keep her calm.” (fieldnotes)*

*“People understand, they know what you’re going through.” (fieldnotes)*

The photograph of Sian (Figure 13) was chosen to illustrate how sense of being understood was experienced in contact with staff as well as other service users. Thus the sense of a community, of staff and service users, was really important – people understood what it was like to live with long-term mental health problems as well as sharing stories of survival. There were also shared stories about the place, concerning the art work on the walls, the trees in the garden and even the local rules for playing ludo. The photograph of us playing ludo (Figure 14) was an example where the group decided that in order to illustrate how social networking took place in the social lounge, it was necessary to have a photograph of people playing ludo. Eleanor said, with great amusement, that she really enjoyed playing ludo in the social lounge:

*“Ooh I’m excited, back to normal.” (audio-recording)*

Another shared story, only revealed through social networking, was related to the tree in Figure 15. This tree was the ‘Diana’ tree – planted in 1997 when Princess Diana died. It served not just as a memorial to her but to the many other people who had died or moved on from Elm Lodge. In discussing this photograph, there was an acute sense of how suicide impacts on the social networks between service users.

There was also a sense of loss about the group which had been meeting in the Art Room, but had been discontinued because the funding for the art worker had been cut. This discussion was prompted when considering

whether every aspect of social networking at Elm Lodge had been captured in photographs, for saturation of the data. This was an example of something that could not be captured with photographs. It had been the “*highlight of the week*” (fieldnotes) for some people, being an opportunity not just to do art but also to have contact with other service users. The group was an open group, so people were able to establish regular attendance patterns. They had been encouraged to attend a mainstream community art group instead but were hesitant, being aware of the impact of their mental health problems and what social networking might mean for them personally:

*“There is a fear of being ill again: [I am] blighted with illness, although it burns itself out with age.” (fieldnotes)*

*“We all vary in how social we are” (fieldnotes)*

There were also discussions of how it felt to come to Elm Lodge for the first time:

*“It’s frightening to come here for the first time and some people don’t want to stay.” (fieldnotes)*

Support from staff and service users was thought to be really important at all stages. One group member thought the different stages of support were suggested in the photograph shown in Figure 16. One stage led to another, like doors opening one onto another.

Another aspect of Elm Lodge which was thought to facilitate social networking was the choice of things to do. For example, playing pool, as shown in Figure 17. Having a choice was very important: “*you have to know your limits and build up from there*” (fieldnotes).

Analysis of the photographs provoked some discussion about whether social networks were sustained beyond the resource centres, especially after discharge. One member of the group had been discharged from day services: with the other group members, there was an agreement that social networks did not generally survive beyond the Social Lounge.

*“It’s nice to meet people outside of Elm Lodge, but we keep it to ourselves.” (fieldnotes)*



**Figure 17: Adam and Alan playing pool**



**Figure 18: Wendy, Alan, Anu, Eleanor and Tony in the garden**



**Figure 19: The noticeboard in the social lounge about community resources**



**Figure 20: The noticeboard in the social lounge about centre activities**

### **Preparing to move on**

While the service users really valued a safe place and somewhere to be with others, they also wanted to capture a sense of how being at Elm Lodge was also concerned with moving on in the long term. Photographs were taken of the information point in the social lounge (Figures 19 and 20). The group emphasised, though, that it was not enough just to give easy access to information. More importantly, there were other people to discuss the information with, sharing opinions and developing social and critical skills.

*“The past can trap you but the past can educate you through your experiences.” (audio-recording)*

*“If you use your senses in social contact, then when you’re in the outside world you’re much better prepared to socialise with people outside.” (audio-recording)*

The Social Lounge also provided service users with a place where they could develop their own initiatives, being a place to publicise and discuss user-led projects.



**Figure 21: The shelter for smoking in the garden**



**Figure 22: Elm Lodge from the car park**

## Changing times

This final theme drew together discussions which emerged from analysing the photographs, and considering the aspects which could not be captured visually. There was a shared view in the group that services were changing for many reasons. The smoking shelter in the garden, for example, represented changing attitudes to smoking in mental health services and was one of the first subjects chosen for a photograph, being strongly associated with social networking (Figure 21).

There was a tension between the concept of Elm Lodge as a treatment area and the service users' experiences of self-help within it. The photograph in Figure 22 was used to discuss how far the "treatment area" extended.

*"Elm Lodge, the building and its grounds have been defined as a 'treatment area.'" (fieldnotes)*

Defining the purpose of day services had an impact on what was allowed to happen at Elm Lodge, and what was not.

*"We're told come here, can't help, no social chat, come in, do the groups, leave." (fieldnotes)*

There was an emphasis on participation in groups which were led by staff on a time-limited basis. In this view of Elm Lodge, the centre was a treatment area. Other aspects of attending Elm Lodge became less valued, for example, being able to give and receive support in informal ways. There was discussion about the photograph in Figure 23 of the strawberry patch in the garden. To the group this represented the opportunities service users had to help themselves and each other. This could be in a very practical sense, in caring for the strawberries, or, as has been said before, having a shared resource for support. It was important to get a balance when supporting each other, as all service users were vulnerable to getting ill again. It was recognised that getting very involved with other people's problems might not have been helpful.

*"Hope to be well enough to help someone although we are discouraged from giving each other support." (fieldnotes)*



But informal times together were useful in identifying strategies for survival. Managing the tension between survival and treatment required a flexible approach, especially when combined with the everyday experience of long-term mental health problems.

*“I sat indoors yesterday and I felt like kicking the sofa I was so angry with myself for not going out.” (audio-recording)*

Adam took the photograph in Figure 24 to capture what was needed to keep mental health issues in the picture. It was taken at a 60 degree angle, to suggest that different perspectives are required. The contrast between the bright light and the darkness represented the contrasts in common experiences of mental health problems, experienced as much as Elm Lodge as anywhere else.

*“The dark photo? Contrasts of greys and darks and black and white. Sunspot and the black, the depths of despair.” (audio-recording)*

As the group evolved, service users realised that what they thought was “commonsense” was important and not necessarily appreciated by people not using day services. They increasingly understood that they needed to make the details of their experience explicit, choosing photographs which demanded complex explanations. This aspect of the research, of making tacit knowledge explicit, was significant in the final analysis and is developed in the theme of user involvement.



**Figure 23: The strawberry patch in the garden**



**Figure 24: Dark and light in the dining room**

## Discussion

The group readily agreed that 'safe space' should be at the centre of the model representing the findings (Figure 4) and felt that this was fundamentally important in terms of their lives as service users. Their idea of a safe space was not confined to the social lounge, but incorporated the dining room and garden as places to just be, and to encounter other people with similar experiences. This idea corresponded to the findings of other studies (Pinfold 2000, Burns et al 2002, Philo et al 2002, Conradson 2003, Parr et al 2003). For example, one study revealed service users' perceptions of drop-ins being a public space, yet it was sheltered from some of the negative aspects of a fully public space (Philo et al 2002). In particular, service users were well aware that stigma and prejudice made them vulnerable (Davidson et al 2001, Burns et al 2002, Philo et al 2002, Parr and Philo 2003, Kelly and McKenna 2004, Thornicroft 2006) and consequently viewed spaces where mental illness was an accepted fact as being 'safe' in comparison. This made the spaces a safe place to just be, as well to encounter others in a way which was more under the control of service users, similar to non-statutory day centres and reminiscent of the social life of the old asylums (Conradson 2003, Parr et al 2003). This perspective generated the metaphors of bolthole and oasis, similar to the "safe haven" in Pinfold's study (2000).

This notion of safe space did not sit easily with the priorities of the day services at the time, despite enthusiastic support from the wider service user network. Medical, clinical and organisational agendas emphasised units of treatment, and social disability agendas emphasised integration into the mainstream (Pinfold 2000, Davidson et al 2001, Kelly and McKenna 2004). Yet it seemed that service users were saying that in addition to these agendas, their particular need for refuge and escape had to be considered, echoed in other studies (Davidson 2001 et al, Burns et al 2002, Philo et al 2002, Kelly and McKenna 2004, Parr 2006). While refuge could be found at home, this was not always a positive move (Philo et al 2002, Conradson 2003). The potential isolation of the

home environment drove service users out. The spaces at Elm Lodge were not only a safe destination, but also offered social and occupational opportunities. The social opportunities were associated with support and acceptance. The occupational opportunities were on a domestic scale, everyday but significant in fostering a sense of belonging and productivity, recognised as a key feature of drop-ins (Pinfold 2000, Burns et al 2002, Conradson 2003).

The group sought to emphasise the positive aspects of their safe space, being well aware of the threats to its continued existence, in contrast to conflicts identified in other studies, especially around alcohol and substance misuse, (Pinfold 2000, Burns et al 2002, Conradson 2003, Parr 2006). It is possible that other aspects were not emphasised because of this, although one group member used another resource centre where the policy of integration was more advanced (see Strand C), and so could offer some insight into what had happened as a result.

The other elements of the findings (getting involved, social networks, moving on and changing times) indicated that service users were well aware of and interested in engaging with life beyond the safe space. However, the safe space was not something separate but an integral part of their recovery journey. This reflected findings of Davidson et al (2001), who came to the conclusion that “supported socialization” was not an optional extra component of recovery, but a “prerequisite”. This links with the concept of bonding social capital (Almedon 2005), discussed in Chapter One. The social networks created by service users within the social lounge enabled them to access and assess information about other social and occupational opportunities from other service users. The ‘Out and About’ group at Elm Lodge also sought to address this need.

Perhaps the tension between sustaining a safe place and reaching out to other places reflected a fundamental tension for all places on a domestic scale. Elm Lodge was domestic in scale, with a kitchen, dining room,

garden and lounge. Tuan (1977) analysed the nature of intimate, domestic spaces, conceiving of them as primarily places of shelter and nurture. He argued that all human societies create places of shelter for themselves and particularly for people who are vulnerable, described as a place for a “pause in movement ... to satisfy biological needs” (Tuan 1977, page 138). When a space becomes a safe place to pause, people form attachments and put down roots (Cresswell 2004), for “home is where you can be yourself”. But those strong attachments can become strangleholds, and so there is a tension between feeling safe and feeling trapped. Yet, as Alan said, for people with mental health problems, feeling trapped was something not solely linked to places like Elm Lodge, for at times problems arose wherever a person was. Cresswell (2004) described how being in the wrong place, or out of place, meant that people had to decide whether to reveal or conceal their outsider status as they travelled through different spaces.

Philo (2007) suggested that different scales give different perspectives. Actively considering therapeutic spaces at every scale could benefit service users (Andrews 2002, Andrews 2004). From the service users’ perspective, at their scale, the social lounge and related areas formed part of a bigger picture. The work of Philo, Parr and Burns offered an invaluable perspective on the findings of this strand (Burns et al 2002, Philo et al 2002, Parr and Philo 2003, Philo et al 2005, Parr 2006, Philo 2007). By emphasising human responses to spaces, or particular places, their work appears to call for a more sophisticated understanding of the environmental contribution to mental health and well-being. The language of geography, of maps, of spaces and places, of distance and proximity, of landscapes and buildings, of real and imagined landscapes, deepens understanding (Andrews 2002, Conradson 2003, Parr et al 2003, Andrews 2004, Abrams and Hall 2006, Philo 2007). It also appears to offer a neutral response to long-term mental health problems, accepting them as part of the landscape as it were, without a dominant agenda for recovery or inclusion. Thus a critical stance can be taken, echoing the

findings of this strand, exposing current discourses in a different light. For example, Philo et al (2002) suggested that much of what was considered to be 'social inclusion' at the time was in fact about 'economic inclusion', as if the two were synonymous. This neutrality does not deny the hope of recovery or inclusion, but enables a systematic approach to both the hopes and the realities. Service users' perspectives are central to this approach.

However, this is not to suggest that human geography offers *the* answer to the issues around community care for people with long-term mental health problems. Just as there are limitations in placing too much emphasis on the findings of this strand, human geography has limitations, especially in relation to the realities of service provision. The findings of this strand are supported by the findings of human geographers, and with both being strongly rooted in service users' perspectives, it is important to consider how human geography could be incorporated further into both doing and interpreting mental health research.

It is also important to briefly consider how using photography worked as a research method. There were anxieties raised by people involved and on the periphery, especially about ethical issues, a key issue in using photography (Rose 2007). However, from the moment the group was underway these anxieties proved unfounded. Part of this was due to the careful thought and consultation which were embedded in the project from its earliest stages. However, it could also be due to the fact that although this strand involved work with vulnerable people from an ethical point of view, the dynamic nature of the research that meant there was always scope for them to choose not to be vulnerable, and to take control of the research process. This echoed the view of Faulkner (2004) as being key to successful service user involvement in research. Photography can be viewed as an art and a craft or technology (Rose 2007), and the research focus on place engaged individual and collective interest (Dean and Millar 2005). What was particularly encouraging was

the group's determination to own the research in public presentations beyond the immediate locality and in an exhibition at the university. This was seen as an opportunity to further validate the importance of their work, in a similar way to the community art groups studied by Parr (2006).

## **Conclusion**

This strand of the research aimed to find out if social networks were being formed and sustained in the social lounge. The findings indicated that social networking was one aspect of what happened there, along with the possibility of moving on and responding to changing times. However, none of these aspects could take place unless service users perceived the social lounge to be a safe place: this held central importance. This was a significant challenge to the emphasis placed on social inclusion at the time. These issues are developed in the other strands and within the project as a whole. The specific significance of this strand appears to be associated with the method and with the focus on place. Photography proved to be a rich and adaptable occupation, successfully engaging people with diverse interests and capabilities, and meeting the overall research aim to use an occupational perspective to involve service users. The focus on the social lounge and related areas as a designated space was meaningful to them, directly relating to their experience and enabling them to articulate their views on its part in their survival as long-term mental health service users. The report was used as a basis for commissioning further development work in collaboration with service users (Appendix S), to ensure that ongoing funding was dedicated to providing a safe space for social networking.

## Chapter seven

### Strand B: Getting better by going out

#### Overview

This chapter is an account of the second strand of the research, which was concerned with exploring social and recreational activities and their accessibility to people with long-term mental health problems. Relevant literature has been reviewed, followed by details of the method used. The findings of this strand involve a fuller account of the research process and outcomes, which are then discussed in relation to the particular focus of this strand.

Locally, the emphasis on promoting social inclusion had an impact on day services and service users and staff were being encouraged to identify and/or use social and recreational activities in the community as an alternative to day services. There were many known activities but it was difficult to know which were good to go to. While choosing an activity depended on an individual's interests and needs, it was recognised that everyone could use information about facilities such as cost, location, and opening hours. However, to become socially included, people also needed to know whether a friendly welcome was likely, making a feeling of being included or belonging more possible. So this research aimed to examine local social and recreational activities known to mental health day service users, looking not only at practical issues, but also at what sort of welcome could be expected. This was carried out by service users, using a checklist which they designed, piloted and used to gather information (Appendix J). The findings were put together to provide an information resource, a poster, for day service users and staff (Appendix K). It is hoped that these findings will form the basis for future initiatives.

#### Search strategy

The literature identified here was located through an online search including the databases Academic Search Premier, Blackwell Synergy, Medline, ASSIA and IBSS. Additionally, issues of the following journals,



contemporary to the research (2003-7), were hand searched: *British Journal of Occupational Therapy*, *Journal of Occupational Science* and *Mental Health Occupational Therapy*. Keywords used were social, recreational, leisure, networks, contact, mental, illness, health, problems, community, in various combinations. Literature reviewed for strand A was also used in relation to discussion of the findings, along with searches for articles on specific venues in relation to social inclusion and mental health. Interestingly, there was more literature from the learning disability field on specific community resources – within mental health there was a focus on employment and vocational training which reflected the political and organisational imperatives at the time relating to social inclusion.

The literature reviewed was broadly concerned with how social and recreational activities could contribute to the promotion of recovery and social inclusion. This contribution was considered by some writers along with other factors promoting social inclusion (Faulkner and Layzell 2000, Sayce 2000, Repper and Perkins 2003, Rogers and Pilgrim 2003, Wallcraft 2005, Granerud and Severinsson 2006, Spandler and Vick 2006). The occupational therapy literature reviewed was more focused on social and recreational activities, or leisure, and terminology appeared to be more significant to occupational therapists, possibly because of the specific focus on occupation. Thus this review examines social inclusion in relation to this strand, the terminology issue and the specific contribution of occupational therapists.

### **Recovery and social inclusion**

Recovery in terms of mental health has been defined in varied ways (Roberts and Wolfson 2006), distinguishing between the idea of a cure, and the experience of transforming life with a mental health problem. Recovery as transformation requires consideration of life beyond symptoms, linking with social inclusion (Davidson et al 2001, Deegan 2001, Repper and Perkins 2003, Wallcraft 2005). The use of mainstream community resources has been seen as an indicator of social inclusion,

for example being employed in a local company or using the local swimming pool (Sayce 2000, Office of the Deputy Prime Minister 2004). Locally, there was an ongoing discussion at the Day Services Forum about how this could be achieved. The occupational and social dimensions were acknowledged, echoing the service users in the study by Granerud and Severinsson (2006, page 291) who proposed that social integration was “*to have a meaningful daytime activity and to collaborate with other people.*” Social exclusion was recognised as a major factor in preventing people from fully participating in community life (Sayce 2000, Repper and Perkins 2003, Office of the Deputy Prime Minister 2004, College of Occupational Therapists 2006a). Rogers and Pilgrim (2003) suggested a combination of two factors acted as a barrier to inclusion: low self-esteem arising from the mental health problem itself, exacerbated by the experience of rejection within the community. Hence people preferred to spend their time in safe places, as identified in the previous strand and by studies such as Pinfold (2000). Heasman and Atwal (2004) suggested that, in relation to leisure, a lack of a companion was also a barrier.

Similarly, financial hardship was recognised as a primary factor in social exclusion, and access to the direct payments scheme was being promoted for people with mental health problems (Office of the Deputy Prime Minister 2004, Spandler and Vick 2006). This scheme, initially introduced for people with physical disabilities, was designed to enable service users to take control of the support they received from social services. This was achieved by allocating them funds to pay for support appropriate to their individual situation, rather than resources defined by what statutory services could offer. In theory this enabled them to gain equal access to the community with appropriate support (DirectGov 2007a). Examples given by Spandler and Vick (2006) included mental health service users who pooled their direct payments to fund a staff member to facilitate their arts group and another who funded a personal assistant for support on trips to a shopping centre. However, these examples were vulnerable to local variation, as the principles of user-

control and independent living were not always deeply understood by service providers (Spandler and Vick 2006). Direct payments were as vulnerable to financial pressures and controls as any other resource in the statutory sector. There were efforts to promote direct payments locally but none of the service users involved in this strand had had direct experience of the scheme at the time.

Thornicroft (2006) has indicated that the issue of how to access community facilities, and what makes them accessible, particularly to people with mental health problems has not been detailed in the literature. In a practical guide for staff working for social inclusion and recovery, Repper and Perkins (2003) gave attention given to what makes places feel accessible and safe for people with mental health problems. Their recommendations were focused on mental health service buildings, but the twenty ideas listed included many which would improve any venue, for example, ensuring that toilet paper was available (Repper and Perkins 2003, pages 142-4). While it might seem extraordinary that this kind of detail was required, it appeared to suggest that what was important for people with mental health problems was no different to anyone else in many respects. Respecting their needs for comfort, safety and privacy would go a long way to improving accessibility for everyone. The benchmarks for privacy and dignity (issued in 2001 and revised in 2003) were again focused on NHS care, but incorporate fundamental principles of respect to guide staff (Department of Health 2003).

It is possible that the difficulty in identifying specific needs in relation to mental health and accessibility was the reason why a search to locate specific guidance on accessibility to public spaces for people with mental health problems was unfruitful. Access guides responding to the Disability Discrimination Acts, 1995/2005 were primarily concerned with access for people with physical and/or sensory disabilities (Department for Communities and Local Government 2003, DirectGov 2007b, Disabled Enabled Ltd 2007, Office of Public Sector Information 2007). This aspect of access has been a focus for occupational therapy for many years, with

priority given to the built environment rather than to other aspects (Riley 2002).

Having access requires a means of getting to an identified destination. In the context of social inclusion, this is where the dual use of the word “community” could create confusion. In relation to access, community can be both a destination, such as a particular location, and also the means of accessing community resources. For example, a person might go to a swimming pool, located in her local community. Alternatively, she might belong to a swimming club, a human community or social group, enabling her to access the pool in her local community, the place. This aspect has been studied by anthropologists, who have recognised the interplay between community as a location and community as a defined social group. A community has been defined by Rapport and Overing (2000, page 63) as the “arena in which one learns and largely continues to practise being social.” What is important is that communities in both senses are universally valued (Rapport and Overing 2000). For the mental health day service users working on this strand of the research, this meant thinking about the potential of particular locations in the community to facilitate a sense of belonging and acceptance. From a social perspective, one of the primary issues associated with mental health problems is the threat to community participation, or social life, in terms of physical location and social context (Tew 2005).

This is developed further in studies of user perspectives on what contributed to their recovery, which included social and recreational activities but distinguished them from social relationships (Faulkner and Layzell 2000, Wallcraft 2005). For example, Wallcraft (2005) identified “*good relationships*” and “*enjoyable activities*” as contributory factors to recovery, separating the two, yet it would be difficult to imagine an activity being enjoyable if it were in the context of an unhappy relationship or vice versa. Faulkner and Layzell (2000) placed social and recreational activities in the category of self-help strategies. Self-help in this context would appear to mean those resources which can be accessed without

support from others. What was relevant to this strand was whether it was appropriate to distinguish between social support, and social and recreational activities, and to what extent the two were interdependent.

### **Leisure**

Studies by occupational therapists clearly identified the need for social support to access activities, as well as the possibility of accessing more or different support from the activities themselves (Lloyd et al 2001, Heasman and Atwal 2004). From an occupational perspective, these aspects appear to reflect different understandings of how people choose to use their time and the inherent difficulty of categorising activities by nature and purpose. Occupational therapy research has considered leisure in relation to health and ill-health, particularly mental health (Thibodaux and Bundy 1998, Cook and Howe 2003, Fieldhouse 2003, Shimitras et al 2003, Passmore and French 2003, Heasman and Atwal 2004, Minato and Zemke 2004, Pieris and Craik 2004, Lye and Griffin 2005, Craik and Pieris 2006). The preference for the term 'leisure' could be because one of the most common categorisations of occupation used by occupational therapists is that of productivity, self-care and leisure (Christiansen 2005). This section considers the literature in relation to efforts to define and categorise leisure from an occupational perspective and specific issues in mental health.

It is not clear if leisure could be considered synonymous with 'social and recreational activities', the term used in this strand. Thibodaux and Bundy (1998) argued that leisure was more than a way of using free time as it reflected evolving identity and hope for the future. Personal choice was central to the concept of leisure. Searches for literature indicated an academic preference for the term 'leisure', yet locally the term 'social and recreational activities' was preferred. In the spirit of the participatory nature of the research, the local terms were always preferred over academic language when conducting the research. Wilcock (2006) argued that leisure was not emphasised in approaches to public health until the industrial revolution in the UK. When industrialisation shifted the

majority of the workforce from being self-employed to being employees, a work-leisure split occurred. Paid working hours were distinguished from other unpaid hours, in which people could pursue self-care and leisure activities in theory. Subsequently leisure evolved into a separate industry, which has increased in significance in recent times (Neumayer and Wilding 2005, Wilcock 2006). Neumayer and Wilding (2005) suggested that leisure has been commodified and devalued by contemporary society with adverse consequences for health. Wilcock (2006) has also explored this, following Marx and Ruskin by suggesting that this artificial and imposed categorisation of time use has resulted in occupational alienation and imbalance. As a theoretical alternative to work-life balance, the activity-rest continuum proposed by Wilcock appeared to offer a more inclusive concept than that of self-care, productivity and leisure, especially for people who were not economically productive. From this perspective, leisure could be either activity or rest, depending on its occupational function. For example, reading a book could be active or restful, depending on whether the book was a walking guide used outdoors by a hiker, or a novel read by a person relaxing at home. However, the literature on leisure will be considered, as it is relevant to this strand.

So, leisure cannot easily be categorised (Neumayer and Wilding 2005, Craik and Pieris 2006). Specific occupations or activities which might be assumed to be leisure activities have been studied and found to be complex, fulfilling multiple functions and having specific individual meanings (Thibodaux and Bundy 1998, Lloyd et al 2001, Fieldhouse 2003, Passmore and French 2003, Heasman and Atwal 2004, Minato and Zemke 2004, Pieris and Craik 2004). Shimitras et al (2003) categorised leisure occupations into 'passive', such as watching the television and reading, and 'active', such as sports, arts and holiday travel. However this categorisation appeared to be primarily based on how physical an activity was. Baxter et al (1995), Christiansen and Townsend (2004) and Neumayer and Wilding (2005) have suggested more sophisticated categorisations, such as leisure as time use, specific occupations or a

state or mind or being, concerned with freedom of choice but always influenced by moral and cultural views.

The activities identified by the service users in this strand reflect the dominant culture in the setting at the time. Going to the cinema, to the library, shopping and church were all well-established and recognised activities. The work of Bennett and Silva (2006) also suggested that choices about leisure and other 'cultural' activities emerged from a complex combination of factors. They argued that it was inappropriate to assume that because a particular group was regarded as being socially excluded, this meant that the individuals within the group did not access such activities. Thus measures to increase social inclusion by promoting involvement of these groups in sports, leisure and arts projects were simplistic and not likely to succeed. Factors such as gender and age were equally important in choices made (Passmore and French 2003). This echoed the view of service users in the consultation period of this research. It was not appropriate to assume that a person with a long-term mental health problem did not visit museums, for example, just because s/he was viewed as socially excluded. Indeed the service users believed that between them they had a better knowledge of local resources than staff and it was important to draw on that expertise.

One aspect of leisure which seemed generally agreed was that it was a valuable use of time and an essential component of a balanced lifestyle (Shimitras et al 2003, Heasman and Atwal 2004, Lye and Griffin 2005, Passmore and French 2003, Minato and Zemke 2004, Craik and Pieris 2006). This is a particular issue for people who are not in paid employment. The adolescents in Passmore and French's study (2003) were not in paid employment and three functions of leisure were presented in the findings: in relation to needs for social contact, achievement and time out. A leisure activity had to be meaningful to the individual and have a recognised function, echoed in the studies conducted by Pieris and Craik (2004, 2006) and Fieldhouse (2003). The long-term mental health service users in their studies emphasised the

importance of leisure in the absence of paid employment. As a valuable use of time, leisure activities did not just act as a time filler, but contributed to improvements in social functioning, self-esteem and symptoms (Fieldhouse 2003, Pieris and Craik 2004). Another, larger, study of occupational therapy with people with psychosis in primary care included leisure activities in a range of interventions (Cook and Howe 2003). This study was a sophisticated analysis of the complexities involved in enabling people to become engaged with meaningful occupations, not only identifying possible occupations but supporting people in the process of engagement and actively adapting the environment to facilitate access (Cook and Howe 2003).

For this research, it was recognised that service users would have different views and knowledge of local social and recreational activities. It was important that the knowledge was shared in an accessible way, while also recognising that what was meaningful to one person might not be to another, and that people would engage with particular occupations for different purposes. Thus the method was oriented to gathering this knowledge and making it accessible locally to inform discussions about social and recreational activities. The research question and aims were:

What local social and recreational activities are accessible to people with enduring mental health problems?

1. To gather information on the accessibility of local social and recreational activities.
2. To summarise the information to support existing information resources.

## **Method**

### **Preparation and consultation**

This strand of the research took place during summer 2006. Before, during and after this period, partnerships with service users, staff and



others were sustained. The Day Services Forum had provided the original impetus for this strand, as with the others. In this case, the focus emerged directly from the first social networks day held in July 2004. The agenda for the day was concerned with opportunities and barriers for participation in social and recreational activities in the community.

One of the outcomes was that there was a request for more information – people felt that if they were to build social networks in the wider community, they needed information about where to go and what to do. The day's activities had generated useful information, and some service users felt strongly that it should be made available to everyone and so a small group decided to create a booklet. There was also recognition that more information was available via the local newspapers, and that service users might like to speak to someone about what they could be doing, especially on a Friday afternoon in preparation for the weekend when statutory services closed. The same small group who decided to create the booklet worked with staff to set up a telephone advice line. This initiative was called the BITRA: 'Borough Index to Recreational Activities', associated with both the booklet and the telephone advice line. Staff supported the initiative in many ways, for example by providing a room and a telephone line, and distributing the booklet.

The interest in the BITRA, both the index and the telephone line, was to some extent dependent on the service users involved and their ability to sustain awareness of its existence. In September 2004 a meeting was held with the service users involved with the BITRA, and other users to discuss whether it could be developed further as part of the research. There was enthusiasm for this idea, in particular finding out which activities were welcoming to people with mental health problems, and what knowledge already existed in the local area. There was general agreement that service users needed to go out and investigate the suggested activities for themselves, especially as staff knowledge of local places to go was perceived to be limited.

## **Design**

This strand was designed to create an opportunity for service users to evaluate social and recreational activities. This synchronised with the overall aim of the research to explore how service users could be involved in research. As with strand A, a time-limited research group was proposed, fitting with the culture of the day services where service users usually attended small weekly groups. As there was no existing tool to assess access from a mental health perspective, part of the group schedule included time for everyone to be involved in creating a way of assessing activities, which evolved into a checklist (Appendix J). When the research had been proposed, investigations by the Consumer Association, published in the '*Which?*' magazine ([www.which.magazine.co.uk](http://www.which.magazine.co.uk)), were used as an indication of the approach which could be used. A systematic yet simple means of gathering information was required.

The checklist (Appendix J) could appear to offer an opportunity for an objective rating of social and recreational activities but this was illusory. In the spirit of the participatory action research, service users chose the activities to be studied, defined the components of the survey and gathered the data. Being potentially based on one anonymous visit to an activity, the findings were limited in their generalisability and possibly their credibility. The intention was to create a resource for local service users and staff, which would not only provide suggestions but also, and more importantly, provoke discussion as to what constituted an accessible social and recreational activity for individual service users. It was believed that the checklist would provide a focused and structured means of gathering information, and, having being designed by the research group members, would have a credibility and authenticity for them, facilitating involvement.

## **Empowerment and participatory action research**

A key informing principle in the design of this strand was that of empowerment, as part of the participatory action research process. It was

anticipated that the ongoing process of consultation and negotiation would continue throughout the strand itself. Three aspects of the process are highlighted here:

- Starting from where the service users were
- Providing structure but expecting uncertainty
- Believing in success

Starting from where the service users were had practical and theoretical implications (Koch and Kralik 2006). On a practical level, this involved being sensitive to service user expectations associated with the setting as much as the research (Hammersley and Atkinson 2007). For example, for me, taking responsibility for setting up the room and providing refreshments was partly required because of the group being located in a mental health centre where there were restrictions on service user access. This was balanced by their knowledge of the everyday working of the centre. Talking about these everyday aspects each week was important, but a more important aspect was in relation to their knowledge of the research topic (Breton 1999, Evans and Fisher 1999). This involved sharing and discussing knowledge of local places, reflecting Freire's approach to empowerment with its emphasis on naming and critical reflection (Freire 1970). It was important to acknowledge that individuals within the group were at different states of awareness of their own expertise and so careful attention was given to pacing the group (Home 1999). In this way, the group could work together on increasing their own awareness that personal experiences were directly relevant to the research topic and thus had a wider significance (Breton 1999, Home 1999, Staples 1999).

This involved balancing the need for structure with the expectation of uncertainty, as actions of the group were negotiated and conflicts were resolved (Kock and Kralik 2006). Often, this process drew on prior experiences in research, education, therapy and activism, on an individual basis. Whenever appropriate, this would be discussed with the group (Hammersley and Atkinson 2007). Evans and Fisher (1999) described the academic researcher as potential ally in user-controlled

research, sharing skills and knowledge to empower service users. There was ongoing negotiation to identify needs, especially in relation to research skills and this negotiation was often structured around reflection through story-telling (Breton 1999, Koch and Kralik 2006). In this strand, my stories were as much part of the research process as anyone else's, and often stories were subjected to the group's questioning and evaluated in relation to the shared experience of the group. Reflection in action and on action was seen as an essential way of involving everyone in decision-making and action (Freire 1970, Staples 1999, Koch and Kralik 2006).

Underpinning these processes was a belief that the group would be successful because of its very nature. Firstly, as a research group it attracted members who valued research and were interested in asking questions and discussing different ideas (Evans and Fisher 1999, Staples 1999). Secondly, by bringing people together to work together, it was believed that power could be shared to facilitate participation, and as a result the group's findings would be seen as more representative (Home 1999, Staples 1999). Finally, it was believed that the group would be successful because it was assumed that those who chose to be involved had something to offer which would be useful. This in some ways was the most challenging aspect, demanding that those involved recognised their own expertise and competence, and, as Freire put it, were able to confront their 'internal oppressors' (Freire 1970, Breton 1999). The occupational focus of the strand facilitated this process of recognition, as did the tangible products (Breton 1999, Staples 1999).

### **Recruitment**

Recruitment of participants in this strand occurred within the wider context of the research. Following ethical approval, the people who had expressed an interest in the research as a whole were informed by letter. The second social networks day in November 2005 provided an opportunity to promote the strand, as part of a display about the research as a whole (Appendix A). Contact with service users who had expressed

an interest continued via the Day Services Forum, the Hillingdon User group and other meetings, as well as further letters (Appendix T).

The strand was scheduled to start two to three months after Strand A, and so communication at that time was concerned with both strands, reporting the progress of Strand A, and promoting Strand B (Appendix T). In addition to this, the strand was discussed with groups of service users and staff at the business meetings at Alder House, Elm Lodge and the user group. Flyers were also distributed (Appendix U). As with Strand A, it was made clear that people were welcome just to turn up and find out more about the strand before they made a commitment to it. Thus the participant information sheet (Appendix E) and consent form were used when a new recruit first attended. Some of the details of how people came to join the group are discussed further in the Findings section of this chapter.

Three service users had expressed an interest in this strand from an early stage, although, as it turned out, only one of them joined the group. This person was Angela: she had heard about the strand at the user group meeting. At that meeting another person (Gabrielle) expressed interest but was too busy. She later became more involved in Strand C. The other person who had expressed an interest was Graham who had been very involved in the BITRA telephone line. Unfortunately the timing of the group did not suit him. There was a period of negotiation, but ultimately it was not possible to find a convenient time, so we agreed to try and keep in touch by email, which he had access to. The group eventually consisted of Angela, Alan, Dean, Adam, Sally, and me.

### **Procedure and schedule**

A room at Alder House was used to ensure easy accessibility for the service users. This room had large tables, making the practical activities associated with the checklist easier. Although there were serious constraints on the availability of the room, eight Tuesday mornings were eventually agreed. The group started on May 16<sup>th</sup> 2006 with a follow up

meeting on August 29<sup>th</sup>. There was a break for the May bank holiday week. Each member of the group had a copy of the schedule to refer to (Table 9). Each meeting has been described in more detail in the Findings section below.

<b>Table 9: Schedule for Strand B</b>	
May 16 <sup>th</sup>	Introduction to the research, followed by break while participants give written consent. Introductions. Agreeing ground rules Preparations for information gathering: practical issues
May 23 <sup>rd</sup>	Devise checklist for recording information. Select activities for pilot and main research
June 6 <sup>th</sup>	Discuss and refine checklist following pilot testing
June 13 <sup>th</sup>	Discuss progress and troubleshoot practical issues
June 20 <sup>th</sup>	Discuss progress and troubleshoot practical issues and begin analysis
June 27 <sup>th</sup>	Analyse findings
July 4 <sup>th</sup>	Prepare findings for publication and presentation to Day Services Forum
July 11 <sup>th</sup>	Reflect and close.

### **Ethical considerations**

There were many ethical decisions on an ongoing basis, requiring interpretation of the original proposal and confirmation with the research group, the local staff and the research supervisors. For example, as this strand involved users travelling and taking part in social and recreational activities, the group members agreed in advance where they would go to ensure that due consideration was given to their comfort and safety. They

were encouraged to choose activities in which they normally engaged, and were discouraged from selecting activities currently associated with known risks to health. The collaborative nature of this research fostered a joint sense of responsibility to minimise or prevent harm, which was promoted by the structure of meeting every week for the duration of the strand. Funding for the activities had been agreed on an ad hoc basis with the Area Voluntary Services Participation Fund. However, only one activity (going to the cinema) required funding which was met from my own funds. The checklist for recording findings did not include identifying details, to maintain confidentiality throughout. However, the service users did want their involvement in the research to be known and requested that their names were included on the poster displaying the findings. Consent forms, audio-recordings and fieldnotes were stored securely at the University.

## **Findings**

The group met for eight meetings, with a steady level of attendance although it was only for two weeks that everyone was present. There were four service users directly involved: Alan, Angela, Adam and Dean and a member of staff (Sally). The group designed, piloted, adapted and then completed the checklist for a range of activities (Appendix J), drawing in other service users to increase the scope of the project. The checklists were logged and findings organised to facilitate analysis, which primarily involved detailed discussion of the findings. The group decided that the best way to communicate the findings was to create a poster to display in all the local resource centres (Appendix K). The final meeting was spent organising this. Members of the group were also involved after the strand was completed in presenting the findings locally and at national conferences, which resulted in other service users elsewhere being invited to get involved in similar projects.

## **The group process**

This section is focused initially on a detailed account of the group process, followed by details of the group products, the checklist (Appendix J) and the poster (Appendix K).

### ***Week one***

After receiving an overview of the research and giving signed consent to take part, the group spent the first week discussing what was going to be involved in the research. Ground rules were agreed:

- To have a break when you need it
- Everyone has a turn to speak
- Say what you think but respect other people
- Keep things in the group unless we've all agreed

The research question and aims were used as a reference point for discussion. At first, this was focused on which local social and recreational activities would be suitable to be included. There was a discussion about the costs of the research, and how it would be conducted. Angela and Alan were present for this meeting, and it was agreed that more members needed to be recruited to make the research group viable.

### ***Week two***

Adam joined the group in week two. While he had an opportunity to read about the research from the Participant Information sheet (Appendix E) and to ask questions, everyone else considered strategies for managing the task, given the small numbers in the group. Angela suggested that the checklist could be completed by day service users attending the resource centres, and the group could focus on collating the information. This was felt to be a very helpful suggestion and so the group decided to proceed with the strand using this suggestion. The ethical issues arising from involving more people in information gathering were discussed within the group and in supervision. Then discussion shifted to the design of the checklist itself. The creation of the checklist was structured into three



distinct phases. Firstly, small record cards were used to create questions for the checklist. There were three main categories of questions agreed:

1. Practical information about the activity
2. Issues of accessibility from a mental health perspective
3. Rating the activity as a whole, identifying good and bad points

The second category was the basis for prolonged discussion, which continued in subsequent groups and is discussed further below. Having created questions, the next phase began. Sample scales for rating were made available so the group could identify the different characteristics of each scale. Finally, there was the task of matching the questions to appropriate rating scales, and placing the questions in a logical order. It was agreed that the group members would pilot the checklist before the next meeting. Before the next meeting, I compiled the pilot checklist (Appendix V), following what was agreed, and sent it out to the group members.

### ***Week three***

Angela did not attend this week but Dean joined the group. Dean had attended the Day Services Forum regularly. That day, he was sitting alone in the lounge alongside the Arts and Crafts room, waiting for the Forum that afternoon. He was invited to join the research group in the morning, and within a few minutes came to join us. This was another critical point, discussed more fully below.

We piloted the checklist and discussed what changes needed to be made. These changes were concerned with the wording and simplifying the rating scales. We made the decision to publicise the checklist at the Day Services Forum that afternoon before distributing it to the resource centres. This discussion was recorded as an example of the group's decision-making process. In particular there was a prolonged discussion over what to ask in relation to the specific aspects of mental health and visiting the activities. There was a shared view that it was a very

important subject to investigate but there were many facets to it, making it difficult to synthesise a simple question which would generate meaningful answers. In particular there was discussion over what happened if someone did ask about mental health problems:

*“I’m slightly quizzical about why they ask but at the same time I’m happy for them to talk about it.” (audiotape)*

It was difficult to separate out what was associated with mental health issues and what was applicable for everyone, so eventually it was agreed to ask very specifically how the place or activity affected a person’s mental health, for better or for worse.

In previous weeks, hot drinks had been offered but not taken up and Alan had got very involved in fetching cups of water from the water cooler in the reception area. This was increasingly distracting for the group, so for the first time this week fruit juice was brought along to share which enabled the group to focus once again.

#### ***Week four***

Sally was away from the group on duty and Angela was in hospital. She had been in contact with me and I visited her on the ward as she wanted to give me some checklists she had completed. In the group session, distribution of the checklists was discussed. Some completed checklists were returned by week four and so there was a discussion about how to manage the information gathered. Index cards were created for these places. Adam, Alan and Dean decided to go to the cinema together as part of the research. A third of the group time was used to agree all the arrangements: they planned to meet for lunch beforehand and then see a film, ‘X Men.’

#### ***Week five***

Alan and I met initially. Angela was still in hospital and Dean had already sent his apologies, saying he’d done enough research for one week, being involved in the cinema trip the day before. There was no sign of

Adam or Sally. After half an hour, Alan and I agreed to postpone the meeting.

### ***Week six***

Alan, Dean and Adam attended week six. I created an agenda for this group to structure the meeting after missing a week. Some time was spent discussing the trip to the cinema and filling out checklists on it. A good number of checklists had been received and so there were some administrative tasks to do. Then the group began to discuss how the findings could be presented to other service users and staff locally. The day before, Adam, Alan and I had been at the private view of the exhibition which included a display of the research from Strand A “The social lounge and beyond”. They were inspired by this and wanted to create a poster to display the findings of this research.

Also during this week, Adam and I visited Oasis, a group which met at Elm Lodge, and filled out a checklist in discussion with them.

### ***Week seven***

Everyone came along to week seven, including Sally, and Angela who was on leave from the hospital. We analysed the findings so far, and looked at the gaps and inconsistencies. There was some discussion about using a spreadsheet to summarise all the findings and it was agreed that in the time available it was impractical for group members to learn the necessary skills – they had other priorities. However, I showed them the spreadsheet programme (Excel) to make sure they were happy for me to do this administrative task. We then had a discussion about how to organise the findings into the poster, which was recorded as an example of how the group worked in practice.

### ***Week eight***

The final week was held in the “Therapy Kitchen” rather than the usual room. Again everyone was present, except Sally, who visited briefly to say hello to everyone. I brought some food along to this meeting to mark

the end of the group. I also brought along certificates of participation for everyone (Appendix R). Most of the meeting was spent discussing the findings which had been summarised from the spreadsheet into a document. Decisions were made as to which data to focus on, and which to ignore for now. The prospect of creating a poster focused this discussion, thinking about what would draw people's attention. At this point the group decided that it would be important to have photographs to illustrate the poster. They felt strongly that I should take the photographs mainly so I could go and see some of the places which were important to them. Then there was a shared reflection on what it had been like to be involved in the research. This was recorded, to be used as part of the overall analysis.

Because the task was not completed, a follow up meeting was proposed for August 29<sup>th</sup> to put the poster together. A date, time and venue were agreed, as well as how the day would be structured. By this stage the group had also had two opportunities planned to present the research, to the Day Services Forum and to a national mental health occupational therapy conference.

### ***The final meeting***

Angela and Dean came to this meeting and we decided the layout and design of the poster. Afterwards I used this mock-up to make a digital copy, ready for printing. Several copies were made. Four very large versions were made for each of the resource centres and for presentations, and smaller versions were made for the Oak Foundation and for each of the group members. Finally a digital version was made available locally so other venues could obtain a poster.

### **Checklist findings**

Analysis of the completed checklists involved logging each checklist, giving it a number and putting key details on an index card. Responses to each item on the checklist were entered into a spreadsheet and

organised into tables for the group to discuss in week six. This discussion demanded reconsideration of the research question and aims. With the group's permission, audio recordings were made on three occasions, to capture the group discussion for use in relation to the overall research question, concerning user involvement. A fieldnotes book was also kept, along with audio recordings of personal reflections before and after each group meeting.

Forty-five responses were received, covering thirty-eight places. Two checklists covered two mental health resource centres in general, and so were excluded by the group, as were two checklists which covered distant seaside towns. There were no obvious patterns to the places identified in relation to the checklist components, so general statements could not be made, for example that it was necessarily easier to get to a shopping centre than to a nature reserve, or that people would be more likely to talk to you at a social group than in a museum. Each checklist reflected a very individual experience and so was represented at least once in the poster (Appendix K).

For this chapter, the process of anonymising the chosen places indicated broad categories:

- Art galleries, cinema, museums, theatres and zoos.
- Bingo, ten pin bowling and swimming pool or Lido
- Churches, including coffee bars and drop-ins
- Libraries
- Nature reserves, gardens, parks, woods, canals and lakes
- Neighbourhoods, town centres and villages
- Restaurants
- Shopping centres and garden centres
- Specific social groups and user groups for people with mental health problems

The group speculated that gender differences influenced responses, for example the places that might be difficult to visit alone included local

woods which might not feel safe to women. However this category also included a shopping centre, which might be more a reflection of specific difficulties arising from mental health problems. There were a number of different places which presented difficulties in access without private transport, in contrast to the churches, libraries, restaurants and the social groups which were easier to access. Where there were uncertainties about specific details, such as cost, toilets and refreshments, the group double-checked information using their own local knowledge.

There was some discussion as to how to understand the responses to “Places where people usually talk to you”, “Places where people always talk to you”, and “Places where people never talk to you”. It was recognised by the group that it could not be assumed that it would always be good to go to a place where people always talked to you, and bad to go somewhere where people never talked to you. For example, the cinema and the library were marked as places where people never spoke and that was agreed to make sense. However, in that case it seemed that conversations with library staff were not included, in contrast to museums and shopping centres, where it seemed that conversations with staff *were* included. The checklist did not give scope to consider the distinction was made between talking to people already known, and talking to strangers. Similarly, the responses to “Places where it’s comfortable to start up conversations” were felt to be very individual, depending on what sort of conversation was involved.

“Places where there are always like-minded people (not just mental health)” had an occupational or social focus, such as bingo or the social groups. Bingo was considered a five-star place to go to, along with churches, a swimming pool, a restaurant, a theatre, the local shopping centre and a central London museum. Again, this section of the checklist aimed to get an overall individual opinion. The five stars were symbolic rather than numerically significant. Seventeen places were identified as affecting mental health for better or much better, again including a diverse range of venues. Places having no effect on mental health were equally

diverse. The group felt it was important not to draw conclusions about why people chose particular places or categorised them in particular ways. It was not possible to know this information from the checklist, nor was it necessarily helpful. However, it was believed that it was important to communicate the findings via the poster, which evolved as an account of the research overall alongside lists of the places under each component of the checklist.

## **Discussion**

This strand was ambitious given the time period, aiming to convene a research group which could work together and produce a useful outcome within eight meetings. The success of the strand was dependent on how effectively the group could work together in that time frame. The interplay between this research, the previous strand and the Day Services Forum was critical and it would have been difficult to conduct this strand independently from the larger project. Staff and service users supported the research by distributing the checklists, making rooms available, encouraging people to get involved and providing opportunities for the findings to be presented. Service users, knowing the research as a whole, got involved by pointing out the relevance and usefulness of this strand. The process of getting service users involved in the group and information gathering was dependent on local knowledge of the research. Likewise this knowledge prompted a positive response to the findings, as presented in the poster.

However, the slow process of recruitment threatened the existence of the research group, perhaps indicating the challenging nature of the task. This could be understood in terms of the task being too ambitious, yet it was achieved. A more plausible explanation could be that the task felt too risky, mirroring Home's observations on how the process of empowerment requires participants to take risks in personal development (Home 1999). It could also be that the widespread scepticism locally about the accessibility of local social and recreational activities also

affected willingness to get involved. This seems to raise questions about the extent to which people felt they could challenge the drive for social inclusion at the time. However, for those who did get involved there was a strong belief in the importance of doing research, reflecting the views of Evans and Fisher (1999).

There was a strong reciprocal theme in the group which has not been emphasised in the literature. The service users traded their knowledge and ideas in return for the opportunity to explore new and old ideas in a different context. As such, the group offered opportunities to develop skills and interests and thus personal development, which has been noted in the empowerment literature (Breton 1999, Evans and Fisher 1999, Staples 1999). But there was a major difference here from truly user-controlled research, in that the group members were acutely aware that this research was initiated and sustained by being a doctoral study. This did not seem to be a negative factor. Hammersley and Atkinson (2007) highlighted the advantages of the novice researcher in engaging assistance in the field. However, what seemed more significant was the fact that there was a high level of trust on all sides that the service users could and would make a valuable contribution, at the same time as generating useful information for themselves and others.

Facilitating the group was also challenging at times because of the erratic involvement of Sally, the member of staff. However, in many ways this was positive for service users, who in her absence were able to take a stronger role in facilitation, particularly for Adam. From an ethical point of view, the service users were regarded as a vulnerable group of people, and so having a staff member present was a useful way of providing swift access to support services if required. However this vulnerability may have been overstated and indicative of an overprotective and risk-averse approach to ethics, as suggested by Faulkner (2004). There was some concern when Angela was in hospital under section, and efforts were made to clarify that her difficulties were not being exacerbated by participating in the research. Contact with key personnel indicated this



was clearly not the case. Having established this, it seemed most appropriate to respond to her efforts to keep in touch, and sustain her involvement as far as was practically possible. This may have indicated an extreme example of the challenges faced in facilitation but principles of clear and honest communication were as effective as in any other situation (Home 1999, Koch and Kralik 2006).

Personal opinions were central to this strand and it was hoped that the findings would stimulate discussion and new ideas. The checklist enabled more service users to be involved, sharing their opinions but remaining anonymous. This anonymity prevented over-arching conclusions being drawn about the chosen activities, opinions and the demographic details of each participant, but may have prompted the good response. The responses did not capture any experiences of social exclusion, but were not designed to. However, given the widespread experience of social exclusion and prejudice for people with mental health problems (Sayce 2000, Thornicroft 2006), it may have been very valuable to know which places were currently accessed by other service users.

The components of the checklist showed some resemblance to the list created by Repper and Perkins (2003) in relation to mental health services. Could the checklist be used as a way of auditing access in a similar way to access audits for people with physical, sensory and/or learning disabilities (DirectGov 2007b, Disabled Enabled Ltd 2007)? There are several factors to be considered. The diversity of places and the innumerable interpretations which could be placed on the responses to the checklists suggests that it is extremely difficult to generalise. People with mental health problems benefit from the same strategies that would make a place welcoming or friendly to anyone. However there is an issue about the visibility of mental health problems. Social inclusion could be about people with mental health problems accessing community resources (Sayce 2000, Repper and Perkins 2003, Office of the Deputy Prime Minister 2004, College of Occupational Therapists 2006a), but a

key aspect is whether the resources they are accessing require them to make their status as service user invisible.

The wide range of places known to and used by service users in this research could suggest that social inclusion already happens to a degree, in the sense of using mainstream resources (Bennett and Silva 2006). In contrast to other studies, in the responses there was no mention of adult education classes or pubs, bars and clubs (Passmore and French 2003, Heasman and Atwal 2004), perhaps reflecting the particular age and interests of the service users involved. When the strand was presented to the Day Services Forum, other service users pointed out that it was one thing to mingle with the crowd and make a one-off visit to a gallery, and quite another to visit a place on a regular basis.

It could be argued that a particular understanding of social inclusion informed the impetus for the research. This understanding was focused on visible re-integration into the community in terms of relocating service users into particular places rather than others to demonstrate social inclusion (Repper and Perkins 2003, Office of the Deputy Prime Minister 2004). However, social inclusion is not just about community as a location but also community as a social group, or people with shared interests (Rapport and Overing 2000). There is a paradox then, in recommending that service users use community resources. The emphasis on non-human resources, such as particular locations, suggests that relocation would be sufficient, yet this ignores the human dimension of community and the fact that by definition, social networks and groups are exclusive (Rapport and Overing 2000, Capra 2002). To become included involves accessing a human community resource, network or group which actively welcomes service users and does not require them to hide their service user status (Sayce 2000). Often, the only way that this can be achieved in reality is through denial of the status of service user, in other words, to make the mental health problem invisible. This is achievable for one-off visits to relatively anonymous venues, but can become problematic if the person seeks to visit on a regular basis.

Thus it seems that social and recreational activities offer two possibilities for inclusion. Using categories defined by occupational therapists may help to understand this. One is a one-off experience, such as seeing a film or a play, or visiting a museum. This type of activity could be associated with time use and entertainment (Baxter et al 1995). It would have more significance than merely using time, and could be viewed as significant in terms of recovery or personal development (Thibodaux and Bundy 1998). The other is through regular involvement in a specific activity, such as visiting a nature reserve, coffee bar or shopping centre. This type of activity fosters a sense of belonging (Fieldhouse 2003, Rebeiro et al 2001, Wilcock 2006) and often combines occupational and social purposes.

While there were places where people could go and be alone, suggesting a refuge or asylum, and also reminiscent of the therapeutic landscapes explored in Strand A (Williams 1999), it could not be assumed from the checklist responses that this was the primary reason for going there. There were also places where social contact was more likely, and others where the contact would be with familiar people, not strangers, which has been valued in other studies (Faulkner and Layzell 2000, Wallcraft 2005). The cinema trip was significant in this strand, not just because it enabled service users to access a mainstream community resource, but because they could do it together.

### **Limitations**

There are many places and activities which were not considered. This research did not distinguish between those places which offered opportunities to meet new people, and those which do not. Future research could address this gap. A longer duration for the strand could have helped, especially in making the most of the willingness of service users to be involved both directly and at a distance. This strand took place in early summer, deliberately chosen to coincide with a season where people tended to go out more. A different season would have been

likely to be associated with different activities. More time and resources would have enabled those directly involved to learn more skills related to research such as entering the data onto a spreadsheet, writing and sending out letters, and finalising the checklist. Future research would need to take into account the importance of fieldwork (Hammersley and Atkinson 2007) and the practicalities of participatory action research and empowerment (Breton 1999, Home 1999, Staples 1999, Koch and Kralik 2006). However, there has to be a balance between the process and the outcome and it is possible that future versions of this research would have to have more emphasis on the outcomes to gain funding.

## **Conclusion**

The aim of this strand was to identify which local social and recreational activities were accessible to service users, based on their direct experience. A diverse range of places were identified, indicating that many mainstream resources were used. However, the findings indicated a distinction between those places which could be visited regularly, and those which were a one-off, anonymous visit. This distinction raised the problem of finding places to belong to, where stigma would not be an issue. The research findings were made available locally in a poster which was displayed locally in resource centres, where it was accessible to service users and staff.

To meet the overall project aim, service users were involved in every aspect of the research process. They developed the ideas proposed in the consultative stage and gathered data which could be used immediately in the local setting. This data also had implications for understanding social inclusion in terms of social and recreational activities. Focusing on social and recreational activities, it was evident that service users engaged with a variety of opportunities which they were prepared to recommend to other service users. However, they drew a distinction between those activities or places which could be visited occasionally and those which could be visited regularly. Regular visits

were important to service users because it was to these places and activities that they felt they belonged. This sense of belonging was important for the user-led groups, studied in the next strand.

## Chapter eight

### Strand C: A state of flux

#### Overview

This strand of the research was concerned with three user-led groups. For this research, a user-led group was defined by the service user members taking responsibility for leadership, recruitment and organisation of the group. Staff were not present at group meetings but might offer support to user-leaders. A significant characteristic of these groups at local level was that they were viewed positively by service users, staff and managers, and in different ways reflected collaborative work carried out by service users and staff. The groups were viewed as a means of combating social exclusion, reducing dependency on day services, and building and sustaining social networks. Capital Volunteering, a London-wide initiative to increase involvement in volunteering, had a strong local presence and allocated funds to support two of the groups involved in this strand.

(<http://www.capitalvolunteering.org.uk/index.php>)

However, it seemed that user-led groups were in a state of flux and it appeared to be important to capture this, using narrative inquiry. For this strand, many of the service users involved played a more conventional role for qualitative research, with the majority being interview participants. This was originally intended to provide a contrast with the other strands. The interviews were conducted and initially analysed by Ken, who was completely independent of the services and worked primarily as an oral historian and playwright. He had interviewed me for another project elsewhere and his skills as an interviewer led me to seek his involvement in this strand. His involvement enabled an emphasis to be kept on the stories of the groups and secured my distance from the data collection, as by this stage in the research my independence from the local setting was compromised by my familiarity with many of the local people and places. This helped with recruitment. In the context of the participatory action research, some service users became very involved in recruitment,

setting up the interviews and communication of the findings locally. This shaped the strand, extending it from the original plan of focusing on one group to include three active user-led groups.

The stories of the groups enabled the intricacies of group life to be uncovered, as a living and changing phenomenon. Using a narrative frame was chosen in order to make the findings more accessible locally, being based on recognisable situations and experiences. This chapter offers a detailed account of the strand, including a presentation of the findings and a discussion of the implications.

### **User-led groups**

The idea that service users could lead and provide mental health services for themselves has been strongly associated with the mental health service user/survivor movement (Wallcraft et al 2003, Beresford and Campbell 2004). Originally this movement was associated with a rejection of the paternalism of statutory services in particular, and increased the recognition of diverse perspectives in a general cultural shift (Barnes and Bowl 2001). The mental health service user or survivor movement has particular features which distinguish it from the disability movement (Beresford and Campbell 2004). One key difference is that mutual support and activism are both regarded as functions of the movement, so that people are supported as they engage in political action (Beresford 1999b). This acceptance echoes feminist understandings of politics, where personal life is considered to be as political as public life (Charles 2004). The groups in this strand appeared to be concerned with mutual support, primarily in the sense of self-help for personal recovery. But all three groups emerged as a collective response to service changes, and so could also be seen as a political act. The history of the recovery model is rooted in service users seeking to take control of their own lives, which in itself is a political act (Brown 2001). Self-help has come to mean different things to different people, aimed at personal recovery and/or

mutual support and/or political campaigning, and so this term was used to locate literature which might inform this strand as it progressed.

The literature reviewed here has been located through searches using online databases such as ASSIA, Academic Search Premier, CINAHL, Medline and Google Scholar. Texts and documents associated with the UK survivor movement were also consulted. The term 'user-led' was used initially to search for literature but did not give access to anything perceived as relevant to this strand. The term 'self-help' appeared to be more widely used, along with the terms 'consumer-led' and 'mutual support' in the North American literature. It was believed that findings from groups within other settings could be informative, and that it was important to understand the scope of the concept of self-help in current literature. For that reason, and because of the wealth of literature on self-help, only articles published from 2002 onwards were included. One paper was rejected because although published in 2002, it was based on secondary analysis of data collected from 1992-3 (Hodges and Segal 2002). The year 2002 was chosen because locally, this was when the previous review was undertaken (Bryant et al 2005) and at that point, only one user-led group was referred to and it was just beginning.

The main purposes of exploring the literature was to establish whether the local experience at the time of conducting this strand (2006-7) reflected what was happening elsewhere. North American literature dominated this topic, but there were three key UK sources which placed the local experience in context (Davison 2005, Lewis et al 2003, Wallcraft et al 2003). Wallcraft et al (2003) reported on the state of the UK user/survivor movement in 2001-2, using multiple methods to engage with local groups as well as with key national figures. The majority of responses to one method, a postal survey, reported being involved in self-help and mutual support. This category included practical support with housing and benefits advice as well as social support and creative activities. The responses were from groups with links to national non-statutory organisations as well as small local groups, and 56% had a paid



worker. Wallcraft et al's report seemed to suggest that the groups had a shared belief in mutual support, common experiences of funding issues and of being part of local networks. These three elements, the beliefs, the resources and the context, seem critical to understanding the common concerns of the many different forms of user/survivor activity encountered in the study.

Wallcraft et al (2003) highlighted that the personal and political dimensions of mutual support could not be separated clearly. This is in contrast to the systematic review of self-help 'interventions' undertaken by Lewis et al (2003). They indicated that self-help could be as simple as just reading a book from the library, but included audiotape, videos and computer-based tools in their review. However, the word 'interventions' signalled a focus on specific strategies for recovery, which did not seem to include face-to-face contact with other service users. In relation to this research, one critical aspect was that local service users sought to gain contact with each other.

This emphasis on specific processes of recovery is illustrated by self-management programmes. Davidson (2005) distinguished between UK programmes concerned with specific health conditions such as the Expert Patient Programme and the more recent Chronic Disease Management Programme, and 'generic' courses. There are benefits and disadvantages to both approaches, which Davidson (2005) suggested are largely related to the specific needs of the service user and his/her support networks. The complex issues associated with long-term mental health problems require more varied and holistic responses, as illustrated in Wallcraft et al's study (2003). Survival seems to be more about surviving the mental health system than overcoming symptoms (Campbell 2005).

The North American literature confirmed the issues already discussed, but with larger studies, such as the survey of self-help organisations by Goldstrom et al (2006) in the United States. Here the organisations offered a range of services including advocacy, education, drop-ins,

befriending, creative and social/recreational activities, and research activities. The most common services involved access to information, social and recreational activities and telephone support. This was an extensive survey, identifying 7,467 groups and organisations in contact with over a million people (Goldstrom et al 2006). Again there was great variation in how services were organised and provided, but a common theme of self-help, concerned with recovery and access to other service users, was echoed in the definition of self-help by Hardiman and Segal (2003).

The personal recovery and political change agendas were combined in the accounts of a large participatory action research project in Ontario (Ochocka et al 2002, Nelson et al 2006a, Nelson et al 2006b, Ochocka et al 2006, Janzen et al 2006). Their work indicated that participation in self-help initiatives was associated with many benefits including increased community integration and mental health stability. It seemed as if having a safe place to meet with other service users then enabled participants to progress to other settings, echoing the findings of Strand A of this research (Ochocka et al 2006). However, their project was based on a number of initiatives in combination, all of which were involved in a range of activities including advocacy, education and training (Nelson et al 2006). Changes to the mental health system were reported (Janzen et al 2006), through increased awareness of positive outcomes from user-led initiatives impacting on policy design and implementation.

Self-help extends from the individual to the wider community, which Corrigan et al (2002) suggested is due to the fundamental difference between traditional statutory services and user-led initiatives. In their view, traditional services are based on a time-limited relationship between a healer and patient, in contrast to user-led initiatives which are essentially communities which evolve as a response to the changing needs of the community members, a view shared by Hardiman and Segal (2003). While this might appear similar to the contrast between the medical model and the social model of disability, what is interesting about

Corrigan and Phelan's (2004) conceptualisation is that the community of service users is separate from the wider community, and specifically oriented to the needs of people living with severe mental illness. However their membership of this community does not prevent them from also being a member of the wider community. This could be seen to be in contrast to the social model of disability, which calls for the wider community to change so that everyone can be included, meaning that segregated communities will not be needed (Oliver 1983). Corrigan et al's studies (2002, 2004, 2005) investigated the GROW self-help organisation in the United States, which had been established for many years around core beliefs and directives aimed at facilitating recovery.

One example of a GROW directive is 'decentralising from self and participating in community' (Corrigan et al 2002), which was the most prevalent theme in their analysis of testimonies by members. The second part of the study (Corrigan et al 2005) provided validation for this theme – interviews of the current members of GROW suggested that sharing and caring with people through interpersonal relationships comprised the biggest contributing factors to recovery. However the interviews were reported to be two hours long, which suggests a sample with the capacity to engage in this method, and to tolerate social contact for a prolonged period. It could be that people who struggled with this were excluded from the study. However, the user-led initiatives encountered in the literature predominantly involved group settings and emphasis on a process of support and recovery for people with long-term mental health problems, challenging assumptions about the ability of people to engage with both the setting and the process.

Bellamy et al (2006) were particularly interested in how user-led groups managed the group experience for members, and used observation to generate data to analyse how well the groups were functioning. This was determined using an index, based on the assumption that groups which were functioning well would have similar characteristics. However, because their sample was from settings which included paid staff, just

over half the groups had staff leadership to some degree, and it is not clear whether these staff members were ex-service users or not. Thus it is difficult to draw conclusions about their insights into leadership and group functioning specifically in relation to user-led groups. However there was a clear indication that functioning varied not only between groups but also within groups and that good leadership was not continually or solely associated with high levels of functioning.

This issue, of what makes a group function well, was important for this strand of the research. It was believed that an understanding of the stories of the groups would give an insight into how difficulties are negotiated and resolved. This had already been explored by Mohr (2004), in an ethnographic study of an advocacy group for carers. Over two and a half years, Mohr observed the group in action and interviewed group members. Distinct phases in the life of the group were identified from these data. The 'exploratory' phase was characterised by people coming together to explore a shared experience together. The 'shaping and shaking' phase involved negotiating how this process could occur in a way that benefited everyone, leading to the 'structuring' phase, where formal agreements were enacted. However, having established structures, these were then challenged in the 'turbulence' phase. The challenges were externally generated as well as internally. The final phase identified by Mohr was 'maintenance', a stable phase where negotiations continued without threatening the structure of the group.

Mohr's study (2004) indicated processes and phases already recognised as characteristic of groups, such as the forming, storming, norming, reforming and performing model (Tuckman 1965). Another common feature, also observed in all the studies considered so far, was the recognition that people could participate in the groups in a number of different ways, having different roles. For this research, an interest in occupation generated a focus on to what extent a user-led group was about sharing experiences verbally for support, in contrast to having shared experiences by doing things together. Mancini et al's study of

user-leaders of user-run organisations (Mancini et al 2005) indicated that while supportive relationships were key to recovery, using different strategies to manage symptoms and being involved in meaningful activities were equally important. The group might provide an opportunity for information exchange and social contact, but a measure of progress was being able to engage in new activities, and thus gain a new sense of self.

With service users leading groups, it seemed there is more scope for the preferred activities to be culturally appropriate, socially inclusive and holistic, as demonstrated in an example from Brazil (de Fatima de Novais Gondim 2006), where traditional healing, music and dance were included in an initiative to provide an easily accessible resource for service users. In the UK, where statutory services are increasingly organised within categories of particular health problems, for example personality disorders, or categories aligned with stages in the journey of recovery, this approach could appear radical. Regardless of need or stage of recovery, everyone was included in the Brazilian example and also in another example from the Ukraine (Lucas and Vasylychenko 2006). It would seem that the sense of community in a user-led environment is dependent on accessibility and shared experiences, not just experiences which are brought to the group but also experiences within the group, from doing things together. Isaksson et al (2007) proposed that social support is a pre-requisite for participation in occupation, but the literature reviewed here seemed to suggest that the two are mutually supportive. Doing things together brings people together at the same time as enabling them to share common experiences and support each other.

The barriers to bringing service users together for this purpose are multi-dimensional. Barnes and Bowl (2001), in their analysis of empowerment and mental health, claimed that tension arose from the prevalent belief that a person has to be rational and autonomous in order to participate in society. Efforts to contain those who are not rational or not autonomous are often associated with compulsory detention and treatment. Yet these

same people have a major contribution to make to the user/survivor movement, and successfully do so (Wallcraft et al 2003). It is possible to perceive the outcomes of user-led projects without appreciating the individual stories which contribute to the process of generating such outcomes. This strand of the research aimed to uncover some of those stories.

In summary, the idea of a group as a community within the wider community was critical to the understanding of a user-led group for this strand, with an emphasis on mutual support and shared occupations. Prior professional knowledge of group processes raised the issue of how groups start, survive and thrive. This strand of the research was concerned therefore with exploring the stories of user-led groups in the local area, based on the question:

*What do people do to initiate and sustain a user-led group?*

Research Aims

1. To explore the stories of user-led groups from the members' perspectives.
2. To identify themes to inform how these groups are initiated and supported.

## **Method**

### **Narrative inquiry**

Narrative inquiry has evolved to reflect the universal use of stories to share experience and communicate meaning (Hansen 2006), and the different positions people occupy in relation to those stories. Stories, or narratives, are a recognised source of knowledge and are thus attractive to researchers seeking to make sense of human occupational and social life. The key differences in approaches within narrative inquiry or research appear to depend upon how the narrative is interpreted and used to advance knowledge (Chase 2005). While there is a general rejection of using narrative to provide proof or universal truth, there are different ways of responding to narratives.

For this strand, a narrative inquiry was chosen because of the universal accessibility of narrative, both for the narrator and for the wider audience, within and beyond the local setting. Stories are central to working and living with mental health problems, for so much of the experience cannot be observed or understood from the outside. Garland-Thomson (2007) suggested that “fresh and feisty” stories of living with disability are very important, to challenge the predominant cultural story of what it is to be normal or ordinary and to give access to a world that is often otherwise ignored or misunderstood.

Focus groups may have been a more efficient means of gathering the stories but there was a risk of a focus group mirroring each group itself, which in turn could have facilitated or inhibited members from responding, depending on the groups’ level of functioning. Perspectives on the groups’ functioning could possibly have been obtained through a questionnaire, although this would have been a less sensitive means and possibly therefore less informative.

It could be argued that the emphasis on narrative did not fit with the participatory and occupational perspective of this research as a whole, based on the view that storytelling does not have the same potential for actively involving service users in evaluating and shaping service development. However, stories are recognised as a means of understanding the motives behind actions (Clouston 2003, Hansen 2006). In this sense the stories of the groups were not only about what happened in the groups but also why. This was perceived by service users involved. Clouston (2003) presented narrative as a key means of engaging with service users, not just in research but in everyday life, to understand what they want to do and why. Action and motive are central to narratives (Mattingly 1998). Clandinin et al (2007) suggested that there are three elements framing actions, and exploring these elements facilitates understanding of motive or meaning. These three elements are

temporality, or the transitory nature of experiences; sociality, or the context; and place, or the specific location of the story.

### **Ethical issues**

This strand of the research was approved by the Brunel University research ethics committee and the local NHS research ethics committee in 2005 (Appendices B and C). Particular considerations for this strand were to confirm that the method (interviewing) presented minimal risk to participants and interviewer and that strategies were in place to ensure their safety and comfort. This included conducting the interviews where support was available if required, and close liaison between the interviewer, researcher and local mental health staff.

It was important to be honest about the interviewer's status as a playwright and his lack of expertise and knowledge of mental health services. It was made clear to all participants that the findings could be used as a basis for a fictionalised play script, but that this was something to be explored separately to the research itself, by the interviewer and service users.

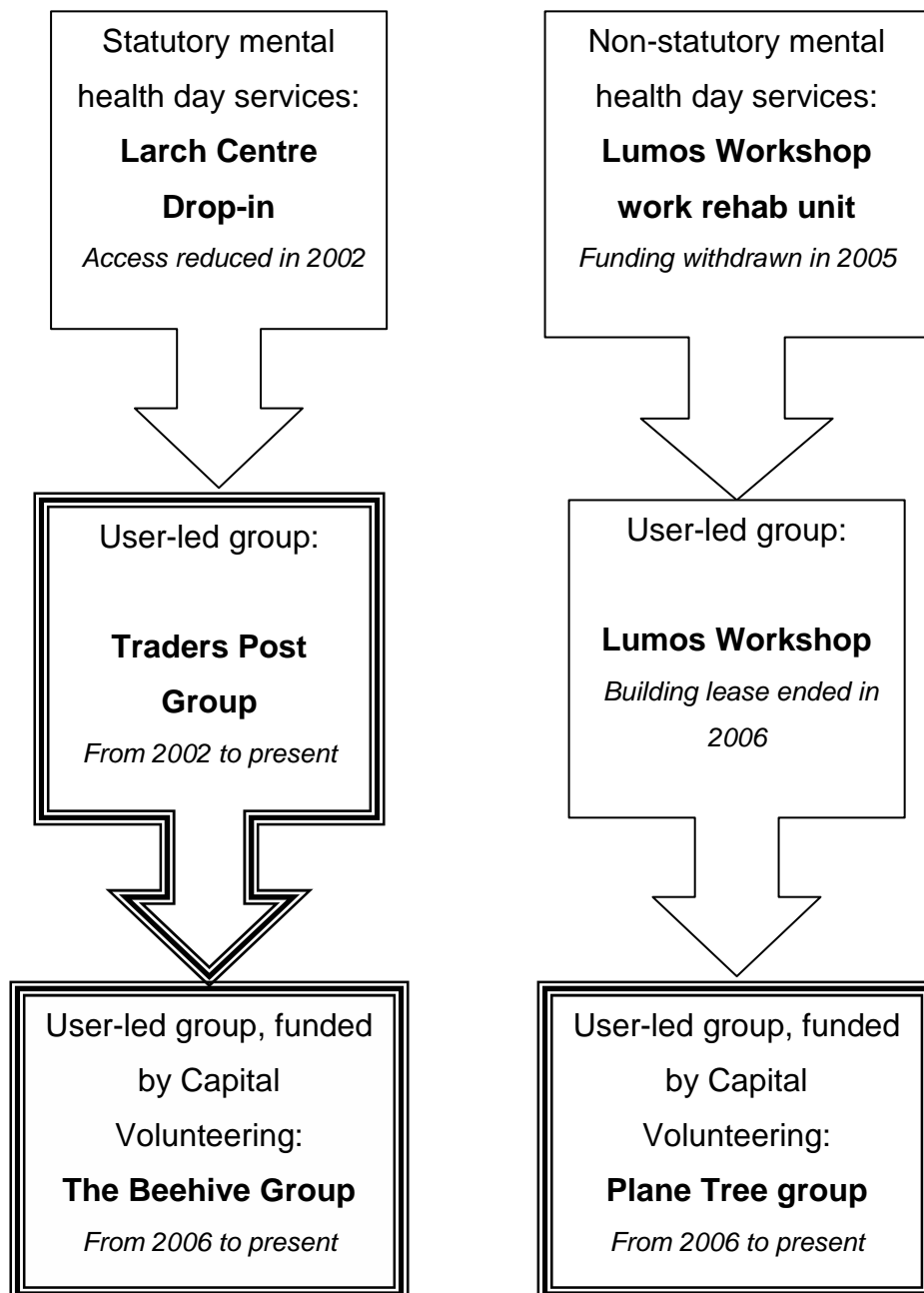
As with other material generated, all data was stored securely at the University. Each participant was given a copy of the recording of their own interview.

### **Participants**

A convenience sample (Holloway and Wheeler 2002) of participants were asked to participate in an individual interview of up to one hour's duration either at the group's base or nearby. There appeared to have been about twenty people who could have participated at the time. The eleven participants in this strand were all current or ex-members of at least one user-led group in the local area. Their membership was associated with experience of mental health problems and local mental health services for all but one participant, who subsequently withdrew. Three groups,



outlined in bold in the Figure 25 and in existence at the time of the strand, were involved (Traders Post and the Beehive group in the north of the Borough, and the Plane Tree group in the centre of the Borough). Lumos Workshop (central to the Borough) and the Larch Centre drop-in (in the north) were also included in the interviews and analysis, having been a key part of past service provision.



**Figure 25: Overview of groups in Strand C**

### **Recruitment procedure**

From November 2005 and throughout 2006, opportunities were taken to explore which group might be best to approach for Strand C. Originally it was intended to focus on one group which was well established. There were a number of local groups which could be considered. For example, one support group had a paid co-ordinator. The weekly meetings were in two halves, with the first half being user-led. However, there was a strong presence of volunteers in this group and the paid co-ordinator was very active in supporting the group. Several other groups were thought to be user-led, but on further questioning of staff and users this seemed to mean that the users determined the focus of the group. The actual organisation and leadership of the groups remained in the control of paid staff. However, it was known that one user-led group (Traders Post) had been initiated around the time of the review which preceded this research (Bryant et al 2005).

In April 2006, I was invited by service users to visit another user-led group at Lumos Workshop, as they were seeking my support to keep the initiative going. There was some interest in the Strand C research, but their priority was the immediate problem of the group's survival, which unfortunately was unsuccessful – a fuller account is given below. There was subsequent contact with some of the group members at other meetings who told me they had established a new group. Another service user, Alan, who had been very involved in the previous strands, offered to liaise with the Traders Post group in October 2006. A meeting was organised with the group, and liaison followed this with the Larch Centre manager, Linda, to secure an interview space. The Larch Centre was just around the corner from the pub where the Traders Post group met.

Ken, the interviewer, visited Traders Post on several occasions, interviewing four people. Two of them were also members of the Beehive group and suggested that he gathered information about this group too. The two groups were strongly linked, with the Beehive group being a more recent initiative. It was felt to be appropriate to extend the interviews

to this group, generating another three interviews, although one person subsequently withdrew. Attendance at both these groups was low and all those who were interested had been interviewed, yet more interviews were required to add depth to the data. So the leader of both groups released names of ex-members, and a letter inviting a further nine people to participate (Appendix W) was distributed from the Larch Centre, with Linda's support. Another interview resulted from this, from a service user with experience of both groups. This process, of obtaining names and organising distribution of the letter, was complex and heightened awareness of the particular way the Larch Centre operated. It seemed appropriate to look further afield at the same time and identify another user-led group in the area.

Geraldine, the Day Services Development Manager, suggested that the Plane Tree group could be approached as the group was now well-established. One of the leaders (Gabrielle) responded quickly and with enthusiasm to initial contact, offering to organise a meeting for Ken and an interview space in the same building. Three interviews were conducted as a result.

The three current groups studied (Traders Post, the Beehive group and the Plane Tree group) were very different from each other and the participants' responses were varied, depending on their role in the group, and the role of the group in their life. It was agreed at this point that the ten interviews were sufficiently varied and rich to provide a detailed insight into service user perspectives on user-led groups.

This process of recruitment had two significant aspects. One aspect was the wider context for the strand: by this stage the research was well-known and respected locally, which facilitated informal contact. The other aspect was Ken the interviewer. His independence convincingly placed the participants in the position of expert, not only from their experience of the groups, but from the wider context of surviving mental health problems and mental health services. His skill as an interviewer, based

on being a playwright and oral historian, ensured that the interviews were largely successfully balanced between personal stories of recovery and the stories of the groups. At the time of writing, the idea of a play is still just an idea – the material gathered from these interviews could be a contribution to a final product, but its final shape is not determined by any means.

### **Interview procedure**

For each of the three groups, interviews followed a meeting between Ken, the interviewer, and group members. The original intention was that Ken would agree interview dates and times in advance with group members. The Traders Post group was very close to the Larch Centre, where the Beehive group was also held, and interviewing space was made available there. This offered an opportunity to adapt the recruitment process to be more responsive to the culture of the groups, which placed a priority on a welcoming, flexible and undemanding approach. People could come and go as they liked, or felt able to. The idea of fixing appointments for the interviews seemed intrusive and ran counter to this informal and amiable culture. The recruitment process was adapted for all three groups so that final consent to an interview was sought on the day, using the consent form. While this could have resulted in individuals feeling pressurised to participate, in reality it meant that Ken could be sensitive to their willingness and readiness to participate.

All interviews were conducted on an individual basis, with a digital recording made of the participant's responses. The duration of the interviews was from four minutes to fifty-six minutes, with half of them lasting over forty minutes. Interview questions were primarily concerned with the story of the group and the role of the individual within it, with an initial question about the service user his/herself (Appendix X, Topic list for interviews). The majority of people were aged between 50 and 59 (n=6) with one person over sixty, and three under fifty. The youngest person was thirty-five years old. Their places of birth varied from very local (n=2), London (n=4), the Midlands (n=4) and Europe (n=2). In Table

10, they have been linked with the groups which they referred to during their interview – it is very possible that they also had had contact with the other groups. For example, Eddie may well have used the Larch Centre drop-in, but this was not disclosed in the interview.

**Table 10: Participants and groups in Strand C**

Name (pseudonyms)	Gender	Traders Post	Beehive group	Plane Tree group	Larch Centre drop-in	Workshop	Lumos
Alan	M	■			■		
Bethan	F	■	■				
Christine	F		■	■			
Dee	F		■	■			
Eddie	M	■					
Fiona	F	■	■		■		
Gabrielle	F			■			■
Helena	F			■			
Juliet	F						■
Kevin	M	■	■		■		
<b>Total</b>		<b>5</b>	<b>5</b>	<b>4</b>	<b>6</b>	<b>3</b>	

### Analysis of findings

After listening to each audio recording at least once, the interviews were transcribed verbatim in a lengthy process. Simple symbols were used to indicate when people spoke simultaneously, interrupted each other, hesitated or conversation flowed without hesitation. A sample of a transcript is in Appendix Y. Analysis involved two stages. The first stage involved Ken and I in a simultaneous and independent process of coding the transcripts, using qualitative data analysis software (NVivo and N6). A node framework, based on the interview topic list, was agreed but on the understanding that additional nodes could be added for findings that did not fit the framework. The coding and primary emerging themes, and possible interpretations were discussed. There was broad agreement and

the findings were merged in NVivo. A sample report has been provided in Appendix Z.

This stage was built on using principles of narrative analysis to develop a narrative account of the plot for each group, along with a socio-cultural analysis (Gbrich 2007). Models of narrative analysis were considered to organise the multiple voices for the narratives and in recognition of the complex contextual aspects of each group. Longacre's model of narrative structure (Cortazzi 1993) offered the suggestion of considering episodes, having set the scene and before the ending. This was preferred to the more widely used Evaluation model devised by Labov (Gbrich 2007, Chase 2005, Cortazzi 1993) which had a similar notion of 'complication'. Particularly for groups still in existence, the idea of episodes seemed more authentic. Another model considered was the 'three-dimensional-space approach' as described by Ollerenshaw and Cresswell (2002), thought to be less useful for this strand because of the multiple narrators involved for each group. However, the multiple narrations led to a very simple framework being used, identifying the past, the present and the future.

The socio-cultural analysis involved consideration of the group narratives in the wider context, including emotional responses, individual stories, the local setting and my own perceptions and responses. However, very specific details of emotional responses and individual stories have not been discussed here, to protect identity and to respect the possibility of misunderstanding or misinterpretation. Thus one aspect of performance is ignored here (Cortazzi 1993). Hansen (2006) provided an interesting analysis of the idea of context, pointing out that, paradoxically, context is both separate from the main text yet also intrinsically bound to it. Thus it is not possible to disentangle experiences of severe mental illness from the stories nor it is appropriate, but this aspect will not be systematically presented here. My distance from the interviewing process prevented a mental health professional lens from being used to some degree for the interpretation of responses, for the benefit of the group stories.

At the time of the interviews, the three groups (Traders Post, the Beehive group and the Plane Tree group) were all a story still unfolding. Future possibilities were explored with each participant. The two other groups, Lumos Workshop and the Larch Centre Drop-in, were predecessors, and stories about these groups were shared by a number of participants. These groups were significant to the participants and so have been included in the narrative accounts below. The findings are therefore organised into three sections: setting the scene, current groups and the future. Precedence has been given to the participants' accounts. However, these have been shaped by knowledge of the context, both locally and historically from professional and personal experience of such groups. In this sense, the narratives offer an interwoven account, resembling the narrative ethnographies described by Chase (2005) and the ethnonarrative approach described by Hansen (2006).

There was a tension generated by the emphasis on the narratives of the groups, rather than those of the individual participants. However, telling a personal story of mental health problems is required repeatedly in clinical settings, and it is possible that the focus on the groups was welcome. Chase (2005) discussed the issue of capturing a story which fits with the research aims, rather than the story the narrator wants to tell. This was a key issue in this research, with two participants in particular sharing stories of their lives beyond the groups. These stories have not been subjected to in-depth analysis, not being directly relevant to the research question for this strand and the research overall. However, in the first section, setting the scene, a brief account of the service users' more general experiences of mental health issues has been given alongside the accounts of the earlier groups. Choices have to be made – the study by Slaughter et al (2007) made it clear that even just choosing a framework for interpretation of data can limit what is discovered, yet it is necessary for clarity and communication.

## Findings: setting the scene

Three aspects of the findings are presented here to set the scene. Firstly, the service users' experiences of mental health issues, to place the groups in the contexts of their lives. These experiences are followed by accounts of the two groups which preceded the main focus of this strand.

### Service user experiences

Everyone who was interviewed had prolonged contact with mental health services, often preceded by times when they were very lonely and isolated:

*"I would just sit in a ball with the door open with the cat ... it lasted four years I suppose." (Christine)*

The potential for isolation and loneliness in their lives remained as they recovered, for example in relation to housing, *"I'm stuck in a little one-bedroomed flat"* (Helena). Eddie reported that when he was not at the group he was probably *"lying in bed."*

There was a shared recognition that it was important to get out and see other people, even if that was very challenging:

*"I would have just stayed in bed feeling iller and iller if that's the right word and it made me get out of bed it made me have a shower." (Dee)*

*"Part of being a human being is socialising the more you shut yourself away indoors the more you neglect yourself but by coming out ... it's a big effort sometimes." (Kevin)*

A particularly vulnerable time was immediately after discharge from in-patient units:

*"When you come out of hospital you are not perfectly well you do need safety and security and to feel that you're not alone because quite often maybe you can hardly talk at all ... that is only the beginning of your process of getting better." (Gabrielle)*

Juliet suggested that although a person might want to go back to work and resume their lives if they could, they also needed time to *"to come to*



*terms with what has happened to you*". Many people had a long history – *"nobody's ever really said anything nice about them"* (Gabrielle) and it took much more than medication to recover:

*"The medication is a tiny tiny part of it ... having the support of other people who've got some idea of what you've been through is ... the key to people getting better."* (Gabrielle)

Meeting with other service users meant you were more likely to be more readily understood and accepted:

*"If you're with somebody else who's been there or is there with you words aren't necessary you know you can communicate freely without worrying if they think oh my god heh I'm talking to a nutter."* (Bethan)

This extended to understanding experiences such as the drug side effects:

*"If your leg's going up and down which often does happen with drugs stuff like that you know it's ok all their legs go up and down heh I'm just fine you all know that."* (Bethan)

So, having opportunities to meet with other service users were seen as being beneficial to motivate and support people in their recovery process. As well as benefits to themselves, service users recognised that there were also benefits for the people who cared for them:

*"Unless I stay well myself you know it won't help ... she [my wife] has angst about me and when I'm hospitalised that goes up."* (Alan)

### **Larch Centre drop-in**

This resource for service users was referred to many times in the interviews, in relation to the Traders Post Group and the Beehive group. There was a shared belief that changes in local and national policy had undermined the drop-in and led to the two other groups being established. The drop-in was part of a wider day programme, associated with active support from service users and staff, social contact and cheap food. It was held in the Larch Centre social lounge. A large open-plan ground floor area was available, with comfortable chairs, a coffee bar and

a garden area. Profits from the coffee bar, which was run by service users, were used to buy garden furniture. People could make the transition from avoiding all social contact to getting involved:

*“When I first got ill I would never come out of my house... I wouldn't talk to anybody I sat in the corner and then it got me involved.” (Kevin)*

There was an active approach to supporting people because everyone knew each other well, including telephone follow-up and rapid response to minor issues. But service users were also expected to take responsibility for themselves:

*“If you couldn't attend a group you had to phone in it's like a job you had to have a reason to not attend and it made you get yourself here” (Bethan)*

The decline of the drop-in was associated with a change in government policy:

*“Heh the government it's a way of saving money basically and they have to call it something we can't say oh we need to save some money so we'll call it this it sounds kind doesn't it.” (Bethan)*

This was not viewed positively, partly because of the way the policy was interpreted locally – *“not exactly a communist purge”* (Alan) but nevertheless it did not reflect service users' views at the time:

*“It was a bit of er a blunt cut off ... well the drop-in is only going to be for people that have groups or appointments and that was it ... so people just weren't allowed to come a lot of people start turning up and then they was asked to leave ... I've seen lots of people that used to attend here wandering round ... completely lost ... they said that we were using it as a social club ... that was the point for most people ... just coming in because they had nowhere else to go ... you can go to a few places that do cheap meals but then you've got to sit by yourself.” (Kevin)*

This change in policy appears to have started in 2002 at the time of the previous focus group study, encouraging service users to use mainstream community resources instead of the drop-in. Within the Day Services Forum, there had been discussion following Strand A, in autumn

2006, around who should be eligible to attend resource centres on an informal/drop-in basis. It seemed quite possible that the strength of feeling about these changes had facilitated the growth of the user-led groups as well as influencing this research in many other ways.

### **Lumos Workshop**

In the centre of the Borough, this user-led initiative existed for up to sixteen months, closing in April 2006. It was located in a small industrial building very close to the town centre, St Peter's and the base of the Oak Foundation. Prior to becoming a user-led initiative, it was a staffed project funded by the Oak Foundation:

*"Well it was due to close there was a big protest ... it was originally about eight years ago it had staff and everything they made lamps stained glass lamps out of coloured glass and they also had about eight computers." (Gabrielle)*

Service users had campaigned to keep the centre open by offering their own unpaid labour to support it. Both men and women were involved equally, with Gabrielle and another male service user taking a leading role. Their negotiations were successful in securing commitment from the Oak Foundation to fund the remaining months of rent under the lease terms.

*"We built it up ... all manner of people dropped in and we never had a single problem except for money heheheh much to our amazement and people grew in confidence people who wouldn't have hardly spoken let alone said oh well I'll take charge for a day." Gabrielle*

The service users involved in leading the project knew each other. They recruited new members with great success through the network of service users involved in other activities and their contact with people on the inpatient admission unit at the Rowan Centre. They had a shared vision for the group:

*"Our single aim was to build confidence and of course once somebody can become more confident from coming from sort of almost nothing they then can [make]... an enormous amount of*

*progress ... .. we almost had it open five days a week ten thirty till five ... with people with mental health problems actually taking responsibility for each day and us having food at lunchtime and drinks it was exceedingly successful.” (Gabrielle)*

The service users preferred this group setting to the resource centres:

*“But they [the resource centres] are to me at least well if you like mental institutions I mean I go there when I want to but it’s not something that I feel I feel that in a space like here or Lumos Workshop we were more free to feel normal.” Juliet*

Funding issues continued throughout the project’s lifetime, as the lease on the building was due to expire and the Oak Foundation did not have the funds to renew. I was invited by the service users to visit the centre in the final days, which was a useful and inspiring trip. They had dedicated and growing support from service users. The centre was divided into three main areas for craft activities, computer skills and social networking. Sadly, continued financial support from non-statutory or statutory sources was not available, and so the centre closed in the summer 2006, much to the disappointment of those involved with it. At that time the local statutory and non-statutory agencies were facing an unprecedented financial crisis which was common across the UK at the time.

(<http://www.guardian.co.uk/frontpage/story/0,,1969153,00.html>).

### **Findings: The current groups**

Accounts of three groups are given here - service users had experience of different combinations of these groups (Table 10) and different perspectives depending on their role.

#### **Traders Post**

This group seemed to have emerged from changes to the drop-in at the Larch Centre in about 2002-3. This group met weekly on Monday mornings in a pub very close by. The group attracted people of all ages who knew each other from the Larch Centre. There were between five and ten people involved, depending on the time of year, with more people attending in the summer. The venue was appreciated by some members:

*“well it’s in a pub innit that’s different”* (Eddie). It was also believed to be accessible not just in terms of location but also occupationally and socially - everyone knew what to do in a pub. At the time of the research, smoking was permitted inside the building although national legislation was due to change that imminently. Having access to alcohol was recognised as problematic for some:

*“That’s been the only problem with us having it in a pub it’s hard for some people to resist a pint or whatever.”* (Bethan)

It was an informal arrangement – the pub owners did not seem to be aware of the group being linked to mental health service use. The group was started by service users:

*“After the weekend a lot of people needed the company and so we called it the coffee morning ... we’ve had to meet in a pub unfortunately because they wouldn’t take us [in the Larch Centre].”* (Bethan)

There appeared to be no regular form of support or contact with staff at Larch Centre and recruitment strategy operated by word of mouth. Hence the group appeared to be inaccessible to those who did not already know a current member. The group gave people somewhere to go to replace the drop-in and to have contact with other service users:

*“So it’s basically just somewhere to go ... .. to chat.”* (Eddie)

*“Just a social thing really and maybe you help each other ... not even talking ... just heheh being there.”* (Fiona)

*“People can drop in and drop out they can come for half hour or ten minutes.”* (Bethan)

Group members also did the crosswords in a daily newspaper and ate an all-day breakfast or snacks. Not everybody did everything – one participant did not do the crossword, being *“no good at spelling”*. There was a resistance to talking about problems as it was not a private space. Other people using the pub at this time included nightshift workers on their way home and men sitting alone with a beer and a newspaper. Members of the group reported having conversations with other people in the pub. It seemed there was a gender issue, with men liking the venue being the pub, but women not being so sure. One of the men appreciated

that women might feel 'vulnerable' in the pub. However, Bethan, who acted in a leadership role in the group, felt the group was important because it successfully involved men:

*"I feel very strongly on getting men more involved because (...) men tend to be in mental health a lot more isolated than women."*  
(Bethan)

Leadership of the group was not clearly perceived by those interviewed, except those who acted in a leadership role (Bethan and Fiona):

*"We feel very responsible for being there ... .. if they know we are on holiday they won't come."* (Bethan)

Members believed that they had to take responsibility for their own behaviour, even when this was difficult: *"I don't always but I respect people's space"* (Alan).

### **Beehive group**

This group was set up partly in response to an offer of funding by Capital Volunteering for user-led initiatives, which was launched at the Social Networks day in November 2005. There were up to fourteen service users who had been involved – they knew each other from Larch Centre drop-in and Traders Post group. They were initially encouraged by Fran, a staff member, to apply for funding.

*"One of the staff from the day programme told me that there was money available in capital volunteering ...I wasn't terribly well so the thought of investigating was really too hard ... but after a while I remembered what she'd said and I went back to her for some more information."* (Bethan)

*"Well I was poached by [Bethan] and she said that she needed like six people to start this group so we had a little meeting with [the Capital Volunteering organiser] and that's how we started it really."*  
(Dee)

*"Then they also found that a lot of people didn't particularly like going there [Traders Post] because it was either smoky or because of the drink factor so they organised one also upstairs here on a Monday afternoon."* (Kevin)

There was difficulty in getting a venue – several were identified but were unavailable unless a ‘normal’ person or staff member was involved for ‘insurance’ purposes.

*“Some of the money was going to be spent on hiring a hall each week but nobody would insure us because nobody wants a bunch of loonies in their hall.” (Bethan)*

So the group started at the Larch Centre in an upstairs room known as the ‘gym’. It had a sprung floor and tables, including a table tennis table which was not used. Leading the group involved preparing the room, welcoming new members and making sure the group ended on time. The contact with Capital Volunteering seemed to be minimal at the time, and in terms of accounting for use of resources. Some of the money from Capital Volunteering was used to buy board games such as scrabble, and art materials. The option of art activities gave people something to come back for, as Christine reported “*put it away and carry on the next week*”.

*“For me it’s a time to be able to concentrate ... do a piece of art work and get lost totally in it and it’s less intense if you’re not well holding conversations is very difficult you can’t concentrate on conversations for too long.” (Bethan)*

This focused but relaxed atmosphere was also important as a means of contrasting with the other groups at the Larch Centre, which emphasised punctuality and time-limited involvement. The difficulty in coping with this kind of approach and sustaining commitment was also attributed to the reality of life with a severe mental illness:

*“People will be one hundred percent committed like the six we started with and then they’ll fall ill and for months maybe and this does happen.” (Bethan)*

There were problems with getting people involved and sustaining their involvement, possibly because of the absence of an overt meaningful purpose to the group:

*“As this is so laid back and relaxed so if you can’t be bothered then you don’t bother coming.” (Bethan)*

One problem seemed to be that the group felt they were completely separate from the Larch Centre, with minimal contact, despite using the same building and working with the same people.

*"I think we could do with a bit more encouragement and things it's just I would put it as children come in from school you don't want to do much with them oh go sit in front of the television keeps them quiet out the way." (Kevin)*

There appeared to be no support for the group's efforts to recruit members and so they ended up being dependent on staff occasionally suggesting people, and relying on the people they knew already. This placed a difficult pressure on the group leaders, who wanted to recruit new members but also wanted to be sure that the group would be a safe place.

*"You can't advertise because we could get people coming who we can't really cope with and then how do you say no ... I mean if they're hearing voices things like that that's fine anything like that it's no problem really it's just violence." (Bethan)*

The group had access to emergency support but this was known to potentially involve *"six members of staff have to get hold of somebody"* which naturally was a scenario the group wanted to avoid at all costs. In contrast there was also a sense of vulnerability to the staff. The group's location meant that staff could come in and check on people, which appeared to undermine its independence.

Conversation and activities such as playing scrabble were equally important although there was a sense that the activities were more important – Dee indicated this: *"The conversation's important but it's sort of more about the activity."*

This emphasis on activities was not always meaningful:

*"Felt a bit like when ... you're in a mental hospital they give you activities there things to do it just felt a bit like that" (Kevin)*

There was a sense that the group was possibly oriented to women's needs – men had been involved but had not sustained their involvement. The group was described by one person as being like a *"women's knitting group"*, because the women present spoke about their problems, in contrast to the men who spoke about *"mainly what's happening you know in the world"*. As every new member was requested to sign an



agreement not to focus on problems, it was not clear to what extent this reflected the way the women used the group – Fiona did not like focusing on problems because *“I think it makes you feel worse”*.

The reluctance to engage with problems seemed to be related to a sense that this was best left to the professionals. When asked how the group would respond if someone really needed to offload, Bethan responded:

*“I’d probably have to take them out take them outside somewhere have a little chat or just say well this is just we’re not trained we can’t help just like for a relaxation and fun group.”*

The idea of mutual support was not very apparent in this group – it almost seemed as if it was not appropriate:

*Ken [but I’m you just might help each other even if  
Bethan yes  
Ken even by listening to each other  
Bethan yes but we can do that out of there though*

### **Plane Tree group**

This group, which had between five and eight members, met in a room in the church community centre very close to Lumos Workshop. The group started after some of them were invited to attend a central London function for Capital Volunteering, at about the time when Lumos Workshop finally closed:

*“One of the speakers must have said something about a self help group and [Juliet] ... said maybe we could do it here.” (Gabrielle)*

They received practical information and advice from the local organiser of Capital Volunteering:

*“She was great when I told her my idea she helped me to realise it and I didn’t know how to go about and she helped me to think of what we needed to think of the funding to think about how we wanted to publicise it.” (Juliet)*

They used their local knowledge and networks to get the group started, finding a venue at St Peter’s and members and securing Capital Volunteering funding. The church rooms used were regarded as a community resource, used by lots of people. Recruitment was most successful by word of mouth:

*"I've been connected with this church in the past and its counselling service and I knew what a key place and I knew they had lots of rooms to let out." (Gabrielle)*

*"It was one person to one person a leaflet is anonymous whereas when you speak to the person ... I would like to think that if you do something worthwhile then other people talk about it in a positive way ... that would have a knock-on effect." (Helena)*

*"I don't think people decide to go to a group just on their own ... I was quite willing to meet up with somebody meet up to have a coffee ... tell them about the group ... go and collect them bring them along because obviously it's like any job you go for you don't know where you're going you've never been before and you certainly don't know who else is going to be there you know you need to feel comfortable don't you." (Gabrielle)*

They were motivated by a shared vision to meet a shared need:

*"Learn about mental health at any rate I mean I found it's a huge learning curve." (Gabrielle)*

*"You do probably cope you always start looking forward to things which is something better than just coping ... once you learn that by relating to people by doing things with people you feel better." (Juliet)*

The strong leadership of the group was admired by Helena: *"I don't know where they get their energy from"*, and it was difficult for participants to imagine what would happen if the two leaders (Gabrielle and Juliet) were no longer available. The group was set up to meet weekly: mornings were preferred to encourage people to get up. The group was structured around each person having a chance to report on their experiences during the past week, sharing information about local events and trips out, funded by Capital Volunteering. The trips had recently extended to involve a short European holiday.

The members negotiated the structure and focus of the group:

*"I thought it was going to be some sort of psychotherapy group but it didn't turn out that way ... on the very first meeting there was one member of the group who started talking about her problems and another member of the group said I don't want this group to be a place where we just complain I want this group to be something where we cheer ourselves up." (Juliet)*

*"I was very adamant that it didn't become a moaning shop."  
(Helena)*

This active engagement with issues specifically relating to surviving mental health problems was a strength of the group. One participant spoke of planning to leave the group, but the active response of other members enabled her to return and feel that she could "*steer it back*". Members had to get to know each other's difficulties in order to do things together:

*"But other people will have fears about travelling on trains people have all sorts of phobias and it's not till you're doing things that you discover these things." (Gabrielle)*

However, there was also recognition that they had to be sufficiently well to "*make use of the group*" (Juliet) – the group could support people to some extent but needed the back-up of services. One example given was of the group supporting a member to communicate more effectively with her doctor about her needs. One very important aspect of the group was to be taken seriously:

*"To know when you say I couldn't get up this morning I couldn't sleep last night and you're saying that for the hundredth time this year nobody's going to laugh at it everybody's going to take it seriously it's incredibly good you know you don't feel you are being a burden and that's very important because lots of us feel a burden to family or other members who are well and don't understand our condition." (Juliet)*

There was an awareness that the group's members were all aged between forty and sixty, and mixed feelings as to whether this was a good or a bad thing. Similarly there were mixed feelings about the fact that the group appeared to be evolving into a women's group. It was recognised that some women had problems with men and that if men sought to be involved, the group would have to adapt. Men known to the group from other activities had apparently chosen not to get involved.

The group usually continued their conversation over lunch in the church café which was run by other service users. The group evolved, a network within the wider network. Helena spoke of preferring it to another mainstream community group she attended:

*"I feel a lot safer and a lot happier in this group ... then I think to myself hang on why am I so comfortable with people who have just been in hospital ... so I'm kind of like toing and froing and try and be comfortable with both." (Helena)*

*"From there we organise meeting each other at each other's house ... I can contact people and say what are you doing today I'm feeling lonely do you want to come to my house or somebody will ring me." (Juliet)*

## **The future**

The future of each group was discussed, where possible, in each interview. It seemed that the future depended very much on how well established the group was, and how many people were committed to sustaining it. Traders Post was well-established and it seemed that members assumed it would continue to exist indefinitely. This was in contrast to the Beehive group, where it was not clear whether sufficient members could be involved to make it viable in the long term. The uncertainty over funding from Capital Volunteering also influenced views of the future for both this group and the Plane Tree group. However, members of the Plane Tree group appeared to be more confident about continuing to meet, possibly in each others' houses.

## **Discussion**

This section will consider the broad themes which were common to all groups, the implications for the local services, limitations to the strand and final conclusions. Consideration of service user involvement in the research will be presented in Part Three.

The perception that local user-led groups were in a state of flux appeared to be supported by the stories revealed by analysis of these interviews. A state of flux was not viewed as undesirable, but as a state fostering profoundly important creative action, and thus new possibilities as diverse as the people involved. An influence here was the Fluxus art movement, which produced diverse products and 'happenings' without an obvious purpose other than to challenge thinking about art and its products

(Kellein 1995). To go to a pub on a Monday morning to conduct doctoral research fieldwork (for the Traders Post group) seemed simultaneously absurd and authentic.

The idea of a state of flux also relates to complexity theory, which suggests that human activity can be represented as a continual cycle of self-maintenance, to ensure survival (Capra 2002). The regular meetings of each of the groups explored in this strand enabled them to survive, especially as members did not use other means of communicating such as texting, email, web-based social networking or instant messaging. If the group did not repeat the action of meeting together again and again, it would not survive. Those people who decided not to attend relinquished their status as a group member. The regular meetings also enabled new developments, so the Beehive group appeared to have emerged out of the Traders Post group. It could be argued that the Plane Tree group represented some aspects of the Lumos Workshop group which the service users valued highly and sought to protect.

What did the groups need to survive? Common to the three surviving groups were members, a venue, shared occupations and a sense of purpose. Each of these will be explored briefly in turn. Being present at any of the groups was enough to make you a member, although the Beehive group required people to sign an agreement not to discuss problems and to give emergency contact details. Interestingly, this group faced most problems in achieving a critical mass of members, with attendance being low. The relative isolation of this group, in a room upstairs and separate from other social areas, may have also affected accessibility. The Traders Post group was on the face of it more accessible in this sense, with a very immediate sense of belonging not only to the service user group but also the wider context of the community of people who used the pub on a Monday morning. However, it would not have been possible to just drop-in on this group without knowing an existing group member beforehand. This was in contrast to the Plane Tree group, which was accessible by invitation only yet was networked so

effectively that it appeared to be relatively easy to contact potential new members and invite them along.

Traders Post offered its own challenge, being in a pub, although members recognised that there was a choice about drinking alcohol. Beyond this challenging choice for some, the informal nature of the group seemed key to its success. Group members could choose how they engaged with the group at an individual level. It was acceptable to say nothing but just be with the group. It is interesting to speculate to what extent doing crosswords facilitated this: this activity demands a balance of sitting and thinking as well as sharing ideas, accompanied by a tacit acknowledgement of different knowledge and skills. Capra (2002) suggested that successful communities were characterised by strong connections and it would seem that one of the strengths of the Traders Post group was that the occupational choices available to members were meaningful and manageable. However, the impending change to the legislation on smoking potentially reduced choice and raised speculation about how the group would adapt.

Occupational choice was raised as an issue for the Beehive group, with its emphasis on creative and recreational activities. However, it seems important not to focus on these activities as limiting the group, given the other issues around its location and difficulties in recruitment. The Plane Tree group's experience suggested that choosing activities is a complex issue and subject to negotiation and experimentation. At the time of the interviews, this group was experimenting with going out and visiting places and encountering challenges not only from the weather, but from group members' individual difficulties. A key activity for all three groups was focused on food and drink, echoed in the importance placed by the Larch Centre drop-in on the coffee bar, which was successful not only in providing a focus but also in raising funds for the centre and providing work experience for service users.

The issue of whether the state, represented by health and social care agencies, is responsible for the actual provision of shelter, informal social contact and food has been actively questioned, especially as a response to the social inclusion agenda. There is a political preference for the provision of funds for individuals to fund their own supported access to mainstream facilities (Leadbetter et al 2008). Yet these user-led groups suggested that service users valued opportunities for mutual support as well as shelter and food. The emergence of the Traders Post group seemed to be directly related to the withdrawal of statutory NHS services from this type of provision. Similarly, in the evolution of the Plane Tree group, the work rehabilitation aspect of Lumos Workshop appeared to have been abandoned, possibly temporarily, but the emphasis on a safe place, social contact and food was retained. The Plane Tree group had found that it was necessary to negotiate the core purpose of the group on an ongoing basis. For all these groups it was felt to be undesirable to focus solely on problems, not just because it was possible to get help elsewhere, but also because it was believed that it was not helpful to do this.

The core values of the groups, beyond bringing service users together, were varied. Traders Post appeared to primarily value social contact, and the Beehive group valued a safe space. The Plane Tree group took a more wide-ranging approach. The idea of a separate community of service users who valued being together was important to all, although Traders Post and the Beehive group were having to adapt because the Larch Centre drop-in no longer fostered this sense of community. The transitional nature of the community was well-recognised – group members spoke of moving on and also supporting those in the initial stages of recovery after a hospital admission. While the individuals might change, though, the experiences did not. For those with many years of experience, the groups offered an opportunity to share that experience and offer insights on others' experiences.

Capra (2002) distinguished between formal, designed structures and informal, self-generating networks. The key characteristic of the networks is that they are in a process of constant regeneration, in response to changing perspectives of individual members. If this conceptualisation is applied to the groups studied in this strand, it raises interesting perspectives on the interface between the groups and the mental health services, which are inevitably formal structures because of the issues of resource and risk management. These two issues, of resource and risk management, were particularly acute for the Beehive group. The uncertainty over long-term funding threatened the group, as it did the Plane Tree group. Capital Volunteering, the source of the funding, occupied an interesting position locally. It was a non-statutory organisation invited to contribute to social inclusion work by the local statutory organisations, but the funding was not secure and was susceptible to central government interpretation of policy. The service users readily perceived this, with a sense of making the most of what was available while it was there, and with a measure of scepticism.

Risk management is pervasive in mental health services because of the particular issues around irrational and antisocial behaviour associated with mental health problems (Barnes and Bowl 2001). For the Beehive group it was a particular issue because of the isolated location, the lack of access to back up and the problems over recruitment. The Plane Tree group, with its links to the acute unit and the wider service user network, seemed less vulnerable, although this may have also been connected with its strong identity as a group. Traders Post appeared to have no issue with risk management at the time which was interesting, given the setting and the informality of the group. The localised public setting may have promoted a sense of accountability and responsibility on the part of the members.

The degree to which group members believed they could help each other seemed to be critical to the success of the group, and it would seem that the struggles of the Beehive group were strongly related to the



constraints placed on them. This belief, in mutual support, corresponds to empowerment. What was striking about the Beehive group was that the refusal to engage with problems of service users was based on the belief that these problems could be addressed elsewhere, and that it was not the purpose of the group to take this on. In contrast, the Plane Tree group actively engaged with the problems people faced. However, both group leaders had professional qualifications, which probably gave them confidence in taking this approach. The members of the Traders Post group did not take a view on speaking about problems – it did not appear to be an issue.

### **Conclusion**

This strand of the research was concerned with what people do to initiate and sustain a user-led group. Drawing on the experiences of service users, narratives were developed for three current groups. These groups were in constant flux, evolving from earlier initiatives and having uncertain futures. Survival depended on being able to recruit new members, sustain mutual support and occupational choice. Locally, the interface between the mental health service organisations (statutory and non-statutory) and these groups was significant. The wider community of service users formed and reformed within the organisations, and the groups were dependent on effective and continuous communication with this community for survival. It was in the organisations' interests to foster the groups, for they appeared to be the most responsive to service users' needs. But fostering the groups required ongoing communication, not control, and recognition of that this process of support required ongoing commitment and knowledge of strategies to promote empowerment.

This in turn impacts on the issue as to what extent the service users feel empowered to engage with each other in an act of mutual support. The groups are needed because of the whole experience of mental health problems. While some clinical services seek to focus on relieving symptoms, there will still be a need for a more holistic approach. The experience of hospitalisation and/or prolonged social withdrawal can set

people apart and disrupt their lives. Services are increasingly configured to try to prevent these things happening but for the people who do experience them, the need remains to verify their experience through contact with other service users and make a gradual recovery.

Drawing conclusions such as this from just ten interviews is controversial and raises questions about the limitations of this strand. However, these issues were echoed in the literature and in the wider context of the research as a whole. There is also a difficulty with focusing on groups which are still evolving and which have developed since the time of the interviews. Making relevant local recommendations in this context is difficult. Yet the key issues appear to remain fairly constant and open to debate and discussion. It would seem that the issue of the interface between user-led services and mental health services raises challenges for all involved, for to a large extent they are interdependent and overlapping. It is hoped that these findings will contribute to the ongoing debate.

## **Introduction to Part Three**

Part three of this thesis is concerned with the findings from the analysis which was conducted once the active phase of the research had been completed. The three strands had a separate life of their own yet they were also very much part of the whole research. This stage of the analysis was concerned with drawing the research together, including the strands and capturing other aspects which characterised the different stages of the research. A detailed account of how this was done has been explained in Chapter Five. There was shared reflection and discussion about the research, alongside discussions about how the findings should be taken forward and in preparing formal presentations. However, this stage of analysis was a systematic process conducted away from the local setting and without the formal involvement of others. Reflective notes indicating how this process was initially conceived are in Appendix Z and a sample from the work using NVivo is included in Appendix AA. For reference, table 7 is presented again, but with additional information about how the events were coded in terms of the research process (Table 11, page 261). This is to show that each stage of the research process was considered in the final analysis, and that many events were concerned with multiple stages.

This process of analysis seemed to signal a shift from participatory action research to critical ethnography. This is not to say that critical ethnography did not inform what happened during the strands of the research, far from it. But the strands of the research were focused on specific issues, with energy directed to facilitating participation and action. It seemed very necessary to ask afterwards what made this possible, and how the findings of the strands were shaped by the context for this research. Each of the next three chapters considers this context, highlighting the many varied factors involved. Thomas (1993) suggested that a risk with a critical ethnography was to forget the task of appreciating difference:

*“To appreciate difference means to disrupt common sense and place unfamiliar objects in a new context. When this is done successfully, we are rewarded with insights into the culture of study that prompt us to think about our own culture in new ways by searching for analogous concepts that make the alien culture seem more familiar and our own culture seem more alien.”*  
(Thomas 1993, page 66)

The themes emerging from this stage of analysis and interpretation have been organised in relation to the research topic: an occupational perspective on user involvement in mental health day services. There were many findings to report in relation to each aspect of the topic and so three chapters have been used for each aspect. Findings are reported and discussed within each chapter on each aspect of the research topic, starting with day services, then considering the occupational perspective and then service user involvement, which leads to a summary of the research outcomes. The theme of insider-outsider has been used to draw the themes together and to synthesise conclusions about this research.

This stage of the research involved examining and reviewing documents, letters, fieldnotes, audio recordings and reflections on informal conversations and discussions, and these are used to illustrate the findings. As ideas and themes emerged, they were discussed in supervision and informally with those people who had been involved in the project and were still in contact. Some of the sources from the active phase have been included in the Appendices:

- C19, Report for newsletter, Appendix H
- M45, Evaluation, Day Services Forum, Appendix L
- M18, Leaflet used at meeting, Appendix AB
- M24, Letter to service user group, Appendix AC
- M41, Report on second social networks day, Appendix AD
- C45, Letter for day services review, Appendix AE

Event date	Event code	Event name	Stage in research process				
			Notifying	Shaping	Doing	Reflecting	Reporting
14/10/03	M3	Day service forum meeting					
06/07/04	M12	Social networks day					
31/08/04	C19	Newsletter					
13/12/04	C8	Letter to service users					
25/01/05	M18	Meetings with service users at Alder House and Elm Lodge					
7/03/05	C22	Letter from Andrew, service user					
15/06/05	M24	Meeting with service user group					
01/11/05	M41	Social networks day					
8/2/06	M60	Research group meeting, Strand A					
28/06/06	M68	Meeting with Oasis group					
11/07/06	M71	Research group meeting, Strand B					
21/11/06	M37	Day services forum					
20/12/06	C3	Letter from Adam, service user					
10/1/07	C51	Telephone call to Gabrielle, service user					
20/03/07	M45	Day services forum					
24/4/07	C45	Letter for Day Services Review					

**Table 11: List of sampled events for final analysis with coding for research process**

## **Chapter Nine**

### **Day services: findings and discussion**

#### **Overview**

The combined effects of the emphasis on social inclusion and the financial crisis in the health and social care statutory sector had a significant effect on mental health day services, raising questions about the future of day services. Locally, occupational therapists were being encouraged to refocus on social inclusion and give more attention to facilitating recovery, ultimately aimed at gaining paid employment, echoed elsewhere (for example Corbett and Howe 2007). The non-statutory sector was seen as the future provider in terms of social support and shelter (Lingwood 2005a). Locally, these issues were significant as the research unfolded. Service users and staff perceived a threat to the day services and saw the research as an opportunity to explore what was important to protect and what needed to change to benefit service users.

The overall analysis of the findings has suggested that the research itself mirrored processes in day services, which were characterised by the staff designing and offering opportunities for participation to service users. But this research also enabled service users to create and design opportunities for themselves, drawing on their knowledge of the day services setting through long-term use. Different aspects of the day services are explored here. Understandings of what day services were for, and what changes might be required, were informed by how the service users were perceived by others and by themselves in terms of their needs as a group. This related to beliefs about the services themselves. As social networking was the chosen focus for the research, evidence of this topic in the findings is presented.

#### **Findings**

##### **Perceptions of mental health day service users**

Communicating and working with service users reflected particular views of them as people, patients or consumers. There were contrasting and

similar views expressed by service users themselves, service providers and within the research itself. Service users recognised their expertise on life with mental health problems:

*“Until you actually say something, the doctor does not know what is worrying you: they don’t know any more than you tell them. You can’t always get it out.”*

*M60, service user, audiorecording of research group meeting.*

*“We’ve always known that we support each other.”*

*M71, research group meeting, audio recording of service user discussion.*

They recognised their experiences could make them vulnerable and dependent on others:

*“Having help and support from the staff and other users is important – being with people you can trust.”*

*M60, research group meeting, audio recording of service user discussion.*

From a service provider perspective, service users were also viewed as vulnerable people who needed to be directed to particular established services or processes. This emerged particularly in discussions on how to take the findings of Strand A forward and create a safe space for service users, for example this proposal shared by staff in the Forum:

*“Pointed out the resources already available through acute care pathways and the CRHT Team [Crisis Response and Home Treatment Team]. Proposing two mornings a week as ‘contact mornings’ Wednesday and Friday from 1030-1230 for people on enhanced CPA [Care Programme Approach]. Opportunity to meet with staff, employment link, CAB [Citizens Advice Bureau] for information and advice, run by a new appointment community link worker. Plus providing a hot meal twice a week, possibly Wednesday or Thursday.”*

*M37, Day Services Forum, fieldnotes*

In the second Social Networks Day the view of user as consumer, in a very literal sense, seemed to take precedence, with displays of new initiatives and brief presentations by those leading the initiatives:

*“In the 16 months since the first social networks day a range of initiatives had sprung up, and many were seeking to recruit service users. Thus there was an interesting tension on the day between it being a bit like a recruitment fair, and being an action day.”*

*M41, Social Networks Day, personal reflection*

Finally, and equally in contrast, service users were regarded as potential service providers themselves, as volunteers and leaders. At the second Social Networks Day, this was felt to be particularly important and so Lou, a service user from another area, was invited to participate and share her experience as one of the leaders of a service user-led independent social and recreational project.

In the research, placing a priority on inclusion and service user expertise generated challenges for staff. They had to synthesise the views of service users as vulnerable people and service users as consumers within their daily contact in their work, as well as potentially engage with service users as collaborators in the research. For Sian, who worked in the research group for Strand A, this meant that there was conflict between being responsive to what she was hearing from service users in the group, and knowing the constraints placed on staff responses beyond the group. In shared reflections on the group sessions, we discussed the pressure to “*toe the line*” and not raise expectations that her role within the group could necessarily extend beyond it. Yet the new possibilities emerging from both the research and the modernisation of day services had an impact on expectations of service users.

The view of service users as potential leaders and service providers applied to some extent in the way they were perceived in relation to the research. The information sheets associated with the strands and meetings to promote the research focused on the service users’ autonomy in defining their role (Appendices D, E, F, AC). This was necessary not just from an ethical point of view, but also to convey that everyone could take part if they chose to and their contribution would be valued. Thus they were seen as people who could be listened to and their expertise was recognised. The letter sent to the service user group (Appendix AC) was structured using the questions service users had



asked at the meeting and summarising the responses from the researcher:

*“Who is the research targeted at? It is widely recognised that day services involve many different groups of people with different needs. Again this was a really useful question: the answer is people with long established contact with services, rather than people who are acutely ill. But beyond that, anyone who uses day services or has used day services recently can be included.”*

*M24, meeting with service user group, letter to follow up meeting*

Locally some services were focused on Asian people with mental health problems, such as the Oasis group, and their preferred way of engaging with the research was as a group, enabling them to make use of volunteers and interpreters as representatives:

*“I was aware from the second social networks day how dependent the Asian women were on having interpreters to make their views known.”*

*M68, meeting with service user group, personal reflection.*

This meeting took place as part of the data collection phase for Strand B. It was the second meeting where the researcher was accompanied by a service user working as a research collaborator, in this case Adam. He was a familiar face to a number of service users present. The first time this happened, the service user concerned (Andrew) was well-known and trusted by those present as a service user representative, which was also helpful:

*“I was accompanied by Andrew, service user and representative on the LIT [Local Implementation Group], [user group] etc. He was interested to be part of the process.”*

*M18, meeting with service users, reflection.*

His presence appeared to reinforce that the view that service users had some influence as consumers but that it was important to continually engage with proposed changes as they emerged, and doing the research could be one way of doing this.

### **Beliefs, values and assumptions about day services**

The modernisation of day services was imposed from outside (see Chapter One), within a climate of ongoing changes in all health and social

care services. It was both challenging and exciting to conduct research in a setting where the core structure for service provision was being questioned. Challenges arose from understandings of social inclusion and exclusion, at times overshadowed by economic factors. It was exciting to be able to respond to these issues with service users' perspectives and ideas. Some of the products associated with this research were familiar forms of responses to these changes, for example the newsletter (C19). Locally, newsletters were used to combine news about services with service user contributions, such as the poetry in the newsletter about the Social Networks Day. Poetry gave service users a chance to express their beliefs about the day services:

*"I've been here now for quite some time  
And made a friend or two  
Happy faces all around  
That say I like you too  
Please don't tell me – go away  
As being here just makes my day!"  
C19, Newsletter, service user contribution.*

This contrasted with the clinical and organisational language used within day services:

*"There was a discussion about implementing care plans and accessing services through a care package, psychiatrists and having a severe and enduring mental illness."  
M3, Day Services Forum, fieldnotes.*

The 2002 review (Bryant et al 2005) had also influenced beliefs about day services, capturing the tension between the demands of the modernisation agenda and the wishes of service users. Some members of the service user group (event M24) remembered me from the review and wanted to know my views on the situation three years later. I agreed to summarise my views in a letter on this and other issues discussed (Appendix AC), which included this section:

***"What are your views on current day services policies? In essence I am concerned to take into account the different needs people have within day services. Not everybody can keep a paid full time job, and our research has shown that many people really value the opportunity to get support from each other in group and social settings."***

*M24, service user meeting, letter to follow up meeting.*

Fears that the modernisation agenda would override service user wishes emerged during discussions in the Forum as well as in the research groups:

*“At the moment if you’re not actually attending a day group, you’re not allowed to come along.”*

*M60, research group meeting, fieldnotes.*

*“[I] learnt service users’ fears about day services”*

*M45, Day Services Forum, written response in final evaluation*

At times, discussions about these changes were focused on perceived threats to existing services and a fear of being abandoned or forced to do something which was impossible, inappropriate or unsustainable. Service users highlighted the reality of stigma in the wider community:

*“... the emphasis on violence, people don’t want to be named in association with it [mental illness].”*

*M71, research group, audio-recording of service user reflections*

They emphasised how they valued peer support. They also were aware of increasing demand for mental health services and questioned the motives for modernisation.

*“There was a view that the social networks day was ‘just about saving money’ and getting day services on the cheap, and I could see their point of view. It could appear to be much cheaper to have service users going out and using mainstream services instead of expensive NHS services.”*

*M18, meeting with service users, personal reflection*

The economic argument became stronger as the NHS financial crisis took hold in 2005. In this context, it became increasingly likely that service users would engage with the opportunity for activism as part of the research, seeing it as a means of advocating their own beliefs about day services. In a discussion at the end of the first strand, service users identified these potential uses for the findings:

*“To influence government decisions in the departments as well as in the health service: especially with the current emphasis on employment and welfare benefit reform. To support new initiatives*

*such as dining clubs and volunteering opportunities for people with mental health problems.”*

*M60, research group meeting, audio recording of service user discussion*

These elements fed into the final recommendations for the day services review in 2007 which were summarised into a letter to the review team (Appendix AE). Here is an extract:

*“Many long term day service users often have multiple problems and experiences, not neatly fitting into a ‘pathway of care’, and it seems appropriate to propose that day services are best placed to offer professional support to this group to facilitate their recovery. Similarly, by offering shelter, a safe place and a structure for the day, day services can be an essential element for people who are recovering in a more straightforward way.”*

*C45, letter to project development worker*

The core values of day services (Pring and Vacher 2004, Appendix AF) had identified different roles within the services, all of which could be developed, which was one reason for focusing the research on social networking.

### **Social networking**

Service users were drawn to discussions about social networking, sharing their knowledge. They also raised their concerns about the difficulties in developing and sustaining networks.

*“We want to socialise with women without having to pretend to be something other than ourselves. We want to know where or if there are good places to go. We like coming here because it’s safe, but we’re told to move on. Where can men go?”*

*“Users weren’t clear what a social network was. Social networks and relationships are painful issues, very personal. For men particularly it was hard to form relationships [and] it was especially difficult to form relationships with women. Much of the social networking was controlled by women or based in environments associated with spending money or alcohol. Occupation based networking is easier “you can be yourself”.”*

*M18, meeting with service users, fieldnotes.*

At the first of these meetings, it was noticeable that all the service users present were men and all the staff were women. The possibility of

considering gender issues in more depth was considered, especially as it seemed as if day services were one of the few places where men who were mental health service users could have friendly contact with women with less risk of being misinterpreted.

*“I think when you’re going to fall ill, to actually have a social network of friends even before you fall ill is important as well as afterwards.”*  
M60, research group meeting, audio recording of service user discussion.

There was also evidence of strong social networks established by service users, for example in connection with the self-help group studied in Strand C:

*“[it] involved volunteering at Riverside, on the wards and in the internet café, doing social things together such as karaoke, the social group at Mill House.”*  
C51, telephone call to service user, personal reflection.

When these discussions happened with staff present, it helped to raise awareness of the complexities of facilitating involvement in social networks.

*“It put into perspective what people identified as social networks and what activities supported, encouraged or hindered people being involved socially with others.”*  
M45, Day Services Forum, written response to final evaluation.

In preparing information about the research, these discussions and reflections were used, along with personal reflections on social networking.

*“I also thought in terms of the person (who wants to be in a social network, and why?), the environment (where do these networks happen?) and the occupation (what do people do in social networking? How do we know it’s going on?) I thought about feasibility and mental health, and the inevitable considerations of risk and barriers to accessing social networks. This made me think also about responsibility and ownership.”*  
M12, Social Networks Day, personal reflection.

*“People have social networks for support and enjoyable times with other people. There are three main strands to this research: exploring how a place can be used to make and keep social networks exploring whether activities in the community can make social contact easier*

*exploring what experiences people have of user-led groups.”  
M24, meeting with service user group, leaflet to explain research.*

It was necessary to discuss the purpose of the research repeatedly. The ideas above evolved within discussions in meetings and reflections afterwards. These discussions were not solely focused on the research. The interplay between the research and the setting was vitally important.

## **Discussion**

### **The end of day services?**

Throughout this research, both locally and nationally, questions were being raised about the role of day services within community mental health services (Pring and Vacher 2004, Office of the Deputy Prime Minister 2004, Bates 2005, Lingwood 2005a and b, Bates et al 2006, Murkin 2006, Bates 2007). This research contributed to this debate, primarily at a local level as the strands evolved and through my ongoing presence in the field as a researcher. The particular culture of the local day services was mirrored in the research itself with its emphasis on participation, for example in groups and discussions at the Forum. However, new opportunities were offered by the research to service users and staff who could and did play an active part in the research processes of notifying, shaping, doing, reflecting and reporting. Adam and Alan were also co-presenters at national and regional conferences for occupational therapists specialising in mental health, presenting Strand A and Strand B. There was widespread excitement about this shift, which demanded a new perspective on them as people. This shift was not exclusive to Adam and Alan, for it seemed that everyone who became involved experienced this to varying degrees.

One significant aspect of this research was to respond to the different ways in which people were perceived, and how these perceptions changed as the research unfolded and the modernisation project evolved. This aspect resonated with the task of critical ethnography (Thomas 1993). In discussions and documents, there were conflicting perceptions

of who service users were and consequently the role of staff. This was not a simple case of perceptions informed by the medical model in contrast to the social model (World Health Organisation 2001a), although that particular tension did play a part. For example, in discussing the role of day services in containing crises, service users were emphasised as vulnerable individuals needing help, characteristic of the medical model (Oliver 1983, Tregaskis 2002). However, to some extent this seemed appropriate in a crisis as prompt action would be required, focused on rapid problem-solving for the individual. At other times, a focus on individual problems seemed to ignore the very real barriers to recovery placed by society (Tew 2005, Thornicroft 2006), requiring collective action and engagement with the local community in line with the focus of the social model (Sayce 2000, Beresford and Campbell 2004).

However, a confusing aspect of mental health day services seemed to be that they were not obviously oriented to single issues or diagnoses, but aimed to address complex issues with a collective approach, offering occupational and social opportunities (Bryant et al 2005, Catty et al 2005a, 2005b). As such they were vulnerable to misunderstanding, especially when attempts were made to base them on a simple model resembling a market-based exchange of goods and services. As a result there seemed to be an emerging preference for single issue or single diagnosis services, for example personality disorder services or crisis response teams. This is not to say that these services were not required but in contrast to them, day services appeared unfocused. However, the complexity of day services meant potentially more flexible and holistic services, increasing consumer satisfaction. Equally the collective approach potentially empowered service users to influence the services they received (Leighton 2003). There were needs that mental health day service users had in common: for mutual support, shelter and refuge, social contact and meaningful occupation (Bryant et al 2004 and 2005, Bates 2007). These aspects have characterised day services since the first day hospital in the UK (Blair 1948, Farndale 1961, Carter 1981) and

cannot necessarily be found in reliable and appropriate forms in the mainstream community or services oriented to particular diagnoses or stages of recovery (Bates 2007).

Since the publication of Tantam and McGrath's study (1989), suggesting that day services contributed to institutionalisation, it seemed that medical involvement in day services diminished. This could have been equally due to the growth of community mental health teams and the increased responsibility of the multidisciplinary team members in day services staff teams. Locally it seemed as if the psychiatrists were primarily concerned with medication and crisis management although the text by psychiatrists Roberts et al (2006) suggested a continuing interest in wider issues. But Holloway (2006), in the same text, made no mention of day services in a chapter on community mental health services.

For those people whose issues with medication are not the most pressing in their lives and for whom cognitive behavioural therapy has not been successful (Bates et al 2006), social and occupational issues are more significant. Yet it is not easy to categorise these issues, which are often emerging and evolving throughout the recovery process. The different ways in which service users engaged with this research illustrate this. For example, Tony, who chose to become involved in Strand A, was someone who was regarded highly by other service users and staff, being an intelligent and thoughtful man. His presence was very welcome in the research group as he shared his reflections on his experience of the social lounge, confirming and developing the group's ideas. Yet his involvement was disrupted significantly by his physical frailty, for which he needed in-patient treatment during Strand A. Day services offered him an important space during the period between admissions. It was widely perceived that he would not recover, from his mental or physical health problems, and he died shortly after the end of Strand A. There was a shared belief amongst service users and staff that it was a very good thing that he had participated in the research before he died. It was



perceived as a particularly meaningful occupation and source of social contact for him.

The occupational and social dimensions of day services could be seen to represent a response to human rights and justice, as much as recovery of particular capacities. From a social perspective, like all mental health services, day services need to engage with the wider community to enable equal participation in society (Rogers and Pilgrim 2003, Tew 2005) and recognise the factors beyond the individual which prevent and facilitate recovery or participation (Rogers and Pilgrim 2003). The occupational perspective can be indicated by the use of occupation as a central structure to programmes, valuing those occupations which appeared to promote health, beyond paid employment (Townsend and Wilcock 2004, Wilcock 2006). However, these aspects were not discussed specifically in the local services, nor are they clearly evident in the literature in relation to day services beyond the work of Townsend (1998), Rebeiro (1999) and Fieldhouse (2000, 2003), all occupational therapists.

For this research, mirroring the culture of the day services, the social perspective in terms of the wider community was evident in the strands: society as a source of rejection in Strand A, as a destination in Strand B and as a base for participation in Strand C. These aspects are discussed further in relation to the modernisation project and social networking. The occupational perspective was evident in terms of recognition of the potential of occupation in its varied forms to transform not individual lives but services (Wilcock 2006). By creating culturally appropriate and varied occupational opportunities, such as the research groups and the Social Networks Days, it was possible to engage with many different service users and staff in ways that were meaningful to them as individuals. Bringing them together, in collective action, transformed the meanings of the occupations they engaged in. This mirrored best practice not only in the local day services but also elsewhere, for example Rebeiro et al

(2001). It was important to keep these examples of best practice in mind when considering whether it was truly the end of day services as such, or the end of day services as people had known them. Throughout this research, the modernisation agenda generated questions about best practice in day services.

### **The modernisation agenda**

The use of participatory action research meant it was possible to engage directly with the possibilities and questions raised by the modernisation agenda. Critical ethnography supported deep analysis of the beliefs and assumptions emerging and created by this agenda (Thomas 1993). One of the most challenging aspects was the energy channelled towards securing paid employment for service users. The energy originated to some extent from service users' wishes (Secker et al 2001). Beliefs about the recovery model were based on the view that meaningful occupation was a significant goal for many service users, but equated occupation almost entirely with paid employment (Boardman and Robinson 2006). This assumption offered a useful base point for this research in discussions about meaningful occupation in a broader sense, as service users had encountered serious difficulties in accessing meaningful permanent paid employment. Similarly, the Social Exclusion Unit report (Office of the Deputy Prime Minister 2004) was used to identify the four main themes for the work of the Day Services Forum (employment, education, social networking and user involvement). The lack of detail in the report and range of interpretations by service users and staff in the day service forum generated some discussion, especially when issues were periodically raised in the national media around welfare benefit reform.

Thus this research harnessed some of the energy generated by the modernisation agenda, but also offered an opportunity to respond to it. The strands of the research were designed in response to perceived assumptions about social inclusion at the time. In turn, the findings of the

strands challenged those assumptions. Strand B was designed to develop understanding of social inclusion in terms of accessing community venues and resources. By creating a poster, the group members were able to share the findings very quickly and directly, as the posters were displayed in public areas in the resource centres. Presentation of the posters at the Day Services Forum provoked debate about the extent to which social inclusion was achieved by visiting community venues and resources, such as the local nature reserve. Thus there was a reciprocal relationship between the research and the setting, to facilitate interpretation of the modernisation agenda.

In particular, experiences of stigma and discrimination were discussed within the closed research groups of Strand A and B, and in the interviews of Strand C. To some extent this was associated with a fear of rejection if mental health problems were revealed, suggesting an internalised stigma (Thorncroft 2006). However, it seemed that service users made very specific decisions about where it was safe and appropriate to reveal their experience of mental health problems. For example, Adam and Eleanor explored whether it would be possible to join a local art society during discussions in Strand A. They realised it would be difficult to explain to the people they met how they knew each other without drawing attention to their mental health problems, the main factor they had in common. Rather than being subject to an unconscious and powerful belief they would be rejected, they recognised that in some circumstances it was unhelpful to disclose their status as mental health service users (Thorncroft 2006). However, with the combination of side effects from medication, the impact of mental distress on self care occupations and long term dependence on welfare benefits, hiding a status as mental health service user was not successful or possible for everyone which increased the likelihood of social rejection and alienation. This raised questions of what social inclusion was in relation to mental health service users and what would signal successful social inclusion.

These discussions were reflected in the findings of Morgan et al (2007). Political understandings of social inclusion emphasised productivity and participation (Barry and Hallett 1998, Levitas 1998, Byrne 2005) based on the assumption that people had been denied opportunities to be productive and participate. What was not clear was the nature of support required to enable people to take up new opportunities (Beresford 2005a, Morgan et al 2007). The economic crisis polarised funding issues, which repeated a pattern of threatening initiatives not directly concerned with risk management or facilitating return to work (Beresford 2005a). This was a familiar scenario to mental health service users (Smith 2005) and led to the conclusion that the promotion of social inclusion through social networking in mainstream community settings was about saving money. Indeed without a deep appreciation of the multiple factors experienced by mental health service users which impacted on their productivity and participation, aspects of day services seemed to be an easy target for cost cutting, being located in expensive buildings and not associated with acute and risky situations or rapid re-integration into mainstream community life. The longstanding inequity in funding, not only in comparison with other statutory services, but also within mental health services, has been analysed with specific reference to day services by Beecham (2005).

The modernisation agenda was summarised in key regional policy documents (Lingwood 2005a) which emerged as the research progressed. Although nationally occupational therapists had become very involved in the employment aspects of social inclusion, both within mental health services and as part of the Department of Work and Pensions Condition Management Programmes (Thomas 2007), locally there was a balance between sustaining involvement of day services in all aspects of the agenda. The findings of the research were used to justify a proposed new structure for day services, involving professional staff in an 'intensive' treatment team offering individual and group work alongside user-led services and a Borough-funded initiative for a safe space for day

service users. Thus, in some ways, it was the end of day services as people knew them. However, locally, the proposals for modernising the day services diverged from the recommendations of the modernisation agenda in relation to social networking in particular, partly as a result of the research.

### **Social networking**

The importance of opportunities for informal social contact and mutual support had been recognised from the beginning of this research (Bryant 1995, Repper and Perkins 2003, Rogers and Pilgrim 2003) and social networking as a term gradually became more prevalent during the research to some extent within mental health services and more significantly, in the wider world. In 2003, when the Day Services Forum started meeting, social networking had not yet become strongly associated with the internet via websites such as 'MySpace' and 'Facebook'. This occurred during the time of the research, so informal discussions about social networking required people to consider their own personal experiences within and beyond the day services, not only in relation to service development but also in the fashion for online social networking. However it was not evident that many of those involved, service users or staff, had direct experience of online social networking. Discussions tended to be concerned with defining social networking and highlighting the barriers to locating and getting involved in social networks beyond immediate family and the day services. The focus of the research on social networking facilitated this process.

The strands of the research enabled service users to explore particular aspects of social networking systematically. Strand A was concerned with social networking in a particular location or environment, Strand B with social networking in terms of things to do or social and recreational activities, and Strand C with the roles people played in user-led groups. Throughout this research, the occupational perspective was significant in understanding social networks although there was no precedent to draw

on. It seemed that occupation was as ambiguous as the notion of community, both being a means and an ends to social networking (Rapport and Overing 2000, Royeen 2004). Thus, people engaged in occupations as a means of accessing a new social network, for example joining an art classes. However, for service users this raised the issue of disclosure of mental health problems. Occupation as a destination or ends seemed to be less problematic. Service users involved in Strands B and C used their existing social networks to support access to meaningful occupations, for example going to the cinema or a karaoke night. Likewise, social networks could be both a means and an ends.

However, using an existing social network challenged notions of social inclusion, especially if that network was composed exclusively of other service users (Spencer 2004). Social inclusion, in this interpretation, seemed to be associated with invisibility of mental distress and conspicuous production and consumption. This was reminiscent of Deleuze and Guattari's critique of mechanistic views of human life (Fox 1993), where people are regarded as rational and linear processing systems. From this view it is not possible to easily understand people as simultaneously processing, producing and consuming, engaged in ongoing cycles with transient outcomes (Fox 1993). Capra's (2002) descriptions of social networks as complex phenomena were helpful in understanding that they could be both the means and the ends, simultaneously. The idea of parallel sustaining and developing cycles underpinning social networks also helped inform discussions. People could consider social activities which were repeated over time with a sense of belonging and ownership (sustaining), and those which took a person into new places and roles (developing). Almedon's discussion of bonding and bridging social capital similarly informed discussions, particularly in Strand B (Almedon 2005).

It was the concept of bonding social capital, or sustaining social networks, which seemed to be most important to service users. This was

particularly evident in Strand A, with the central importance of the safe place as a precursor for social networking and participation in the mainstream. As discussed in Chapter Six, these findings are supported by the work of human geographers in particular (Parr et al 2004). What transforms a space into a place is a sense of ownership and belonging (Tuan 1977, Cresswell 2004), which contrasts with a sense of alienation. The findings of Strand A indicated that having a safe space makes it possible to get involved. In the service users' view, a safe space is characterised by tolerance and acceptance, particularly of the manifestations of mental health problems. It is also characterised by simple occupations associated with survival and time use. It is also characterised by social networks of people with similar experiences who can share their knowledge. A safe place therefore is not just a segregated space from the mainstream, but a place where people feel they can belong to. Places are primarily defined through social networks (Cresswell 2004), so a place becomes important because of the social connections formed in particular locations. Even if those connections are associated with different locations, particular places become significant as social contact is re-enacted over time (Cresswell 2004). Thus places which might appear from the outside as socially exclusive are not seen that way by the inhabitants or users of the place (Cameron 2006).

This research was deliberately designed to create new social networks which people could own and belong to for the duration of the active phase. Mental health issues were openly acknowledged as being important and relevant to the research and its success, not just in terms of outcomes but also in terms of progress through each of the strands. Some social networks extended beyond the active phase as service users became involved in a research group at the university. The specific occupational forms used to foster the social networks are discussed in the next chapter on the occupational perspective. The concept of occupational alienation was used to explore and understand an occupational perspective on how social networks were created and

fostered, developing the work of Wilcock (Wilcock 2006, Bryant 2008). Critical portrayals of day services had indicated meaningless activities and limited social networks (Rogers et al 1993, Office of the Deputy Prime Minister 2004, Spencer 2004, Lingwood 2005a). Occupational alienation indicates a situation where activities become meaningless because they are repetitive and unchallenging, and people do not feel they own or control the product or process. Attending to creativity, development and ownership could overcome a sense of occupational alienation (Bryant 2008). However this requires direct engagement with service users to generate new ideas and possibilities, evaluate which of these will take things forward and sustain a sense of ownership over the process and the outcomes (Sayce 2000, Beresford and Campbell 2004). This has direct implications for the main resource required, the service users and staff, the latter learning different ways of working collaboratively (Hinshelwood 1998). This understanding informed responses throughout the active phase, with its emphasis on meaningfulness and involving service users, which will be discussed in Chapter Eleven.

The reciprocal relationship between this research and the day services between 2003 and 2007 enabled service users and staff to participate in many different ways, generating insights and interpretations which were used to develop services. Service users became involved in very direct and active ways to shape the development of services, producing resources which continued to be influential over time. The importance of occupation was a key part of this. Social networking was the central topic used to focus action and participation, but the design, process and understanding of the outcomes were also informed by an occupational perspective. Findings in relation to this aspect are presented and discussed in the next chapter.



## **Chapter ten**

### **Occupational perspective: findings and discussion**

#### **Overview**

The occupational perspective for this research was broadly concerned with three main approaches. These approaches included the political dimensions of occupation, in terms of occupational justice (Townsend & Wilcock 2004, Kronenberg et al 2005). A broader view of occupation in context, for the research design, was drawn from the dimensions of person-environment-occupation, understood as a conceptual framework for this research (Law et al 1996). To understand the different dimensions of occupation in terms of the design and implementation of the research, the dimensions of form, function and meaning were used as a conceptual framework for overall analysis (Kielhofner 2002, Larson et al 2003, Nelson and Jephson-Thomas 2003, Nelson 2005). The extent to which these different approaches contribute to understanding the research is discussed in this chapter.

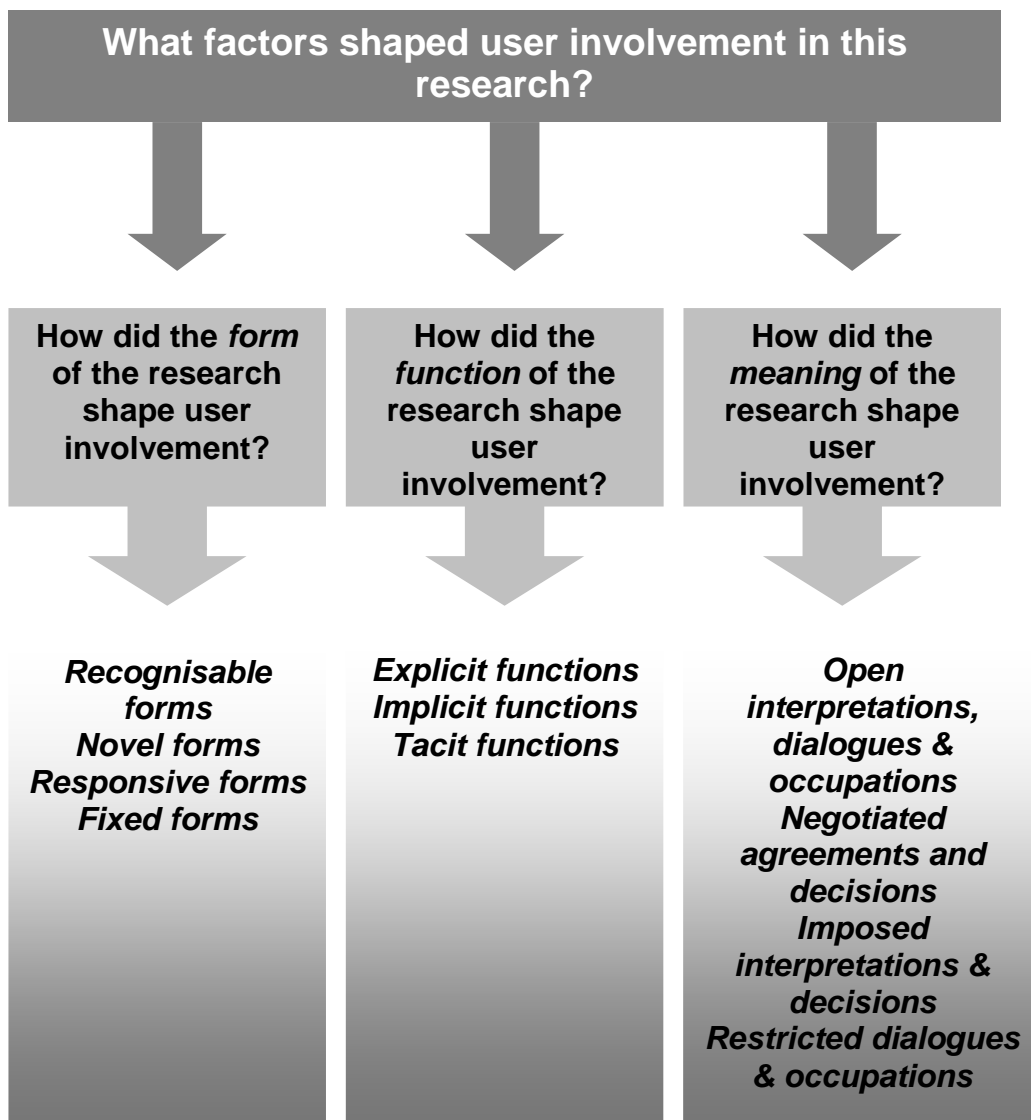
The principles of occupational justice (Townsend & Wilcock 2004) introduced in Chapter Three and discussed at the end of this chapter, informed approaches to participation and user involvement. The framework of person-environment-occupation (Law et al 1996) was used to underpin the three strands, as explained in Chapter Five, and will also be discussed in this chapter. The specific findings of the analysis using the form-function-meaning framework are presented first. This framework was developed by occupational therapists and scientists seeking to understand occupation; by identifying the form, or way, in which people did things; their intentions, or functions of the occupation; and the significance or meanings of the occupation (Nelson 1996, Kielhofner 2002, Larson et al 2003, Nelson and Jephson-Thomas 2003, Nelson 2005).

## **Forms, functions and meanings of the research**

As discussed in Chapter Five this research was complex, involving many forms, functions and meanings in order to engage with people in different ways. The occupational form was understood as the way things were done, for example when discussing the research in Strand C, Ken and I had toast with the service users in the pub, where the Traders Post group met. Analysis of the occupational form was concerned with identifying and categorising the different forms of the research which involved service users. Subcategories emerged to capture the different features of the occupational form in relation to user involvement, which are explained further. The different occupational functions, when purposes were identified and communicated, were also identified and categorised in the analysis. As analysis progressed it seemed that sometimes these purposes or functions were very clear and explicit, and other times not. For example, at the beginning of each Social Network Day, the purpose of the day was announced. The inclusion of new initiatives such as the Green Gym in the second social networks day indicated an implicit function of increasing service user involvement by raising the profile of such initiatives. The possibility of tacit functions was also considered. The third aspect, meaning, was challenging to pin down as the meanings of the occupations associated with the research were constantly shifting. It was an ongoing possibility that people would be alienated or engaged by these shifting meanings. The shifts were affected by changing agendas, such as the topics determined by the Social Exclusion Unit (Office of the Deputy Prime Minister 2004).

A qualitative data analysis software programme, NVivo 7, was used for this analysis which made it easier to deal with the large volume of data from the sampled events. Consideration and comparison of each item of data led to the development of the framework of form, function and meaning to include the categories as shown in figure 26. "Free nodes" were also created for significant statements or data which did not initially

appear to link with these categories. Most of these data were subsequently integrated into the categories.



**Figure 26: Factors shaping user involvement**

### ***Forms of the research***

The research was varied in *form*, to engage people in different ways. Some aspects were determined by the requirements of the approval process: service users involved in the strands gave written consent (Appendix P) and the information sheets were used at key points when discussing the research (Appendices D, E, F). But these were preceded and succeeded by many other occupational forms. These forms were

evident in the data sampled for analysis. As the analysis progressed, it was found that the forms of the research could be categorised into *recognisable, novel, responsive* and/or *fixed* (Figure 26). It was more useful to think in these terms in relation to user involvement than in specific physical forms, for example meetings or letters or telephone calls.

*Recognisable* forms were familiar; making it easier for people to understand what was involved. The very first Day Services Forum set a pattern which was followed thereafter. There were familiar faces not only from those attended regularly but also because staff members encouraged service users from each of the resource centres to come with them. The meeting was held in the social lounge at Alder House next to the cafeteria, and timed so that people could stay after having lunch. The social lounges acted as hubs for Strands A and B – service users would wait there if they were early for the research group meetings. This mirrored the practice in day services where social lounges were used as waiting areas for people attending closed groups.

Alongside familiar faces, places and routines, there were *novel* occupational forms. At the first social networks day, following discussion between service users and staff at a planning meeting, a modified form of speed dating was used as a warm-up activity and renamed as speed networking. People started by introducing themselves to another person nearby. When the whistle was blown after a few minutes, everyone had to move on to another person they had not met before. This was repeated several times. Afterwards, in shared reflections on the unexpectedly large attendance for the day, one factor identified was a rumour before the day about speed dating acting as a novelty attraction for service users. Novelty was also associated with humour, such as the time when an audio-recording was being made of service user reflections on Strand A:

*“(Wendy asks Alan to stop flicking pen)  
(everyone laughs)”*

Alan        *I'll use it to get the wax out of my earhole that doesn't make any noise does it?  
(laughter in group)*  
M60, research group meeting, audio recording of service user reflections.

The overwhelmingly novel aspect though, was being involved in a project which was in significant ways independent of health and social care services:

*"I never thought I'd be involved in a PhD"*  
M71, research group meeting, audio recording of service user reflections.

Participants in Strand A identified *novel* and *recognisable* occupational forms:

*"We've done photography, we've done recording, we've done discussion work, we've drunk tea, we've been for a walk round the houses which actually helps mental health too. We had breaks too."*  
M60, research group meeting, audio recording of service user reflections.

Letters sent out to notify people of events associated with the research, for example the letter analysed at this stage (C8) and the letter sent between strands A and B (Appendix T), offered a different form. They were recognisable, although informal conversations with service users indicated it was unusual to get letters in relation to specific projects, so they were also novel in form.

The occupational forms of the research were also *responsive* to actions of those involved. For example, although the day service forum invited service users and staff to become members, attendance was not required for every meeting, or even for the two hour duration of each meeting:

*"People would arrive after we had started, but there was no difficulty about that. People would also leave early, and again there was no problem – they just said something to the person next to them and went away."*  
M3, Day Services Forum, personal reflection.

Being *responsive* meant constantly considering what was part of the research and what was not. This was a shared process:

*“We then had time reflecting on the group, which I recorded. I stopped the recording when Angela shared an experience with the group which she did not think was part of the research.”*  
M71, research group meeting, personal reflection.

Fixed forms of the research were useful to ensure that everyone had an opportunity to do something. For example, using the checklist for Strand B (Appendix J) when meeting with the Oasis group meant that the discussion was structured and Adam, working as a collaborator, could take a leadership role:

*“After being introduced by [the group co-ordinator], we used the checklist for Strand B as a prompt for asking questions. Adam asked the questions and I wrote down the responses.”*  
M68, meeting with service users, personal reflection.

Most forms of the research were multidimensional, being both fixed and responsive, and recognisable and novel. For example, a mapping exercise used in the first social networks day (item 4, Appendix AG) was not immediately recognisable to the people present, but the tasks associated with it (writing on post-its, engaging in group discussions) were. People were asked to write the names of places they liked to go to. Then they were asked to put these names on flipcharts headed with local areas or one titled “Beyond [the Borough]”. The instructions for the exercise acted as a fixed structure within which people could make their responses. The outcome was a resource detailing locally places accessed by service users, which was used as the basis for the BITRA (Borough Index to Recreational Activities) and Strand B.

### **Functions of the research**

Involvement in the research was shaped by *explicitly* stated functions, suggested *implicit* functions or *tacit* functions which people understood but were not stated explicitly (Figure 27). Analysis using NVivo indicated a preference for explicitly stated functions to facilitate

**How did the *function* of the research shape user involvement?**

***Explicit functions***  
***Implicit functions***  
***Tacit functions***

**Figure 27:**  
**Functions of the research**

involvement, for example in relation to the validity and reliability of the research:

*“The important thing about the research is that it is relevant, or what is the point? The other important thing is to make sure the research is planned and organised, so that when other people hear about it, it sounds worth hearing about. And if changes are recommended, suggestions can be taken seriously.”*  
C8, letter to service users.

Similarly, for the first social networks day, some service users who had recently undertaken leadership training were invited to participate in the planning and facilitation of the day:

*“To provide a real-life opportunity for service users to make use of recent training in facilitation and act as leaders in partnership with us.”*  
M12, social networks day, field notes on planning meeting.

Being explicit about the function or purpose of an event made it easier for people to communicate with each other. One challenge was to ensure that the functions of the research, in contrast with service development activities, were made explicit. For tangible aspects, such as the PhD, this was easier, but for more theoretical concerns it was more difficult. In particular, it was important to be explicit about the occupational perspective:

*“An occupational perspective  
I spent sometime in the shop looking for Christmas cards which showed an occupational perspective, and these were the best I could find. If you look at the front you will see that the reindeers or Santa are all very busy, doing things. And Christmas is a time for doing different things, for many people, so an occupational perspective would mean thinking about what people are doing, and why? And doing things has different meanings for different people, just like Christmas does. So I guess there are things that you would not choose to do, and things you would. And in the same way I am hoping that the research will focus on what people are doing and why, in relation to social networks.”*  
C8, letter to service users.

When there was an opportunity to reflect, service users also stated what explicit function the research had for them as individuals:

*“To influence government policy – that’s one of the things although there’s no quick fix.”*

*M60, research group meeting, audio-recording of service user reflection.*

*“We’re like a little think tank aren’t we? We’re hoping to improve our own situation and others because it gets fed back.”*

*M71, research group meeting, audio-recording of service user reflection.*

An example of an *implicit* function was from a visit to the social group at Elm Lodge to discuss Strand A:

*“I was slightly late and was welcomed by a staff member, who asked what I wanted to do. “I don’t want to disrupt the group”, or the game of scrabble. Another member of staff arrived, all worried because she had forgotten I was coming – I reassured her and we settled down to a game of dominoes with a service user who I knew from the 2002 review.”*

*M18, meeting with service users, field notes.*

Having arrived late, it was important not to disrupt the group any further, acknowledging the primary importance of what they were doing already. This hopefully implied recognition of the value of their occupational choices. An implicit function of the research was that it had to fit with what was already happening where possible, not to replace existing occupational opportunities.

Tacit functions are by definition more difficult to identify and define. One statement in relation to this category was:

*“You’re bringing things out of us, aren’t you, in a way?”*

*M71, research group meeting, audio-recording of service user reflection.*

This statement was striking because it appeared to be a clear indication of the importance of tacit knowledge in the research. In its context, the service user making this observation was supported by the others present. They were surprised to discover what they knew and how their knowledge had been expressed via the research.



### Meanings of the research

Finally, in relation to meaning, it was believed that there was a process of interpreting what was happening, discussing these interpretations and negotiating decisions or agreements (Figure 28). This process could be open, in terms of freedom to express interpretations, engage in and shape dialogues and occupations, and reaching decisions or agreements through negotiation where everyone had a say. Or it could be controlled, where interpretations were imposed, dialogues and occupations were restricted and decisions were taken without negotiation.

**How did the *meaning* of the research shape user involvement?**

***Open interpretations, dialogues & occupations***  
***Negotiated agreements and decisions***  
***Imposed interpretations & decisions***  
***Restricted dialogues & occupations***

**Figure 28: Meanings of the research**

The emphasis on user involvement meant being open to feedback, negotiation and shared decision-making. A response to the proposed research in the early stages included these comments from Andrew:

*“Research into use of the social lounge at [Elm Lodge] strikes me as potentially the most interesting of the three you outline. ... BITRA seems to be the least consequential of the three areas you hope to research ... The user-led Group at [the Larch Centre] could be an interesting research topic. I think it might link up with your first topic ... It would be fascinating if these two areas of research apparently unconnected turned out to be linked.”*  
C22, letter from service user.

In the recruitment phase for Strand C, during a telephone call to Gabrielle it was necessary to make joint decisions on the spot:

*“We agreed that Gabrielle would check with the group tomorrow to see if they are ok with the interviews, that I would discuss with Ken, and Ken would contact Gabrielle to sort out interviews if all was ok. Other possibilities are that I meet with Gabrielle and Ken and the group, but this seems to be overkill. I have explained the research to Gabrielle and it would need to be explained by Ken again when recruiting individuals for interviews anyway.”*  
C51, telephone call to service user, field notes.

Being open to exploring the meanings associated with the research was evident in the research groups. When we reflected on Strand A, there were different meanings perceived by service users:

*“W Why do you think this research has been done?  
Adam Making our views known?  
Alan Helping future generations  
Adam helping Wendy with her PhD  
W Future generations?  
Alan Well whatever the process of mental health care which is going to be needed for a long long time, isn't it?  
Eleanor And those interesting buildings are they going to close down them all?”*  
*M60, research group meeting, audio recording of discussion*

Sometimes encouraging open dialogue generated unexpected developments. At the first social networks day, the programme included:

*“large group reflection time, to gather thoughts and promote critical dialogue and reflection. I planned this after discussing possibilities with people and going for a reflective walk myself along the canal. I used the story of the muddy puddle and suggested they formed ‘huddles’ to share their thoughts. The story was developed by one group into the image of the fish getting sick being stuck in the fish tank (Finding Nemo) – lots of discussion generated by this on what to do next, including references to Chairman Mao!”*  
*M12, social networks day, personal reflections.*

This process evolved to eventually indicate some degree of empowerment at the Day Services Forum for both service users and staff:

*“Well that's the usual view but this is how it seems to me.”*  
*M45, Day Services Forum, field notes.*

At times, restrictions had to be placed. For example, at the first social network day:

*“We expected about 30 people to attend but on the day there were over 60 people, which was a test to our organisational skills as a team, as we were short of physical space, refreshments and other resources, and time, to include everyone in the way we wanted to.”*  
*M12, social networks day, personal reflection.*

The number of people present signalled a shared sense of the significance of this event, being meaningful to many service users.

Restricting and imposing agendas was also a way of getting new information across to people. At the notifying stage of the research, it was important to ensure there was a focus on the research itself, so that people were given an opportunity to focus on what it might mean for them as individuals:

*“I structured what I had to say into three themes – the social networks day, the research and the organisation of the research.”*  
M18, meeting with service users, personal reflection.

Similarly, at the second social networks day it was assumed that people present would find the contribution of Lou, the guest speaker, meaningful. She gave a presentation of her experience of being a leader in a user-led social and recreational project.

There were also pressures to talk about issues using externally generated terms and interpretations, especially at the beginning:

*“[Geraldine] made reference to the National Service Framework recommendations about social inclusion and recovery.”*  
M3, Day Services Forum, field notes.

*“The discussion on core values ... how much of the political speak had already infiltrated the forum or whether in fact people did not know how to speak about it without using the terms from policy documents.”*  
M3, Day Services Forum, field notes.

A comment in the feedback for the first social networks day suggested that:

*“... Whilst it was good to hear the views of others, it was those who were articulate who tended to speak.”*  
M12, social networks day, evaluation report.

This issue of representation also arose after the meeting with the Oasis group during Strand B:

*“The difficulty associated with representation was pervasive – did the volunteers really represent the service users? Could the service users represent themselves? Was it fair to expect a group to agree on their responses to the checklist?”*  
M68, meeting with service user group, personal reflection.

Being open to the possible meanings of this meeting meant that an active approach could be taken during the meeting itself. Adam, who was asking the questions from the checklist, included everyone by encouraging everyone present to make a response. Afterwards, when analysing this response alongside all the others in Strand B, the group felt the Oasis group was an important example of a place where people could be themselves, because of the acceptance and tolerance of mental health problems. So the contribution became more meaningful because it resonated with the experience of the service users in the research group and raised what they considered to be an important issue.

## **Discussion**

### **Form, function and meaning – a micro-view**

The use of the form-function-meaning framework was identified as a way of sustaining an occupational perspective in the final analysis. This strategy revealed details of the research which were related to the three strands and underpinned them. Attention to these details suggested a micro-view on the research. There did not appear to be a precedent for this strategy. The form-function-meaning framework has been used by occupational therapists, especially Nelson (1996), to understand the role of the therapist and the relationship between the different elements and occupational performance (Nelson 1996, Larson et al 2003). From this perspective, user involvement could be understood as occupational performance. However, in this situation, rather than seeking specific changes in occupational performance to demonstrate recovery, the goal was to conduct research. As a researcher, it was important to recognise that those involved could and did work on the forms, functions and meanings of the research to facilitate their own performance, and that of others. For example at the Day Services Forum, Geraldine, the day services development manager, consistently put the research as an item on the agenda so that developments could be shared, those actively involved could contribute to feedback and to give other people an opportunity to get involved.

It was the intention of this research to align with the culture of day services, so that service users would recognise aspects of the research and therefore feel more comfortable about engaging with it. Culture from an occupational perspective is concerned with occupational form (Caulton and Dickson 2007). This is a simplified understanding of culture, which in itself is complex and open to many different understandings (Iwama 2005). However, for the purpose of this research, the culture of the day services was understood as the specific way people did things. Coming from outside made it easier to perceive this and knowledge was gained initially through attending the Day Services Forum and then gradually extending to other forms of day services, for example the social groups. The review which preceded this research (Bryant et al 2005) also provided knowledge of the day services culture, for example the subtle differences between the resource centres.

The critical ethnographic aspect of this research was fundamentally important, for it supported work on understanding of the day service culture, fostering a critical response (Madison 2005). A critical response in this kind of work requires an active engagement with the possibility of difference or as Madison (2005) proposed, “dialogue with the other”, although in this situation it was not always easy or appropriate to define specific groups of people as “other”. In this research, attention was paid not just to different people, but also the different possible occupations and the different ways in which people might engage with them. This applied to the design, implementation and interpretation of the findings of the research. This approach is typical of occupational therapy (Creek 2003) but not of occupational therapy research. Emphasis on investigating the efficacy of specific interventions has taken greater precedence (Duncan et al 2007). Yet this requires generalisations and simplifications which do not do justice to the many different forms of occupational therapy, which are adapted to address the occupational needs of individuals and groups (Wilcock 2006). It was significant that this research required many different occupational forms as an integral feature: the challenge was

creating viable and meaningful opportunities. Further exploration of this challenge might enhance understanding of an occupational perspective in research. What assumptions are being made in the design process? Who will be included and who will be excluded as a result?

These questions are critical to an understanding of function, the second part of the form-function-meaning framework. If an event, or particular occupational form, has a very specific function, then there may be a justification for excluding some people. This echoes fundamental aspects of research design and ethics (Silverman 2000, Holloway and Wheeler 2002, Hammersley and Atkinson 2007). For example, in this research, to focus on the roles of individuals involved in groups in Strand C, it was necessary for those individuals to have direct experience of the groups. This was made explicit in recruitment for Strand C. Moreover, the strand was concerned with user-led groups, and in the consultative phase those groups with staff directly involved were excluded from further consideration. Whilst being clear about inclusion and exclusion criteria is key to good research (Holloway and Wheeler 2002), the occupational perspective appeared to add to the process. For example, with the focus on user involvement, Strand C had been designed to contrast with the other strands in occupational form and function. The service users were asked to contribute their experiences of user-led groups in individual interviews. It seemed that the function of Strand C was meaningful to those participating, especially in the context of the research as a whole. The issue of accessing potential participants is a key consideration, which was significantly assisted by locating the strands within an overall research strategy, enabling service user-researchers to become involved in recruitment (Faulkner 2004, Hammersley and Atkinson 2007).

For this reason there were sustained efforts to make the functions of the occupations explicit so that as each stage of the research was reached, people knew what was being attempted and could negotiate their part in making it happen. This process of negotiation is characteristic of

participatory action research (Koch and Kralik 2006). Because this research was collaborative, the issue of who determined the function of the research and associated events was important. The survivor movement has emphasised the importance of service users determining the agenda for research and thus, where possible, leading it for themselves (Beresford and Campbell 2004). This is in contrast to the experience of tokenism, where user involvement is sought by powerful organisations for appearances only (Beresford 2002). These are two extremes of a continuum (Hickey and Kipping 1998, Beresford 2002) and this research, being collaborative, fell between the two. It was necessary to be honest about the function of this research and to make sure that everyone understood that the primary function was to gain an academic award. But it is possible to have multiple functions, particularly from an occupational perspective. It would be rare to engage in an occupation which has a single function: this is better understood as a task (Creek 2003). Thus the occupational perspective on function provided scope for acceptance of multiple functions, evolving with different occupational forms and subject to different interpretations by those involved.

It was important not to foster misunderstandings, which was achieved to some extent by making the functions explicit. Time for reflection and discussion also gave opportunities for different understandings to be shared, a process informed by knowledge of Freire's (1970) work on collective action, and group work (Finlay 1993). Time for review was important for exploring implicit and tacit functions perceived by those involved. However the method of analysis did not clearly expose this process, which was ongoing and not necessarily captured in field notes, audio recordings or other records. At times it seemed as if the research was such a different experience for people they could not make sustainable assumptions about its implicit or tacit functions and thus demanded explicit explanations. It also seems reasonable to assume that these implicit or tacit functions might reflect personal agendas which did not need to be shared. When presenting the findings of the research, a

period of negotiation was required with co-presenters such as Adam, Alan, Dean and Eleanor, to clarify what role they wanted to take. Locally, the function of the research to inform service development was obvious and the co-presenters were keen to play a part. Beyond the local setting, presentation of the findings was more strongly linked with the function of conducting doctoral research. However, in preparations the co-presenters identified that the presentations also served a function for them personally, developing their skills and giving them new occupational and social experiences.

Preparation, dialogue and negotiation were therefore very significant in relation to identifying the functions of each event and of the research as a whole. Whilst there is emphasis on reflection and dialogue in the literature on participatory action research, it is not often linked specifically with the identification of the function or purpose of each stage (Koch and Kralik 2006). Identifying and agreeing the primary functions with co-researchers and other involved creates a greater sense of ownership (Staples 1999), which in turn nurtures a sense of belonging to a common shared purpose (Manning 1999). The sense of belonging to social networks, which include people doing research together, is strongly associated with tacit knowledge (Capra 2002) and future research could explore this link further in relation to participatory action research and critical ethnography.

Reflection has been recognised as key in developing awareness of tacit knowledge and meanings (Taylor and White 2000). A critical response to the events in this research often meant asking why something was important, or what it meant. This was a reciprocal process, with service users asking about the important aspects of the research. Understanding meaning or significance often meant an exchange, such as Andrew's letter in response to the proposal for the strands (C22), or the image of 'Finding Nemo' in response to the muddy puddle metaphor at the first social networks day. This exchange was a way of finding out what was meaningful to service users and for them to find out what could be



meaningful about the research. These aspects are central to participatory action research but difficult to convey (Koch and Kralik 2006).

As people got involved in the different forms of this research and recognised its multiple functions, meanings were transformed. In Strand A, Adam used the research question and aims as a reference point not only to clarify the research but his role. As he absorbed one aspect, he quickly thought of another. Meanings were constantly shifting in the research and from the data it was difficult to pinpoint moments when these shifts took place. One such moment was when Angela suggested that the checklist for Strand B should be distributed to all day service users who wanted to be involved, beyond the group. Up until that point, the group had envisaged doing all the data collection which seemed a huge task. Involving other service users changed their roles and the meaning of the research for all involved. From an occupational perspective, shifts in meaning have been intricately linked to the experience of transformation through doing something (Hasselkus 2002). Occupational therapists design and adapt occupations to facilitate these transformations, not only in meaning but also in performance (Hasselkus 2002). There is an increasing belief that simulated occupations are inferior to real-life and real-time occupations in facilitating sustained transformations (Townsend 1998). This research, being based in the setting and using the resources available, simultaneously engaged with real-life and real-time occupations and yet shifted their meaning, being in the context of doing research.

This research indicated that it is important to attend to the form, function and meaning of the services offered. The occupational forms of the research should be recognisable, yet offer new experiences. There should be scope to respond to individual and collective agendas, yet be fixed in some aspects for reliability, so people can feel safe in engaging with the research. The primary shared functions of the occupational forms of the research should be explicit, so that people understand what

outcomes are aimed for and how they will be achieved. Dialogue about these explicit functions will help uncover implicit and tacit functions perceived by those involved. Finally, it is important to recognise that the meanings are in constant flux as experience evolves. Some of these meanings are shared and so collective occupation and social contact is vital (Townsend 1998, Leighton 2003). For this research, considering the forms, functions and meanings has been useful for understanding what facilitated and sustained collective user involvement.

### **Taking an occupational perspective – a macro-view**

The use of form and function in design has already been linked with arts such as architecture (Van der Meer and Sudjic 1997). Yet for this research, this framework was not used consciously to inform each phase. For the analysis, the framework offered a systematic way of approaching the data from different angles, but rooted in an occupational perspective. Would it have been helpful to actively think about form, function and meaning during the consultative and active phases? Could this understanding be used in the future so that at the beginning of a participatory action research project or critical ethnography, a researcher could introduce the terms form, function and meaning to structure planning and focus consultation? Discussions could be structured around why the research was happening, the different aspects of it which needed to be shaped and the significance to the individuals concerned. Yet although these different components can be extrapolated and identified, the way they are used as events are unfolding is often an act of improvisation. The art of improvisation is more strongly associated with arts such as music, yet it has been linked with professional artistry (Fish 1998, Fish and Coles 1998). Future research could explore what part an understanding of improvisation and artistry could play in participatory action research and critical ethnography.

The final analysis did not capture details of the two other approaches informed by the occupational perspective, the person-environment-occupation framework and occupational justice. Despite this, it is

important to discuss the influence of these approaches on the findings, as a macro-view of the research. The use of the person-environment-occupation framework (Law et al 1996) was solely in relation to the design of the strands. Strand A was primarily concerned with the environment, Strand B with occupation and Strand C with the person. This conceptualisation was used to promote and explain the research (Appendix A). It did not reflect a particular understanding which had been expressed by service users and staff. During the consultative stages there were diverse and conflicting views of social networking and day services. The person-environment-occupation framework seemed to offer a way of capturing these views without favouring any of them. It was readily understood by those involved. However, in the strands it was clear that it did not make sense to continue using the framework, for each of them included all three elements. Strand A, although overtly focused on the different physical environments in the social lounge and beyond, drew in service users' views on the occupations which attracted them and the significance of their own responses and those of others. Similarly Strand B was primarily focused on what people could do, but drew in considerations of the different environments which people favoured for different personal reasons. Strand C was focused on the roles people played in user-led groups but these were shaped by where the groups took place and what people did when involved in them.

Thus the person-environment-occupation framework was understood for this research as a basic framework rather than a model. In occupational therapy, these three elements form the basis of models of practice (Christiansen et al 2005, Townsend and Polatajko 2007) with emphasis on the relationships between the three elements. There did not appear to be a precedent to using the three elements deliberately in the design of research. However, it is significant that beyond communicating the occupational perspective to those involved and providing a framework for the basic design, the framework was not used. The person-environment-

occupation framework was a starting point, to inform discussions by bringing in the occupational perspective in an accessible way.

Throughout this research a reflexive approach was consistently taken, as a means of understanding responses to what happened as it unfolded (Taylor and White 2000). These responses were as much about my beliefs as the unfolding events. The occupational perspective was central to these beliefs and because of its central place in my thinking, at times it was important to reflect on and question why this was. Why bring in the occupational perspective? Why not just work with what people knew already? Whilst theorists such as Wilcock (2006) claimed a central place for occupation in human life throughout history, this view was not reflected in contemporary policy or approaches to mental health. To emphasise occupation was to challenge the emphasis of policy and clinical approaches (Molineux and Whiteford 2006). However, this was familiar ground from experience of practising as an occupational therapist, indicated by Denshire (2005) in her defence of her interpretation of her own practice. Misinterpretation and misjudgement of everyday occupations can be commonplace and there has been an ongoing requirement for occupation-focused work to be both clearly presented and open to negotiation and adaptation. This is reflected in the work of Sumsion on client-centred practice (2007).

Thus there was a precedent for me for many years, of looking for ways of communicating the occupational focus of my fieldwork. Having explored ways of engaging people in occupations (Bryant 1991, Bryant 1995), strategies such as using the person-environment-occupation framework were a way of not only keeping an occupational focus, but retaining scope for conflicting and different views to be explored. It was also a means of conveying the complexity of occupation in relation to the environment and personal agendas. It gave a framework for speaking about elements of the topic, social networking, which extended beyond political correctness and the language of social inclusion and exclusion.

By sharing this way of understanding, it was empowering for those involved. Rather than imposing an agenda from outside the project, it was useful knowledge brought in to make the project more readily understood. Similarly, the form-function-meaning framework provided a structure for dealing with complex and multiple forms of data, to facilitate understanding.

However, there was a more fundamental question beyond the use of these frameworks for understanding, concerned with the value of occupation in itself, over and above other perspectives on living with mental health problems such as social, psychological and medical perspectives. Chapter Three analysed the occupational perspective and suggested that it was central to human life, not just another way of seeing things alongside others (Townsend 1998, Duncan and Watson 2004, Hocking and Nicholson 2007). For this research, this meant attending to, and valuing, every indication of participation in occupation or doing, however transient. It was assumed that everyone could participate in some way, through the occupations of the research. Wilcock (2006) has highlighted the importance of participatory action research in developing knowledge about occupation and health, so that local solutions to shared problems can be found which acknowledge difference.

Use of the occupational perspective also required an awareness of occupational risk factors which might negatively impact on participation (Wilcock 1998, Townsend and Wilcock 2004). For this research, three occupational risk factors were given primary consideration as they offered a key to understanding barriers experienced both individually and collectively. The three risk factors were occupational deprivation, occupational imbalance and occupational alienation (Wilcock 1998). They informed responses and decisions for this research in very simple ways. Occupational deprivation was concerned with access, occupational imbalance in the way the research was shared between those involved and occupational alienation in terms of belonging and ownership.

The focus on social networking was indicative of an awareness of the three risk factors. It was important to take a focus which was meaningful to everyone and social networking appeared to be both important and within everybody's experience. So people could access the occupations associated with the research on social networking because they had something to contribute. The possibility of depriving access to the occupations associated with the research by focusing too narrowly was a real possibility, for example on social networking only in mainstream community venues. People had different occupational experiences in relation to social networking, for example, those with a history of alcohol problems had very specific issues about going to bars and pubs. How their contribution was balanced with those of others reflected an understanding of occupational imbalance and balance. There was exploration and synthesis of different experiences of social networking within the research, particularly within the three strands. Finally, by choosing a topic which was meaningful to individuals, a sense of ownership and belonging could be created. If people were alienated by meetings, it was possible to involve them in other ways. For example one service user expressed interested in participating in Strand A because she was very interested in photography, but was not attracted to the small group setting or the prospect of analysing and reporting on the data. So she communicated her ideas and views in the user/staff business meetings at Elm Lodge and by letter, before and after the strand.

The concept of occupational alienation (Wilcock 1998, Bryant et al 2004, Bryant 2008) was particularly relevant to the focus of social networking and in early stages of the research, it was considered as a core focus. This was not taken forward for several reasons. Theoretical understandings were not imposed on the strands once they were underway. The person-environment occupation framework was used for the design, and the form-function-meaning framework for the analysis. In between, the strands were informed by knowledge considered directly

relevant to each topic and the findings. There was an emphasis on action and reflection, with the experience of occupational alienation being just one aspect of social networking. In terms of how the research was conducted, occupational alienation linked directly with literature on empowerment, user involvement and stigma (Bryant et al 2004, Bryant 2008). Ultimately, for this research it was understood as one component of occupational justice (Townsend and Wilcock 2004).

This research did use an occupational justice approach, as defined by Wilcock (2006). This approach places a central importance on occupation, recognising difference within and between groups of people (Wilcock 2006). For example, in Strand B, from the outset it was recognised that the places and activities recommended by some service users might not suit everyone. At the same time, it was recognised that the research itself appealed to different people for different reasons. Using an occupational justice approach could mean that inclusion as an issue in research extends beyond social groupings of people, for example all current day service users, to the occupational capacities of potential participants in relation to the requirements of the research. Dean, who took a key role in Strand B, was recruited because the strand took place in a room next to where he did his voluntary work. This could be viewed as opportunistic but on the other hand, the strands were deliberately located in different places, involving different occupations, to give more people opportunity to participate.

Exploring what it meant to take an occupational perspective in this research has been an unfolding process. It has been possible to link the occupational perspective with principles of research design and ethics. Similarly the emphasis on action and participation has supported the belief in the primary importance of occupation for understanding the process and outcomes of participatory action research. The focus on what people do was very simple yet it has generated many implications for how service users were involved, the subject for the next chapter.

## Chapter eleven

### User involvement: findings and discussion

#### Overview

Service users chose to get involved to in varied ways in every aspect of this research. Beliefs about what could be achieved were influenced by the day services setting and an occupational perspective. The most important belief was that it was imperative to involve service users, guiding approaches to all those involved, structuring the research and underpinning it. Priority was given to generating evidence of service user involvement. This chapter presents the evidence emerging from the final analysis. Leading the research presented ongoing challenges in enabling and sustaining user involvement, illustrated here as the insider view. The final analysis identified some key outcomes which included benefits for individuals as well as for the day services. The challenges of collaborative working and the contribution of the occupational perspective are significant to this research. However, it is proposed that greater understanding of representation, democracy and participation would enhance future research, especially in complex processes such as this research.

#### Service user experiences of the research

Findings from the 2002 review (Bryant et al 2005) indicated that service users were concerned about changes to the day services. However this did not imply that they were resistant to change: in contrast there was evidence that they were seeking to be part of the process of change.

*“I have some rambling thoughts about the research you are proposing, which I would like to share with you.”*  
C22, letter from service user.

*“It’s a bit like knowing there are all sorts of things to try but they are like big boulders, far too heavy to lift and look underneath to see what there is underneath it. Instead we have given people the chance to see that there aren’t big boulders: instead there are little pebbles that are easy to look under and will hopefully be surprised by what they find.”*

C19, Newsletter, service users’ contribution.



This contribution was made to promote the BITRA (Borough Index of Recreational Activities), a core resource for Strand B. Direct engagement with the issues that concerned service users generated opportunities for them to express their concerns in creative ways. For example the crossword in the newsletter included clues for words reflecting and emphasising their experiences of day services: *'talking'*, *'respect'*, *'safe'* and *'support'* (C19, newsletter, service users' contributions).

Service users made more direct responses. For example when staff made proposals on how to take the findings of Strand A forward, there were a number of responses within the meeting:

*"[suggested it's important to] encourage people to talk about it – [people are] frightened of speaking out [as they] don't want to be excluded especially with mental health problems."*

*"suggested relaunching [the Larch Centre] as a preventative programme to prevent people getting ill in the first place."*

*"[suggested formal leadership in drop in sessions] otherwise you get bullying and issues with group dynamics."*  
*M37, Day Services Forum, fieldnotes.*

Not all responses to the research were easy to understand. A letter from Adam (C3) included complex details, diagrams and mathematical calculations. Even when he explained the letter to me later, it was not clear how these details related to the research. On the other hand, his creativity and attention to detail were essential to the successful progress of Strands A and B. Many service users took the opportunity to shape the research even if they had no intention of becoming more involved. Initially, following consultation the focus of Strand B had been on men. After a meeting with another service user group (M24), the response of the women present shifted the focus:

*"At this stage Strand B was still with a focus on men – I dropped this for the final version, not wanting to get into gender issues in a big way and have that overshadow the group. ... At this meeting the women expressed a lot of interest."*  
*M24, meeting with service users, personal reflection.*

Those who did get involved actively engaged with the doing of the research but also with the opportunity to reflect on their own personal experiences. Some of the service users involved in Strand A offered their reflections:

*“It reminds me of college in the seventies when I was studying.”*

*“I’ve enjoyed the last eight weeks and feel something positive’s been achieved by it all. I hope I have an opportunity to get involved in the next one if it ever comes about.”*

*“This group feels positive. I feel willing and able to contribute something.”*

*M60, research group meeting, audio recording of service user reflections.*

There were a range of key roles for service users. Many acted as experts on the services and local opportunities.

*“You come straight out of hospital and straight into the community and there isn’t that safe bit inbetween when you’re more protected for a little while ... I’m not just talking from personal experience I’m talking from the experience of an awful lot of people.”*

*M71, research group meeting, audio recording of service user discussion.*

*“Very enthusiastic about this group – some of them are going on holiday together in two week’s time... They keep in touch with each other and are achieving great things.”*

*C51, telephone call to service user, field notes.*

Andrew did not participate in the strands but communicated regularly throughout the research, providing helpful insights, feedback and suggestions:

*“I was impressed with the meeting ... that clients were being consulted seemingly before decisions were made and that some sort of democratic procedure was in place. However I am not so sure that things have been like this [at the other resource centres]. For this reason I think your research should include at least a brief comparative investigation of how things are being done at these other two institutions. Otherwise your research might be falsely seen as implying that all is well at all three.”*

*C22, letter from service user.*

## An insider view

From fieldnotes, audiorecordings and the continued process of reflection, themes were identified which related to the experience of leading the research and facilitating user involvement. Knowledge of the research process was important in communicating with those involved. The 2002 review (Bryant et al 2005) gave continuity and was used as a point of reference.

*"I used the statements from the 2002 review to start with what people had said before about day services, choosing key statements which summed up some of the tensions."*

*M12, social networks day, personal reflections.*

*"It is possible that you have already come across me ... in the day services review focus groups in May 2002, ... the research has grown out of [this review]."*

*M24, meeting with service users, leaflet.*

Previous experience as an occupational therapist working with day services in another location (1990-6) was also a resource. Although the model of provision there was different, and the shift in political agendas since then meant there were different pressures on services, the basic principles had not changed very much. Experience as an activist was also important for this research.

*"I thought very carefully about how people could indicate they were interested in continuing to participate, as this was so crucial for the next stage, and decided ... that it would be important to distinguish the different ways people could be involved."*

*M12, social networks day, reflection on evaluation form design.*

Possibly the most significant personal resource, however, was experience in group leadership in many different settings, often involving collaborative work, which made it possible to make on-the-spot decisions:

*"Eventually I asked if I could 'hijack' the meeting and [they] said of course, you can be chair. This I refused, but gave out my leaflets."*

*M18, meeting with service users, personal reflection.*

In addition, experience as an occupational therapist meant that it was possible to engage with the complexities of occupation with confidence,

using occupation as a tool to facilitate participation in many different ways.

*“The transient nature of the audience had undermined a shared sense of purpose so I decided to facilitate an activity which promoted personal reflection about social networking. I was also thinking of Kelly’s Personal Construct Theory, where polar opposites, or polarities, are identified, and a person locates him/herself along a continuum, moving near to the polarity they particularly identify with. So for example whether people preferred to go out to social network, or stay at home. We cleared the chairs out of the way and people lined up and spoke to each other. This was successful in energising the group and facilitating more interaction and reflection. It also represented diversity in a very physical way.”*  
M41, social networks day, personal reflection.

Reflection in this research did not just involve reflection on past events, being also part of preparations before each event.

*“In preparation for writing the purpose of the day document, I reflected on social networks .... I used a song by Wilco to inform this reflection (“How to fight loneliness”) which linked my own thinking on intrapersonal, social and occupational alienation.”*  
M12, social networks day, personal reflection.

Expertise in group leadership and enabling occupation meant that it was also possible to reflect in the midst of a particular action and shift the emphasis if necessary. This also meant it was possible to vary roles, shifting from leadership to being present in a less active way. These different roles facilitated contact with others involved.

*“If I get too organised then there is less scope for the group to make their response. It would feel a fait accompli. ... I sensed this last week when we were discussing the poster – it would be so easy for me to do, so easy, but then as I said it I realised that was completely not the point.”*  
M71, research group meeting, personal reflection.

This shifting, from leader to being present in a less active way, reflected how it was necessary to move continuously from being an insider to being an outsider, and back again. Being an outsider was determined by a range of factors – for example being based in the University. However:

*“It was difficult not to feel like an unwelcome outsider with a set agenda, but I think this feeling relates to more to my doubts than to the actual welcome I got. It seems that the service users engaged with*

*the research very seriously and were keen to share their thoughts and ideas.”*

*M18, meeting with service users, personal reflection.*

There were fewer factors determining my status as insider. But what was interesting was travelling between these two points. Coming from the vantage point, to consult with people in the day services was one aspect:

*“it seems as if I’m trying to work out how to remain an outsider yet also be inside. This was difficult given the central place in the forum of the 2002 review, which I was completely associated with, which gave me an authority. ... But also I was an outsider, confused by the jargon and language used by staff particularly, and trying to match what was being said with what was actually happening.”*

*M3, Day Services Forum meeting, personal reflection.*

*“To attend meetings like these was one of the more difficult things to do in the research. It was very difficult to pick up what was going on, and who to link up with particularly. Inevitably my presence forced the issue of leadership – who was in charge, who was welcoming me, who was required to respond and/or encourage responses.”*

*M18, meeting with service users, personal reflection.*

*“The choice of sending a Christmas card was very deliberate, to offset the apparently official nature of the letter, to reflect the emphasis of the research on social networks (that therefore I was setting up a social network of kinds in relation to the research) and to link myself with a non-clinical role.”*

*C8, letter to service users, personal reflection.*

There was also a sense of drawing people out of the day services to the research, so they equally could be simultaneously outsiders and insiders.

*“the issue of trust was important at this stage – I had to trust the interviewer and [Gabrielle] to understand what I wanted to achieve with the research. This was based on my ability to communicate my ideas, but also on their receptiveness. Again, I was building on existing work to build trust, not starting from cold.”*

*C51, telephone call to service user, personal reflection.*

The notion of insider/outsider seemed significant in relation to many aspects of this research, discussed in this and the concluding chapter.

## **Research outcomes**

The findings presented so far have been the product of efforts to understand more precisely what happened in the research and why. It

seems important to balance those findings with the tangible outcomes of the research, which were also evident in this stage of analysis. There was evidence of collaborative working, embedded in the setting. Overall, the findings were used to inform the day services review, initiated locally in 2007. At local level, the research generated very specific opportunities for service users and a number of specific products which were accessible to them. These included new experiences, new ideas and new insights. The photographs taken in Strand A were organised for an exhibition at the University and subsequently displayed at Elm Lodge (Appendix AH). The report was used to justify allocation of ongoing funding to the provision of a safe space at Elm Lodge for service users in the Borough. The poster for Strand B was displayed in each of the resource centres and at the Oak Foundation. The findings of Strand C were shared with those who participated and led to immediate action being taken to increase support offered to the Beehive group, including finding them a new venue and a liaison worker from Capital Volunteering.

Service users recognised the opportunity to work collaboratively:

*“Sometime ago a one-day workshop was put together looking at a number of different things but all related to each other. The overall plan was to give people a chance to work together looking at what activities are available to try in the borough and also outside the borough.”*

*C19 newsletter, service user contribution.*

For many staff and some service users this was a collaboration which lasted for the duration of the research. In a reflection on strand B, this was recorded:

*“I’m struck by the total commitment of the service users to the research.”*

*M71 group meeting for Strand B, reflection.*

Whilst a small group of service users sustained their involvement over a long period, there was evidence of involvement from many others:

*“We met [at St Peter’s] for a second Social Networks Day for day service users, staff and other interested people. The day was attended by 49 people, half of whom were service users. We were*

*pleased with this response, given that the day coincided with Diwali and no transport was arranged for people to get [there].”*

*M41, Social Networks Day, evaluation report in Oak Foundation newsletter.*

*“The voluntary organisation representative said use the volunteer bureau, don’t reinvent the wheel.”*

*M37, Day Services Forum, fieldnotes.*

One aspect which facilitated collaboration was that the research was meaningful to people:

*“it was talking about things you could do.”*

*M18, meeting with service users, fieldnotes.*

*“In the report that the Research Project Group produced with Wendy, ‘The social lounge and beyond’, ... the findings identify that having time to share the experience of mental illness and to form informal links and networks with other service users is crucial to the recovery of service users attending Day Services.”*

*M37, Day Services Forum, letter summarising previous meeting and agenda.*

Because the research was embedded in the overall development of the day services it became meaningful to people through mutually beneficial and complementary initiatives, for example capital volunteering, which led to the formation of one of the self help groups studied in Strand C:

*“the capital volunteering co-ordinator invited people to come up with ideas for user-led projects which could be funded by small grants. Ideas were shared and there was support for a self-help group and an optimism group.”*

*M41, social networks day, reflection.*

Part of the meaningfulness of the research was also established by allowing space for ideas to evolve in response to discussions and reflections.

*“not all views were positive: there is still lots of work to be done. In particular, information needs to be more accessible to users. People who lead services should be going directly to service users to share information and take action to address access issues.”*

*M41, social networks day, evaluation report in Oak Foundation newsletter.*

*“took more and more interest as the strands became clearer.”*

*M45, Day Services Forum, evaluation of the research.*

As the findings of the research emerged and were reported, it was possible for local responses to be discussed whilst the findings were still fresh in people's minds:

*"It was agreed that we would focus on these findings at the next away day for Day Services staff and think about how we can support and facilitate the informal contact of service users and user led initiatives."*  
*M37, Day Services Forum, letter summarising previous meeting and agenda.*

Service users reported that getting involved in the research had benefits for them as individuals:

*"It helped to give me confidence to apply my exponentially growing skills."*  
*C3, letter from service user.*

*"It's helped me I've enjoyed it and I shall miss it. It's helped me to get my confidence to go to do my voluntary work."*  
*M60, Strand A research group meeting, audio recording of service user.*

And this was echoed by a staff member who was involved:

*"I was quite nervous before coming into the group but I've probably got more out of it that I could ever have imagined."*  
*M60, Strand A research group meeting, audio recording of staff.*

One aspect which helped collaborative working was a willingness to reflect on the big issues:

*"Eleanor I often wonder if the buildings will stay permanent not just here other places for people what are ill very ill because I think it's a let down for the people who are cracking up and there's going to be more as the years go on*  
*Alan yes I think it's going to get acute more acute than it is now, there'll be*  
*Eleanor it's going to be terrible."*  
*M60, Strand A research group meeting, audio recording of service users.*

The products of the research facilitated further engagement and reflection and were recalled by those evaluating their involvement in the research as a whole as:



*“poster, confirming own views, presentations, reports, seeing the photographs, ideas about safe space, play, notices, service users value of involvement, how day services could go forward, value of safe space, peer support, involvement, drafts of chapters, day services providing an important and valuable service for people with mental health problems.”*

*M45, Day Services Forum, evaluation of the research.*

The research acted as a catalyst for ideas and insights:

*“proposed the use of volunteers to provide social experiences and not to convert existing groups but to set up a new group.”*

*M37, Day Services Forum, field notes.*

*“are there any such things, such as virtual ramps, for the mental...? ... one virtual ramp is for people who have been through the system to help people who are just starting in the system to get into places, to visit places.”*

*M71, research group meeting, audio recording of service user.*

Finally, there was a shared sense of the research being a positive experience:

*“We’ve done it with gusto, with enthusiasm, with humour, with seriousness, with commitment.”*

*M60, research group meeting, audio-recording of service user reflections.*

## **Discussion**

### *User involvement: benefits and barriers*

Service users were involved in this research from its very beginnings, having contributed to the 2002 review (Bryant et al 2005), which was detailed in Chapter One. The contrast between that review and this research was that service users were involved in agreeing the topic and the ways in which the research would be undertaken. Once each of the strands were underway, service users increasingly took charge at every level. This experience had multiple benefits for them as individuals, for the services and beyond the local setting.

The benefits for them as individuals were concerned with direct benefits in being able to engage in the occupations associated with the research. Because the research offered unique opportunities, the service users

were observed to exceed expectations of other service users and staff. Finally there were spin offs, as the positive experience of participation encouraged them to explore other opportunities. Conventions in gaining ethical approval appear to suggest that benefits to participants should be incidental rather than an aim of the research (College of Occupational Therapists 2003); to clearly distinguish between therapeutic aims and research aims. This research followed this convention, in emphasising the contribution to service development rather than personal benefits (Appendices D, E, and F). Yet there are many benefits for individuals in getting involved in research (Faulkner 2004). From an occupational perspective this is no surprise, for the occupations associated with a participatory research project are more likely to be meaningful to those involved, being directly relevant to their experience. Trentham and Cockburn (2005) argued that evidence of participation in a project will be indicated by both personal and collective transformations. However, these transformations are mediated by external barriers.

The barriers to involvement were understood from the occupational perspective to arise from occupational risk factors (Townsend and Wilcock 2004), as discussed in Chapters Three and Ten. Efforts were made throughout the research to minimise these barriers, understood in terms of access, sharing and ownership. Access to involvement has been understood in terms of access to physical locations and communication material such as documents (Faulkner 2005). However, the concept of occupational deprivation requires a much broader understanding of access (Wilcock 2006), where possible considering multiple barriers to involvement in occupations, in this case associated with research. It was difficult to capture this process from the final analysis. For example, for the meetings with service users, where possible the leaflets produced were in large print and avoided the use of jargon (Appendix AB). To make the leaflets even more accessible, everyone was given a copy and time was allowed for people to read the leaflet during the meeting and to discuss it afterwards. If people had difficulty reading, there was

assistance available. However, the leaflets were just one means of involving service users at that stage. To illustrate the proposed differences between the strands and provoke discussion, a camera (for Strand A), a 'Which?' magazine (for Strand B) and a mug (for Strand C) were brought along.

Understanding the barriers to involvement in terms of opportunities to share reflected a particular understanding of occupational balance (Wilcock 2006). Some service users only got involved occasionally. For example, one person put his name on the mailing list at the first Social Networks Day as being interested in the research and so received regular updates. He appeared during the lunchbreak of the second Social Networks Day and sought me out to give support for the research but apologised for not being able to get involved in the strands. Finally I met with him at the Lumos Workshop, where once again, we discussed the progress of the research. Accepting this level of involvement as valid and important was intrinsic to understanding and acknowledging the barriers that service users faced and the efforts they made to participate.

His involvement was also understood in terms of belonging, overcoming barriers to involvement caused by occupational alienation (Wilcock 2006, Bryant 2008). For those service users who became very involved in the research, there were a range of motivations but a shared sense of finding the occupation of doing research meaningful. Their sense of ownership was discussed at critical points. Staff who had known these service users for many years were struck by this, pointing out that day services did not offer any equivalent occupational opportunities. Faulkner (2004) suggested that being involved in research does mean that mental health service users have to challenge assumptions about their capacity for involvement. One tension throughout this research was the concern that getting very involved could indicate a fitness for returning to work and thus jeopardise eligibility for welfare benefits (Beresford 2007) and this has been recognised as an undermining factor in securing user

involvement in research and development. However, in this research, service users welcomed the relevance to work. For example, once she got to grips with the group in Strand A, Eleanor recognised it as a preparation for her return to part-time work. In contrast, Alan enjoyed the intellectual stimulation gained from reading the literature and discussing issues but remained aware that it was unlikely he would successfully gain mainstream employment which involved these occupations. However he became increasingly active in other development projects within the Borough.

It was as if having been involved in one project, getting involved in others became more achievable. Thus the services gained in a more general sense, from having a larger pool of active service users to draw on for other projects. Locally this indicated a shift in the culture of service user involvement in day services, as staff and service users had a better idea of what to expect. Thus staff had the potential to benefit by getting involved as much as service users. One of the greatest barriers to improving day services has been identified as the resistance of staff to change (National Social Inclusion Programme 2008). Outcomes of a participatory action research project can therefore be about changes in knowledge as well as ways of doing things (Khanlou and Peter 2004). Macdonald and Macdonald (1999) advocated that sharing and gaining knowledge was the best justification for engaging in empowerment, as people could also be empowered in ways that did not benefit the greater good, for example people who belong to action groups based on discrimination and prejudice. These groups are oppressive in their very nature. The cycle of action and reflection is critical to challenging oppressive practice (Freire 1970). In this research specific attention was given to timing, allowing for reflection and preparations, and time for those not directly involved to make their responses.

The work of Freire (1970) was an early and continuous influence for this research. Freire has been recognised by some occupational therapists

(Cockburn and Trentham 2002, Kronenberg and Pollard 2005) as making a significant contribution to understanding the intricacies of collaborative working, but his influence is not widespread. For this research, the image of the 'leader' going to the 'people' was resonant with my experience of travelling to Alder House for the Day Services Forum (Freire 1970). Equally the importance of using the language used by the 'people' was significant, relating to a sense of ownership over the decisions made (Freire 1970). For Strand A in particular, transcribed comments about the photographs were shared each week and service users would emphasise the ways in which they described and analysed experiences. The importance of shared reflection, not only to identify key issues but also to expose oppressive practices (Freire 1970) was also highly valued. For example, Ken's approach to recruiting for Strand C involved meeting with the Trader's Post group on Monday mornings before interviewing individuals. This practice facilitated reflection on the progress of the research, which in turn led to the suggestion by service users present that the Beehive Group should be included. Although it was not perceived as being as successful as the Trader's Post, it was felt that interesting and relevant issues would be exposed by involving the group.

#### *Opportunities for representation*

The strands of the research were deliberately designed to contrast with each other in terms of methods, which created different opportunities to be involved. At the design stage, Strand C was perceived to offer less potential for user control and a different form of user involvement. This perception was based on the method used, individual interviews. However, the experience of doing Strand C indicated many different ways of involving service users, particularly in recruitment and informal discussions about the research. Silverman (2006) considered the tension between emancipatory goals of research and the value of creating knowledge, arguing that knowledge creation was of primary importance. This echoed the discussion above (Macdonald and Macdonald 1999). The difference between the strands was less marked than expected from

the design. This could be because there was an emphasis on gaining a greater understanding of user involvement rather than seeking to influence changes in the day services, an emancipatory project. However, this seems to ignore the multiple reasons why people chose to get involved and the multiple outcomes which did impact on service changes, despite the emphasis on knowledge acquisition.

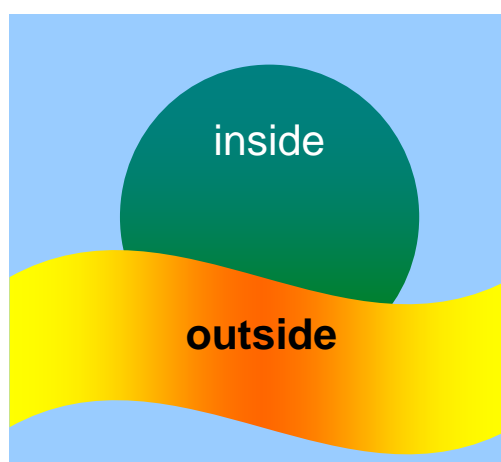
The benefits for the local day services in involving people in this way were that the findings and products of the research were directly relevant to local issues, a recognised benefit of participatory action research (Khanlou and Peter 2004, Koch and Kralik 2006). Because so many people had been involved at one time or another, there was a widespread sense of ownership, again an aim of participatory action research. For example, when I took Ken to the Larch Centre to meet Linda, the day services manager, we met a service user who had attended the Day Services Forum on no more than three occasions. Yet she recognised me and wanted to show me the poster from Strand B which was on display near the reception area. This localised and immediate impact of research is in contrast with other conventions where there is greater distance between the researched and the researchers. Beresford (2002) pointed out that the greater the distance between an experience and the interpretation or representative of it; the more likely it was that there would be misrepresentation. The poster for Strand B offered much scope for misrepresentation, especially in terms of a prescriptive approach to social and recreational activities, yet because locally people had been involved in its production to varying degrees, this was less likely to happen.

The issue of representation and misrepresentation has been used as a point of critique on service user involvement, locally and in the literature (Stickley 2006). The response in the evaluation form for the first social network day (M41) that only the 'more articulate' people tended to speak was characteristic of this view. From an occupational perspective, it is

necessary to question whether people can only be represented through verbal expression of views, as giving equal value to all occupations would highlight the number of people present, the number who stayed for the whole day and the fact that the majority present participated in everything on the programme for the day (Appendix AG). Valuing verbal expressions over and above anything would indeed favour the more articulate (Rapport 2004). However, when these verbalisations are based on direct experience it is difficult to reject their authenticity (Beresford 2002). This research suggests that the priority for involving mental health service users is to identify ways in which as many people as possible can contribute their direct experience. In strands A and B of this research, this was characterised by a dual process of people drawing on their experience of the day services as well as directly using the research methods to share these experiences.

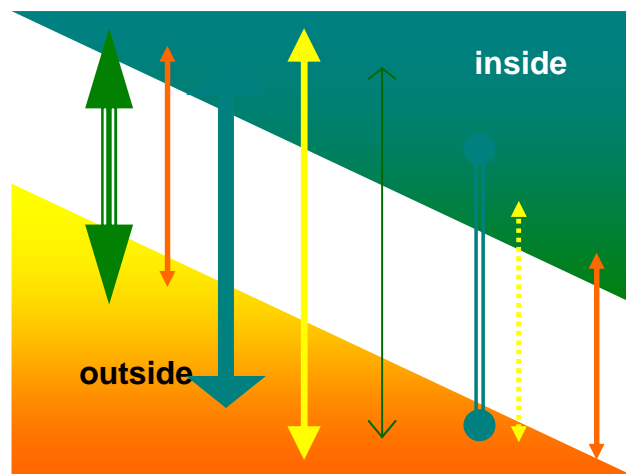
Insider-outsider view: tacit knowledge

One of the problems is being sure about which direct experiences were relevant. For this reason, tacit knowledge was recognised as being a useful concept: it was recognised that this research was dependent on an honest exchange aimed at uncovering tacit knowledge. The figures below (Figures 29, 30 and 31) have been created to explain this idea in more detail.



**Figure 29: From the outside**

In Figure 29, the *inside* shape has been created to suggest the day services setting including the services, the buildings and the people involved. *Outside*, in contrast, is intended to indicate not only myself as a researcher, but also the services, buildings and other people associated with the research. As already indicated, it was not possible or desirable to be totally detached from the setting for this research. However, there was a sense of being *outside*, especially in the early stages, as indicated in Figure 29. The *inside*, the setting, could be viewed from an outside vantage point and could not be fully appreciated from the outside. When my work began to be informed by critical ethnography, it became necessary to start investigating the aspects of the setting which could not be appreciated from the outside. This investigation involved an exchange, as indicated by the two-way arrows in Figure 30:



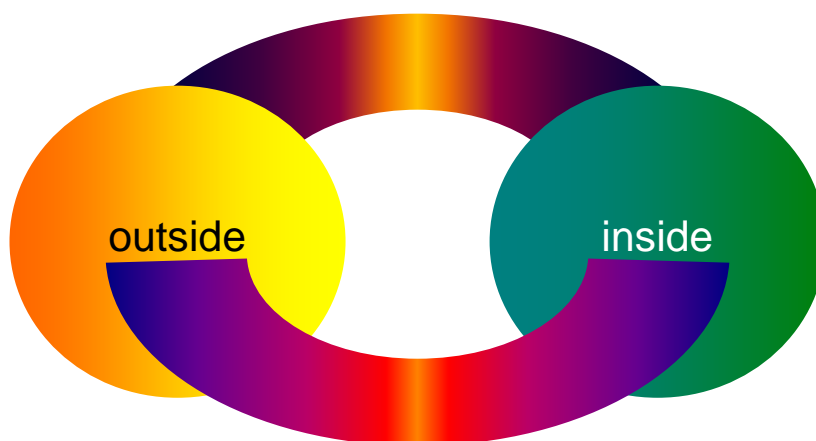
**Figure 30: Investigating the inside**

Different forms of arrows have been chosen as a simple representation of the diversity of information exchanged. There are four colours used, so that the blue and green arrows represent information coming from the inside to the outside, and the yellow and red arrows represent information coming from the outside to the inside. Information about the research (from the outside) had to be shared so that those on the inside knew what



was relevant to share, from their experience. Similarly, information about the setting (from the inside) was taken and studied outside the setting. For example, initially practical knowledge was gained about the history of the local day services. This information was related to the literature gathered for Chapter Two. In turn, the findings of Chapter Two were shared with the Day Services Forum, as a means of reflecting on the wider context for the modernisation project.

The image of information exchange in Figure 30 suggested that the information was travelling, rather than the people involved. As the strands took place, it became clear that the research was not just a case of information being passed between people. Service users and staff became researchers, and I became an insider, leading parts of the Day Services Forum and liaising with others, in order to use facilities and support service user-researchers. Figure 31 has been created to suggest this process:



**Figure 31: Outside and inside linked together**

In Figure 31, the pathway between outside and inside is wider and richer in colour. It is possible to travel between the two in different ways, perhaps changing during the journey. The links between the two seem stronger than in previous figures. The stronger links could mean it was

easier at this stage to understand and know what experience was relevant for both the project and for service development.

Tacit knowledge has been defined by Polanyi (1966) as knowing more that can be told; with a consequence that knowledge cannot always be explained in words. Furthermore, Polanyi (1966) suggested the terms “proximal” and “distal” to distinguish tacit knowledge from conscious knowledge. Proximity gave a knowledge of specific details which was usually overridden by an overall or distal knowledge, making the proximal knowledge tacit. So the service users and staff in this research knew more about the day services than they realised. It was not possible to access this knowledge from the outsider stance indicated in Figure 29, where the inside and outside were separate.

The exchange of information indicated in Figure 30 may have facilitated an exchange of tacit knowledge. For example, the experience of going to Alder House for the Day Services Forum on a regular basis not only enabled me to share some of my experiences as a researcher informally, but also enabled me to experience for myself what it was like to sit in a social lounge and listen to staff and service users speaking about the forum’s work. Playing scrabble at the social group in Elm Lodge, and spending time at the Lumos Workshop and the Traders Post group were all very direct experiences which helped my understanding of the day services. Polanyi suggested:

*“It is not by looking at things, but by dwelling in them, that we understand their joint meaning.” (1966, page 18)*

Joint meaning in this case means both the proximal and distal meaning, or knowledge. However, the point of this research was not just to find out about day services but also to involve service users in the investigation. Thus it was as necessary for them to enter the world of doing research, in order gain tacit knowledge about it, as it was for me to enter their world. As individuals, they did not need to experience each and every aspect of the research, but they did need to take at least a step outside to see what

could be involved. The service users in Strand B regarded learning to use Excel spreadsheets to manage the data as a step too far at that time, having other priorities in relation to the research. The rich, wide link between inside and outside indicated in Figure 31 made it possible for the service users to decide for themselves how to be involved in the research and develop their own tacit knowledge about research.

Polanyi (1966) used the term “*emergence*” to describe how the development of new tacit knowledge is associated with growth or breakdown. This term has been used in connection with complexity theory (Fraser and Greenhalgh 2001, Plsek and Greenhalgh 2001, Capra 2002). New emerging knowledge comes from existing structures, which in this research were the day services in terms of the people, environments and occupations, and the research structure itself. The disturbance, suggested by Capra (2002) as being essential for the emergence of new phenomena, could be seen as the modernisation agenda. Existing tacit knowledge was being threatened by new understandings of day services.

Why was tacit knowledge so important to this research? It has already been identified that it was necessary for all those involved, including myself, to travel from the inside to the outside, and vice versa, in order to know what to ask to discover each others’ tacit knowledge. It was also necessary to build and develop tacit knowledge, to ensure the research was meaningful and useful. For this research, tacit knowledge has been understood as being like a source of energy – it drives and gives meaning to both occupations and social networks. It is not possible to explain it with words, but it is possible to perceive its existence through occupation, or action, and reflection. Thus, to gain and change tacit knowledge, it is necessary to engage in occupation and reflection, as suggested by the fundamental structure of participatory action research.

### Research outcomes

There were tangible and unexpected outcomes for this research, for example the display of the photographs and research summary for Strand A in an exhibition at the University showcasing current research (Appendix AH). Adam was involved in preparing the material for the exhibition, working in partnership with Arts Centre staff. When service users had opportunities beyond the day services such as this, the idea of social inclusion became clearer. The University was a welcoming environment for service users who continued to be involved in their own research after the active phase finished. This was one example of the research having benefits beyond the local services, for the University viewed the project as an example of research in partnership with external people, as part of the strategic plan (Southern Universities Management Services 2002).

Service users and staff got involved in this research because it was meaningful to them in many different ways which were not always apparent from the outset. There was a sense in which the research was a very creative process, open to new understandings but also focused on producing something tangible which could be useful beyond the duration of the project. The way people chose to get involved increased personal and local knowledge of how people can be involved. The pursuit of knowledge has been identified as the primary goal of any research (Silverman 2006) and the exchange of knowledge as fundamental to empowerment (Macdonald and Macdonald 1999). Service user involvement in this research was characterised by the creation and exchange of knowledge, based on direct experience, thus contributing to both research aims and service development informed by service user perspectives. These multiple purposes and outcomes presented academic and ethical challenges yet were contained within an occupational perspective. Understanding of user involvement has been enriched by the occupational perspective taken in this research, with immediate benefits for the local day services.

## **Chapter twelve**

### **Conclusion and recommendations**

#### **Introduction**

This final chapter explores the conclusions drawn from the research and offers recommendations. For clarity, implications for practice, research and policy have been addressed in turn. In relation to practice, both the practice of occupational therapy and generic practice in the day services are considered. The final part of this chapter returns to the concept of tacit knowledge (discussed in Chapter Eleven) as a potentially significant knowledge used in practice, research and policy. At the very end, there is a table summarising the main recommendations (Table 12, page 344).

Because the work undertaken to lead to these conclusions and recommendations has been so detailed, an overview of the research is provided first, from my perspective as a researcher. Appendix AJ (Timeline) contains additional details of each stage. The abstract at the beginning of this thesis summarised the research briefly. At that stage, it was necessary to emphasise the structure and outcomes of the research. This account, in contrast, draws attention to the process of doing the research, to ground the conclusions and indicate the basis for the recommendations.

#### **Overview of research**

The research built on the previous study in which I was involved as a research assistant (Bryant et al 2005). Recommendations from that study were taken up by the local health and social care organisations and my active involvement in the setting resumed. Initially, in 2003, this meant being involved in setting up the Day Services Forum in collaboration with managers, staff and service users of all the day services in the Borough in 2003. Attending the forum gave me an opportunity to build links with other forum members and participate in the forum's work on the recommendations of the previous study. From the outset it was my plan

to conduct participatory research. My understanding of critical ethnography developed through study and reflection on my experiences at the forum.

In 2004, the Social Exclusion Unit report was published (Office of the Deputy Prime Minister 2004) and attention was focused on how day services could promote social inclusion of people with long-term mental health problems. This focus appears to have emerged because the day services were seen as social exclusive in nature, being based in segregated buildings and mainly offering group-based programmes. Thus there was perceived to be a need for reform. Locally this translated into a new focus for the work of the forum. It was agreed that my research would concentrate on social networking as a means of achieving social inclusion, and the first social networks day took place. From here, I engaged in more intensive consultation with the Day Services Forum and service users in other meetings, and began to develop the strands of the research.

The forum continued throughout the research and provided a key and continual point of contact. Recruitment and reporting on the progress of the strands took place there. There were some people who chose to get involved in many different aspects of the research and others whose main contact was via the forum. The three strands offered insights into the use of specific places (Strand A), social and recreational activities beyond the day services (Strand B) and user-led social groups (Strand C). There was a separate research process for each of these strands, yet they also formed part of the overall research. Because they related directly to the work of the day services, this seemed to be understood by all involved.

At the end of Strand C in 2007, I left the forum to concentrate on analysing and writing up the findings for the last year of the research. This final stage was not participatory, although my contact with Geraldine, the day services manager and some of the service users continued.

Geraldine updated me on developments in the day services. Alan and Adam were involved in several presentations of the research, and Alan maintained regular contact because of his interest in the research. Both belonged to a service user research group which we had set up at the University in Spring 2007, in order to create more opportunities for service users to become involved in research. This contact gave opportunities to test the credibility of the findings as they emerged in the final stage of data analysis. This was important as there appeared to be no precedent for the process of selection used to sample from the extensive data gathered. Principles of constant comparative analysis (Silverman 2000) were used to inform the process and the primary research topic remained a focus throughout. Using NVivo facilitated analysis of complex data. All this counterbalanced the limitations of conducting an indepth analysis away from the field and without involving service users. This stage could have been participatory, but withdrawing completely from the setting signalled that attention had shifted to the academic task. So from 2007-8, I was immersed in the data I had gathered and investigating different ways of understanding what had taken place. It is my belief that these understandings will continue to evolve, and so the conclusions and recommendations presented here will also evolve in the future.

## **Practice**

### **Research methods**

It was suggested in Chapter Nine that at the times during the research, it seemed as if the end of day services was inevitable. In the local setting, at the end of the research, the proposed configuration of services encompassed user-led groups, a safe space at Elm Lodge and an intensive treatment team staffed mainly by occupational therapists. This configuration partly reflected the findings of the research, but also had to follow commissioning guidelines in order to secure funding (Lingwood 2005a and 2005b, Murkin 2006). There will always be a delay before research outcomes can impact on the policies which inform

commissioning guidelines. However, the methodologies used in this research meant that some outcomes could impact directly on practice. The advantages of participatory action research for directly informing practice are recognised and confirmed by this research (Cockburn and Trentham 2002, Koch and Kralik 2006, Wilcock 2006). The chosen topic, social networking, was meaningful to service users and a concern for staff seeking to develop the services. Everyone had the opportunity to engage with the process of investigating this topic, or evaluating the research outcomes, drawing on their knowledge and experience. The methods of the research mirrored and developed what was already happening in the day services, by using and creating social networks and meaningful occupational opportunities, in recognisable occupational forms.

Thus there was a direct link between the research, service users and staff. But service development was subject to other pressures. The work in the day services was in the context of funding restrictions, or “disinvestment”, and competitive tendering (Beecham 2005, National Social Inclusion Programme 2008). The use of critical ethnography empowered me as a researcher to question the relative priorities given to service user views, funding issues and political imperatives. I was not alone in questioning these priorities in any sense, but the research acted as a vehicle for those who wished to safely explore alternative interpretations of what was possible. A vulnerable aspect of using participatory action research in service development is that the research could be used as a vehicle, for identifying practical strategies for implementing policies, regardless of the significance or acceptability of those policies. **Critical ethnography is recommended, to foster questioning about not only policies but also practices, which in this research were the focus for service development.**



### **Bonding and bridging in mental health day services**

In relation to day services, the practices which were the particular focus for modernisation were the use of segregated buildings and collective approaches to recovery (Repper and Perkins 2003, Office of the Deputy Prime Minister 2004, Spencer 2004, Bates 2005, Lingwood 2005a and 2005b). This research indicated that the apparent rejection of these practices was not supported by many service users or staff. There was widespread concern as to how people with long-term mental health problems would access support from each other and occupations appropriate to their changing capacities. The history of day services (Chapter Two) indicated an established history in the UK of providing social and occupational opportunities which were valued by service users. This research indicated that service users could build supportive social networks through shared occupations, which in turn enabled them to make better use not only of community resources but also the other mental health services. They supported each other in crisis management and developed skills which they could transfer to community life.

Locally, people were struggling to sustain these aspects of day services and they were not obviously provided in other contexts. The concepts of bonding and bridging social capital (Field 2003, Almedon 2005) were explored in the Day Services Forum, discussions with Geraldine and the Strand B research group members. **Modernisation of day services has to sustain a commitment to bonding social capital as well as bridging social capital (Field 2003, Almedon 2005). The bonding aspect of day services enables service users to support each other and build social networks directly related to their experience and survival of services. Without this, for many people, it is difficult to develop bridging social capital which enables them to make use of mainstream community resources.**

### **Recognising long-term needs**

Bringing service users together under one roof was not seen as totally undesirable (Lingwood 2005a, Bates 2007) but there seemed to be an overwhelming concern not to create long-term dependency on services despite the long-term nature of many mental health problems (Spencer 2004). There did not appear to be much recognition of the many possibilities of practice which fell between trapping people in institutional life, and people not needing services at all. This research captured some of those possibilities of practice, pinpointing the work that took place in the social lounge (Strand A), in the community (Strand B) and in user-led groups (Strand C). However, the practice and work in question was that of the service users, supported and advised by the staff. The service users recognised the importance of the work of staff, but wanted control of the process of managing their own lives. The modernisation project appeared to threaten this control, by removing opportunities for service users to meet together and learn from each other in informal settings and by emphasising mainstream activities without appearing to systematically address the problems created by stigma and discrimination (Sayce 2000, Thornicroft 2006).

There also appeared to be unquestioned assumptions about the occupations which promoted social inclusion and well-being, characterised by paid employment or volunteering, physical activity, healthy eating and education. These assumptions reflected public health priorities, yet did not reflect the many varied occupations which service users valued (Strand B). A key issue for service users was whether they needed to disclose their mental health problem when engaging in a new occupation and if they did, whether disclosure was likely to cause a hostile or unhelpful response. The Oasis group (evaluated in Strand B) and the user-led groups in Strand C were particularly valued because it was not necessary to hide service user status. The groups actively engaged with the challenge of surviving long-term use of mental health services. Their success depended on fostering a sense of belonging and

acceptance. Dependence on each other was a desirable aspect. Yet this dependence was partly built on a basis of sitting, talking and drinking or eating together, an occupational and social environment which might appear to be very institutional and seen to be socially exclusive.

How can service providers and service users work together then, to configure services which are meaningful and helpful to service users, yet avoid being an institutional trap? What is the difference between a service user sitting with other service users and drinking tea in a café, and sitting with other service users and drinking tea in a social lounge? Service users recognised that one of the major differences was that they had to pay much more for a hot drink in a café, and it was much more difficult to linger in a café on a regular basis and know that someone familiar would be there. At times, these considerations could be very important. One difficulty with the impact of the modernisation locally was that it seemed to be very difficult to respond quickly to changing needs when services were dispersed and spasmodic. Service users were discouraged from supporting each other (Strands A and C) and encouraged to use professional services such as their care co-ordinator or the crisis team. Yet this undermined their control of the situation and denied them access to a rich resource of service user experience of services. Day services have been consistently underfunded (Chapter Two) and so it would seem to make sense to make use of every resource available, including the service users as a human resource for each other, if they chose to be.

Occupational therapists, as mental health professionals, have emphasised their use of the client-centred approach and the recovery model. Both are characterised by an emphasis on service user priorities, power sharing and recognising diverse and changing needs (Repper and Perkins 2003, College of Occupational Therapists 2006b, Sumsion 2007). However, there are also pressures to offer evidenced-based services which are cost-effective and time-limited. There are limited resources for community mental health services of any description and so inevitably

staff will act as gatekeepers (Pettican and Bryant 2007). **Imposing constraints on services purely on economic grounds or based on evidence which has only limited relevance to the service users is questionable. This research provides very clear evidence of what day service users with long-term mental health problems value. It is not a simple recipe, but complex opportunities to belong, to receive services which adapt to changing needs and to have control of the process whenever possible.**

### **Service design and delivery**

Using the dimensions of *form, function and meaning* to underpin service design would enable sustained attention to diverse and complex needs. This attention needs to take place at both organisational and personal level, enabling consideration of needs specific to gender, culture, age as well as for each person in their recovery journey. The occupational forms of the services should be recognisable, yet offer the potential for new experiences. The services should be responsive to individual and collective agendas, yet also be fixed in some aspects, so people can rely on them and feel safe in engaging with them. The functions should be explicit, so that people understand what the services are hoping to achieve and how. Dialogue about these explicit functions will help uncover implicit and tacit functions perceived by service users and service providers. Identifying specific functions of services helps service users take control of which services they require. Finally, it is important that leaders or service providers recognise that the meaning of the service received is in constant flux as the service is experienced. Collective occupation and social contact facilitates awareness of meaning, which can help and hinder engagement. Progress and difficulties can be explored through having opportunities to discuss and reflect on the changing meanings of occupational and social experiences. It is likely that these dimensions are already features of day services, but have not been widely recognised or valued. **The dimensions of *form, function and meaning* could be used to inform the future evaluation,**

**design and development of services, based on a more detailed understanding of what is already happening.**

## **Research**

### **An occupational perspective on participatory action research**

Using these dimensions, of *form, function and meaning*, to capture what is happening and what could change, reflects the occupational perspective which was so important to this research. What has it meant to take an occupational perspective? There are several possibilities. Taking an occupational perspective involves thinking about design, which could be the design of services or the design of the research, or both, as in the case of this research. The topic of the research, social networking, was concerned with what people did and where they did it. The design of the research was primarily concerned with creating opportunities for people to participate, but through doing or occupation, which was given equal value to verbal contributions. Similarly, the person-environment-occupation framework (Law et al 1996) formed the basic structure for this research, simultaneously facilitating communication about the design and about the topic. **The occupational perspective seemed to make it possible to ground the research on recognisable but complex experiences. Most occupational therapy research seems to focus on occupation as a topic for research, missing an opportunity to take an occupational perspective to the design of the research.**

This issue has been recognised in relation to participatory action research, which is seen as the method of choice in relation to research informed by the principles of occupational justice (Cockburn and Trentham 2002, Kronenberg et al 2005, Townsend and Whiteford 2005, Wilcock 2006). However, this recognition is relatively recent and has not been accompanied by detailed accounts of how this has worked. This research, with the occupational perspective sustained throughout, offers such an account. Beyond the occupational therapy literature, it is as if the detail of what people do in participatory action research is overshadowed

by the outcomes achieved by their participation. The nature of their participation is not always specified and there does not appear to be evidence of occupational justice in any form being used to inform the design and implementation of research. This is not surprising as the concept of occupational justice does not appear to have a significant presence beyond occupational therapy and occupational science.

The detail, of how people participate in terms of their occupations or what they do in research, would enhance understanding of the potential for participatory action research in terms of service user involvement. Many occupational therapists have very specific expertise in working with mental health service users to facilitate participation: to some extent this is based on an understanding of barriers to participation and how occupations can be adapted to overcome these barriers (Creek 2003, College of Occupational Therapists 2006b). Using this expertise in research could benefit service users and service providers, as has happened in this research. From an occupational perspective, this suggested the experience of transformation through occupation. **Further research could focus very specifically on service users who have been involved in research, to identify what occupations were involved and what transformations were experienced.**

The experience of transformation applied equally to me, as researcher. One aspect which particularly interested me was the process of the research. Although the research protocol gave specific details of what should take place, the participatory nature of the research meant that the exact occupational forms, functions and meanings were negotiated as it progressed. Arts-based metaphors, rather than scientific procedures, seem most helpful for understanding this. Madison (2005) suggested a metaphor of performance for understanding the role of critical ethnographer. Thomas (1993) distinguishes between 'onstage rhetoric' and 'backstage action', especially in relation to analysis of data. This dimension of the research could be explored further, systematically

investigating what a critical ethnographer does and thinks about to take a project forward. For me, a key aspect pervading all my actions was an increasing understanding of the nature of alienation in relation to occupation, creativity and social life (Bryant 2008). This understanding was particularly useful in terms of thinking about ownership and belonging, and at what points these aspects were transformed through the occupations of the research. For example, the moment in Strand B when Angela suggested that the checklist should be distributed to all local service users. This signalled to me that the group were taking control of the research and owning their part of it.

On another occasion, I was struck by one forum meeting where the person leading the meeting split the group into three according to role. The leadership of the service user group was allocated to me. I was very unhappy about this, believing it undermined the service users, suggesting they were unable to lead the group themselves. I also questioned my presence in the group, as I was not a mental health day service user. I discussed this with the service users present, who were dismissive of my concerns and proposed that my leadership would be helpful. They were impatient to get started on the discussion. At this point, quite unexpectedly, my hearing aid battery ran out and I did not have a spare with me. Sharing this with the group had an interesting effect. Three substitute leaders emerged, each taking care to ensure I could hear the key points, which benefited the whole group. Most people in the group were aware of the irony that I needed support to participate as much as anyone else, although I was not a day service user. Rapport (2003) identified irony as being fundamentally important for a critical response to assumptions in social life, imagining alternatives and a means of transforming the self.

It was also ironic that Strand C, although set up to contrast with the other strands in terms of user involvement, actually offered another perspective. Service users were not involved in collecting and analysing

the data, but took an active part in recruiting each other for interviews and in taking the findings forward for their own benefit. This suggested an emancipatory aspect to the research, although this was not the primary intention. Silverman (2006) suggested that the primary judgement which should be applied to qualitative research should not be about the quality of the relationships between those involved or the effects of the research, but the validity of the knowledge which is created. This is particularly important when considering the implications of this research for policy development.

## **Policy**

### **Social inclusion and a safe place**

At the Day Services Forum, policy was regularly discussed. To some extent those present saw the forum and this research as a way of influencing policy not only locally, but nationally. In the early stages, the policies impacting on day services were largely about principles rather than specific strategies, and were therefore subject to local interpretation. Examples from other areas emerged as modernisation progressed and the work in the Borough was used as an example of what could be achieved, particularly in relation to Capital Volunteering. As identified in Chapters One and Two, the arguments used to support the promotion of dispersed day services rather than day centres appear to derive from the belief in the importance of normalisation, or living an ordinary life, also applying to other groups such as people with learning disabilities (Clark 2001). As a principle, there is no doubt that the right to participate in society and be included should be applied to people with long-term mental health problems as much as any other group. Yet this right is compromised by the power of the Mental Health Acts, where people can be prevented from participating and being included through forcible removal and segregation. The fluctuating and sometimes antisocial nature of mental health problems also compromises rights to be included. Many service users have experiences of prolonged uncertainty.



At the time of the research, political energies appeared to polarise mental health service provision by emphasising protection from harm at one end and social inclusion at the other. The long and complicated journey between the two polarities did not appear to be adequately addressed in policy. Where political energies were directed, funds followed. As a result, for day services, there was evidence of “disinvestment” (National Social Inclusion Programme 2008), or cuts in resources. This impacted on the people who fell between the two extremes, having no need for legal or medical containment and yet not being able to realistically fulfil the vision of social inclusion associated with paid employment. Yet they remained dependent on services, such as mental health day services, because of their lengthy journey to recovery, which is not always in one direction and prolonged for multiple and complex reasons.

What has this research offered then, to inform policy in relation to these mental health day service users? It must not be forgotten that the messages of this research are strengthened by the multiple methods used to generate them. **The concluding message from Strand A was that a safe place was fundamental in enabling service users to become involved in other aspects of day services.** Characteristics of this safe place included informal social contact between service users which enabled them not only to regain social skills and develop social networks, but also to learn about how to survive the systems associated with mental health services. The safe place also had very specific physical aspects, resembling a refuge which did not make demands on service users to conceal their mental health problems. It is possible that these safe places are as much about care and opportunity as safety. As stated previously, these messages were confirmed by the findings of other researchers in human geography. The use of photography to gather data enabled service users to become involved in the design of the strand, the implementation of it and the initial evaluation of its findings. Thus, for policy purposes, this represented strong evidence of service user perspectives on mental health day services.

### **Social inclusion and participation**

Similarly, the message from Strand B for day services policy has been strengthened by the involvement of service users at every stage. Strand B highlighted their knowledge as a resource for promoting social inclusion: knowledge which indicated a very diverse and personal approach to social and recreational activities in the community. It seems appropriate to conclude that it is not enough to simply recommend that people become involved in mainstream social and recreational or leisure activities for social inclusion. Occupational therapists in particular need to guard against being seen to prescribe these activities as a means of promoting recovery and inclusion. Strand B suggested that many service users are well aware of what opportunities there are in their local communities – between them they have a rich knowledge. Yet there are still barriers to using that knowledge, associated with the difficulty in belonging. This difficulty can arise because of social rejection by others, because of the lack of opportunities for meaningful occupations repeated over time, or because of an internal sense of alienation arising from mental health problems (Bryant 2008). **Joining a social group, or visiting a museum or a bowling alley can be compromised by any or all of these difficulties, and policy developments should emphasise the skilled work undertaken to support service users in overcoming these difficulties. The skills required perhaps deserve as much emphasis as broader issues such as social inclusion (Hope 2004), and these skills should be recognised in service users as well as staff.**

### **User-led groups**

Strand C focused on service users using each other as a resource in user-led groups. From a policy perspective, the strand indicated that it is essential to support these groups not just because service users find them helpful. **Support is required to enable the groups to thrive, encompassing practical and organisational support as much as financial. In relationship to leadership of these groups, it has to be**

**recognised that the role presents the same challenges as leadership of any group and therefore service users who take up leadership roles require particular support and possibly training.** Fortunately, there is widespread expertise in groupwork within mental health services, both in terms of leadership and membership, which means that this development of day services could be well-resourced in human terms.

### **Involving service users, democracy and occupation**

Issues of leadership and membership, or ownership and belonging, were significant considerations in successfully involving people in this research. But it was not a simple process and required ongoing negotiation. Service user involvement was viewed as a democratic process, and as such, raised questions about representation, equality, access and freedom of speech. Initially, it was necessary to create something that people could belong to. The idea of a forum had been recommended in the report based on the 2002 review (McKay et al 2003) and was taken up by Geraldine, the day services development manager. The forum acted as a base for creating other opportunities. My own concern with creating occupational opportunities, or paying very specific attention to what people were doing and could do, was influential. In retrospect, it seemed that I believed that occupation took democracy beyond words or, that occupation put meaning and passion to the words spoken in the forum. This seemed to be a case of putting the words into action. In turn, the actions or occupations acted as a focus for reflection, discussion and more words. Thus the forum had the potential to be democratic: by bringing direct action and experience into the forum it was possible to add weight to the words. **From this experience it is suggested that policies concerned with service user involvement in mental health services should pay greater attention to issues of democracy, and in particular, how shared occupations can promote participation. If user involvement resembles a democratic act in any way, then all those involved need to explore how people can represent themselves freely and in a way that is meaningful and**

**accessible to others. A focus on shared occupations can enable people to negotiate access, become more aware of meanings and generate direct experience on which to base recommendations.**

### **Final comments**

For service user involvement, it has to be remembered that their tacit knowledge, of surviving mental health problems and mental health service use, may not be accessible through verbal consultation in settings which do not directly relate to their experience. They may not know how their knowledge and experience is relevant, because it is tacit. In this research, the experience of directly engaging with service users in their setting, using innovative and creative research methods, has indicated that service users have valuable and important knowledge to share which could benefit everyone involved in mental health day services. However, the methods in themselves were not the only reason for the success in eliciting the service users' tacit knowledge. Critical to the process was enabling them to own as much of the research process as was practically possible, so that elements of the research could belong to them. This in turn required the creation of a research and development community to which service users and staff could belong to. These issues, of community, ownership and belonging, are fundamental to the development process (Cochran 1977, Capra 2002). It is suggested that in relation to user involvement, direct democracy (Held 2006) is the preferred model. This research confirms this view. Being based on direct experience, direct democracy offers the means for actively engaging with tacit knowledge, harnessing it and moving it forward for the greater good. Conversely, it seems quite possible that if tacit knowledge is not actively challenged and engaged with, developments will favour those already in power who are seeking personal, not collective, gain.

However, the direct experience of people with long-term mental health problems is not always easy to listen to or understand. It can be difficult to understand why people appear to linger in situations which, from the

outside, appear to be unappealing. However, service users are experts on their own experience yet because this is often tacit knowledge, they cannot always articulate their expertise. It is so embedded in their existence they are not aware of all the complex factors which shape it. This research suggests that through occupation, or action, and reflection, it is possible to bring this tacit knowledge to the surface. It is not enough just to reflect on things that have happened in the past, because tacit knowledge is always forming and reforming within the complex processes of development and sustaining that go on in life (Capra 2002). Therefore it is essential to continually reflect and act in a cycle to understand those processes. It is also important to reflect collectively, not in isolation, because of the social context for many mental health services, generating shared experiences.

There is emerging interest in tacit knowledge in relation to user-centred design in other fields (for example, Still 2007). Accessing tacit knowledge through occupation can be understood as doing something, synthesising the sensory and motor experiences, matching them with what is known already, and assessing the new experience. The most disappointing and potentially dangerous situations are where people make judgements without even seeing or trying for themselves the situation they have power over. From this perspective, occupation is fundamental to accessing tacit knowledge, of understanding what is really happening. It is possible to look through a window or listen to an explanation, but this is inferior to experiencing elements of the situation personally. Polanyi's (1966) understanding of tacit knowledge suggested it is not necessary to experience every element, and complexity theory would suggest that if an experience was repeated in as much detail as possible it would still be different (Pslek and Greenhalgh 2001).

Occupation is also the outcome by which we judge recovery and inclusion, yet occupation is so mundane and everyday, so tacit, that the judgement is hindered. Some occupations thus become more valued than

others – full-time paid work, for instance. Those occupations which are so familiar, so tacit, to us, are also the same to service users. If someone has been very ill, one sign of their recovery is that they are able to get up, get dressed and fix themselves a snack. At what point in their recovery does this become tacit? At what point does someone say, “I can do that now, let’s move on to the next thing”? The reality of long term mental health problems is that some days it will be easy to get up, get dressed and make a snack, meaning the possibility of doing other things is more likely. On other days it will be very difficult indeed, if not impossible. People cannot always rely on being able to do the things they need to do.

For this research, it was not possible to make assumptions about what could be achieved, not just because of the prevalence of mental health problems in the people involved, but also because of the wider context, which potentially imposed as many restrictions and unexpected barriers. However, it was believed that by using a simple theoretical structure, with tangible research products and outcomes, it would be possible to overcome these barriers and restrictions. This approach resembled the artistic/holistic research paradigm proposed by Fish (1998), who recognised that products of a creative process could have great meaning not only for those involved in its production but also for others. Service users have spoken about what is important to them about day services. But they have also demonstrated what is important, through doing things together. I have been privileged to do things with them, and so I have accessed their tacit knowledge, and they have accessed mine, as a researcher. Together we have created new understandings.

In particular, we have understood that it is possible to enter each others’ worlds, overcoming alienation through belonging and creative occupations. It has also been possible to access tacit knowledge through occupational engagement and critical reflective dialogue. As a result of this process, new possibilities have emerged. Underlying the process have been three key beliefs. Firstly, that it was possible to communicate

meaningfully about the research with everyone involved, through occupation and critical dialogue. Secondly, that honesty about the functions of the research promoted critical dialogue and reflection. Finally, that every task, skill and activity could potentially contribute to the research process in a positive way and thus has equal value, regardless of who initiated it.

## **Table 12: Summary of main recommendations**

### *Recommendations for practice*

Mental health day services should be committed to sustaining bonding social capital as well as bridging social capital, enabling service users to support each other and build social networks directly related to their experience and survival of services (page 329).

Development of services should take into account the evidence of this research, where long-term service users valued opportunities to belong, services which adapt to changing needs and control of the process whenever possible (page 331).

The dimensions of *form, function and meaning* should be understood and valued to underpin service delivery and design (page 332).

### *Recommendations for research*

Critical ethnography should be used alongside participatory action research to foster a critical response to policies and practices (page 328).

Knowledge of occupation, in its broadest sense, should be used to enhance understanding of the potential for participatory action research in terms of service user involvement (pages 333-4).

### *Recommendations for policy*

Policies designed to improve the care and opportunities for mental health service users living in the community should take into account the importance of a safe place, where people are not required to conceal their mental health problems (page 337).

Policies designed to promote the social inclusion of mental health service users should recognise and use service users' practical knowledge of social and recreational activities and the barriers to participation (page 338).

Policies designed to promote user-led groups should take into account the possibility of an ongoing and constantly evolving need for support from statutory and non-statutory services, in practical, organisational and economic terms (page 338).

Policies promoting mental health service user involvement should be based on an increased awareness of how occupation can be used to express knowledge and experiences of services, which would strengthen the democratic process of involvement (page 339).



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<http://www.keepournhspublic.com/pdf/Cutscompendium.pdf> (accessed 18/01/08).

[www.which.magazine.co.uk](http://www.which.magazine.co.uk) (accessed 05/03/08).



## An occupational perspective *on* user involvement *in* mental health day services

Wendy Bryant  
Brunel University  
July 2005  
*wendy.bryant@brunel.ac.uk*

### Participatory action research

This research seeks to involve people in gathering information to influence the services they receive. Participation in this research means being actively involved. To date this has meant participating in discussions via meetings, phone calls and letters. Some of these discussions have been triggered by activities, for example, speed networking at a themed action day in July 2004. The researcher's role has been to initiate, facilitate and sustain the dialogue between those involved, to develop a focus for the research, which consists of three strands.

Robson C (2002) *Real World Research*. 2<sup>nd</sup> Edition. Oxford, Blackwell Publishers.

### Partnerships

Bryant W, Craik C, McKay EA (2005) Perspectives of mental health day and accommodation services for people with enduring mental illness. *Journal of Mental Health* 14(2): 109-120

In 2002, the researcher was part of an independent team of occupational therapists funded to review day services in [borough name]. The review has led to a range of service developments, overseen by a forum of service users, staff, managers, carers and other interested local organisations. Since it started in July 2003, the researcher has been a member of the forum and contributes to the development of day services as a whole in the area, placing the research in the local context.

## User involvement

Who are users? And why involve them? For this research, users are people who use mental health services as a means of support for living with severe mental illness.

The people involved in this research live in the community, and attend sessions organised by day services, either for a limited period of recovery, or for a longer period over years. Their experience of services is not always positive.

Recent government policy initiatives have highlighted that involving users in research is an important means of improving services.

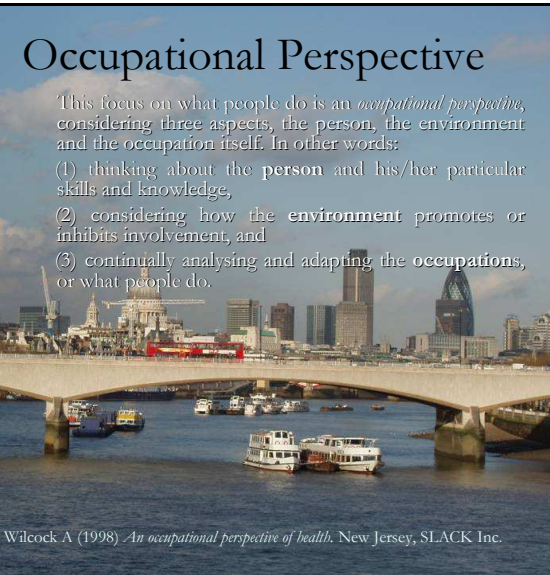
Beresford P. (2002) User involvement in research and evaluation: liberation or regulation? *Social Policy & Society* 1(2): 95-105

## Occupational Perspective

But how do you involve users? What can they do? The researcher, being an occupational therapist, is interested in what people do when they are actively involved in the process of research.

This focus on what people do is an *occupational perspective*, considering three aspects, the person, the environment and the occupation itself. In other words:


- (1) thinking about the **person** and his/her particular skills and knowledge,
- (2) considering how the **environment** promotes or inhibits involvement, and
- (3) continually analysing and adapting the **occupations**, or what people do.




Wilcock A (1998) *An occupational perspective of health*. New Jersey, SLACK Inc.

## Mental health day services

Some people live with severe mental illness for much of their adult lives, and day services have evolved to enable them to live at home whilst still being able to access support and therapy. Recently, there has been a strong emphasis on ensuring services offered are tailored to individual needs, rather than the person having to fit in with what is offered. There is currently a tension in day services in the UK between building-based services and individualised, community-based programmes. Some users in this research are very interested in exploring the benefits of building-based services, for example in Strand A.



Office of the Deputy Prime Minister (2004). *Mental health and social exclusion. Social exclusion unit report summary*. London, Office of the Deputy Prime Minister.



## Strand A: Autumn 2005

Are social networks being formed and sustained in the Social Lounge?

An eight week closed research group will use photography to gather information on how the Social Lounge at one day service resource centre is being used to make and keep friendships and social contacts. The information will be used to inform discussion on how social networks are promoted by environmental factors. The researcher will focus on how a creative, nonverbal approach to data collection can be used to involve users in research.



## Strand B: Spring 2006

How accessible are local social and recreational activities to people with severe mental illness?

An eight week closed research group of service users will develop a framework for rating local community activities, and then use it when participating in selected activities. The findings will be made available via local user newsletters and information sources. The researcher will be focusing on how using a framework involves users in the research process.



## Strand C: Summer 2006

What do people do to initiate and sustain a user-led social group?

Members of a social group, led by users for users, will be interviewed by an external interviewer, a playwright. They will be asked to give their story or narrative of being in the group. The interviews will be analysed to identify core themes arising from membership of this type of group. The themes could be synthesised by the playwright into a play to be performed locally. The researcher will contrast user involvement in this design with the other strands.

**Appendix B**  
**Ethics approval, Brunel University**

**Brunel**  
**UNIVERSITY**  
WEST LONDON

School of Health Sciences and  
Social Care

**Research Ethics Committee**

School of Health Sciences and  
Social Care  
Brunel University, Osterley Ca  
Borough Road, Isleworth,  
Middlesex TW7 5DU  
Telephone: +44 (0)20 8891 0  
Fax: +44 (0)20 8891 8247  
Web www.brunel.ac.uk

22 June 200.

**Proposer:** Mrs Wendy Bryant

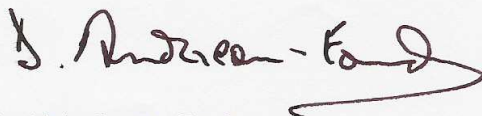
**Title:** User involvement in mental health day services

The Chair of the School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**NB:** Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.



David Anderson-Ford  
Chair, Research Ethics Committee  
School of Health Sciences and Social Care

Ethics approval, Local Research Ethics Committee

<p><b>Local Research Ethics Committee</b></p> <p><b>LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION</b></p>		<p><b>Date of issue:</b></p> <p>25 October 2005</p>	
<p><i>For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.</i></p>			
<p><b>REC reference number:</b></p> <p>05/Q0407/63</p>	<p><b>Issue number:</b></p> <p>1</p>		
<p><b>Chief Investigator:</b></p> <p>Mrs Wendy Bryant</p>			
<p><b>Full title of study:</b></p> <p>An occupational perspective on user involvement in mental health day services</p>			
<p><i>This study was given a favourable ethical opinion by [redacted] Local Research Ethics Committee on 21 October 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.</i></p>			
<p><b>Principal Investigator</b></p> <p>Mrs Wendy Bryant</p>	<p><b>Post</b></p> <p>Lecturer in Occupational Therapy</p>	<p><b>Research site</b></p> <p>[redacted]</p>	<p><b>Site assessor</b></p> <p>[redacted]</p>
		<p><b>Date of favourable opinion for this site</b></p> <p>25/10/2005</p>	<p><b>Notes <sup>(1)</sup></b></p>
<p>Approved by the Chair on behalf of the REC:</p> <p>[Signature] ..... (Signature of Chair/Administrator)</p> <p>(delete as applicable)</p> <p>[Signature] ..... (Name)</p>			

**User involvement in mental health day services**

**Participant information sheet: Strand A/The Social Lounge**

**What is this research all about?** Finding out how people can be involved in developing social networks in mental health day services. People have social networks for support and enjoyable times with other people. The emphasis on what people do is important for this research. For that reason if you decide to join in, discussing what you do in the project could be an important part of it. Strand A of this research involves exploring how a place can be used to make and keep social networks.

**Who is in charge of the research?** Wendy Bryant, a student at Brunel University, will be co-ordinating the research for her PhD. She has two supervisors and also works closely with the Day Services Forum and service users in [name of Borough], who have contributed to the development of this research.

**What am I expected to do as a participant?** If you decide to take part in this strand, you can negotiate what you do with the research group set up for Strand A. We will do our best to involve you in a way that suits you.

You will be required to join the research group, which will meet for 8 sessions at [Elm Lodge]. The research group will be meeting eight times, each session lasting for an hour and a half. A member of staff from [Elm Lodge] will also be a member of the group, which will be led by Wendy Bryant.

This group will be using photography to capture how the social lounge is used to make and keep social networks. This does not mean you have to have your photograph taken – you could be involved in any part of it from deciding what to take photos of, or taking the photographs. Your opinions in sorting and analysing the photographs will be particularly valued. You might also want to be involved in presenting the results once the research is complete.

**What do I do if I'm not sure about the research as it progresses, or have questions to ask?** Let someone in the research group know. Your concerns and questions about the research are important: they can help to make the research work for everybody involved.

**What if I change my mind about being involved, or I have to drop out for other reasons?** You can change your mind at any time or drop out if you need or want to. If you want to rejoin, then you will need to contact one of the research team to find out what's happening. You don't have to let us know, but there is a slip provided on the consent form that you could send to us if you want to drop out of the research.

Whatever you choose to do, it will have no impact on the day services you receive. Your identity will not be revealed, unless you specifically request this. For example, you might want to take part in presenting the research to a wider audience. Information such as your contact details and written records of the

**Appendix D**  
**Information sheet, Strand A**

research, will be stored securely by Wendy Bryant at the University, and destroyed when the research is finished.

**What are the benefits to me as a participant?** Involving people who use services is thought to be one of the best ways of designing services which are helpful and benefit more people. So you could be making a difference to the services you and other people receive. There are no other specific benefits from the research to you.

**What will happen to my contribution?** Your contribution will become part of the research findings, and these will be presented locally. Beyond [name of Borough], there are many other mental health day services and so it is hoped that the findings will be shared at conferences and published. Wendy also will be writing up the findings for her PhD thesis, which will be available at Brunel University.

Thank you for your interest in this research.

For further information contact

Wendy Bryant  
Brunel University  
School of Health Sciences and Social Care  
[contact details]

**User involvement in mental health day services**

**Participant information sheet:**  
**Strand B/The BITRA (Borough Index to Recreational Activities)**

**What is this research all about?** Finding out how people can be involved in developing social networks in mental health day services. People have social networks for support and enjoyable times with other people. The emphasis on what people do is important for this research. For that reason if you decide to join in, discussing what you do in the project could be an important part of it. Strand B of this research involves exploring whether activities in the community can make social contact easier.

**Who is in charge of the research?** Wendy Bryant, a student at Brunel University, will be co-ordinating the research for her PhD. She has two supervisors and also works closely with the Day Services Forum and service users in [name of Borough], who have contributed to the development of this research.

**What am I expected to do as a participant?** If you decide to take part in this strand, you can negotiate what you do with the research group set up for Strand B. We will do our best to involve you in a way that suits you.

This research aims to find out what's involved in making social contact in community activities. You will be required to join the research group, which will meet for 8 sessions at [Alder] House. The research group will be meeting eight times, each session lasting for an hour and a half. A member of staff from [Alder] House will also be a member of the group, which will be led by Wendy Bryant.

With the group, you will be using the BITRA (Borough Index to Recreational Activities) to identify social activities. You will have the opportunity to visit and rate at least one activity in your own time. With the rest of the group you will agree a framework for rating the activities before visiting them and then report back in the next meeting. As a group, you will be involved in drawing final conclusions about the research for this strand. You might also want to be involved in presenting the results once the research is complete.

[Name of Borough] Area Voluntary Services have offered to meet the cost of the social activities where applicable and practical support may be available from the Capital Volunteering Scheme if required.

**What do I do if I'm not sure about the research as it progresses, or have questions to ask?** Let someone in the research group know. Your concerns and questions about the research are important: they can help to make the research work for everybody involved.

**What if I change my mind about being involved, or I have to drop out for other reasons?** You can change your mind at any time or drop out if you need or want to. If you want to rejoin, then you will need to contact one of the research team to find out what's happening. You don't have to let us know, but there is a



**Appendix E**  
**Information sheet, Strand B**

slip provided on the consent form that you could send to us if you want to drop out of the research.

Whatever you choose to do, it will have no impact on the day services you receive. Your identity will not be revealed, unless you specifically request this. For example, you might want to take part in presenting the research to a wider audience. Information such as your contact details and written records of the research, will be stored securely by Wendy Bryant at the University, and destroyed when the research is finished.

**What are the benefits to me as a participant?** Involving people who use services is thought to be one of the best ways of designing services which are helpful and benefit more people. So you could be making a difference to the services you and other people receive. There are no other specific benefits from the research to you.

**What will happen to my contribution?** Your contribution will become part of the research findings, and these will be presented locally. Beyond [name of Borough], there are many other mental health day services and so it is hoped that the findings will be shared at conferences and published. Wendy also will be writing up the findings for her PhD thesis, which will be available at Brunel University.

Thank you for your interest in this research.

For further information contact

Wendy Bryant  
Brunel University  
School of Health Sciences and Social Care

[contact details]

**User involvement in mental health day services**

**Participant information sheet: Strand C/User-led social group**

**What is this research all about?** Finding out how people can be involved in developing social networks in mental health day services. People have social networks for support and enjoyable times with other people. The emphasis on what people do is important for this research. For that reason if you decide to join in, discussing what you do in the project could be an important part of it. Strand C of this research involves exploring what experiences people have of user-led social groups

**Who is in charge of the research?** Wendy Bryant, a student at Brunel University, will be co-ordinating the research for her PhD. She has two supervisors and also works closely with the Day Services Forum and service users in [name of Borough], who have contributed to the development of this research.

**What am I expected to do as a participant?** This research aims to find out what experiences people have of user-led social groups. You have been approached as a member of such a group. You will be expected to attend one interview lasting one hour, located at the mental health resource centre most convenient to you. The interview will be conducted by an independent interviewer who is not employed in statutory or voluntary mental health services in the [name of Borough] area.

You will be asked to share your experiences of being a member of the user-led social group. When all the interviews are completed, you will be offered the opportunity to comment on the main themes emerging from the research. This opportunity will be either with the rest of the group you belong to, or more directly with you as an individual.

**What do I do if I'm not sure about the research as it progresses, or have questions to ask?** Let someone in the research group know. Your concerns and questions about the research are important: they can help to make the research work for everybody involved.

**What if I change my mind about being involved, or I have to drop out for other reasons?** You can change your mind at any time or drop out if you need or want to. If you want to rejoin, then you will need to contact one of the research team to find out what's happening. You don't have to let us know, but there is a slip provided on the consent form that you could send to us if you want to drop out of the research.

Whatever you choose to do, it will have no impact on the day services you receive. Your identity will not be revealed, unless you specifically request this. For example, you might want to take part in presenting the research to a wider audience. Information such as your contact details and written records of the research, will be stored securely by Wendy Bryant at the University, and destroyed when the research is finished.

**Appendix F**  
**Information sheet, Strand C**

**What are the benefits to me as a participant?** Involving people who use services is thought to be one of the best ways of designing services which are helpful and benefit more people. So you could be making a difference to the services you and other people receive. There are no other specific benefits from the research to you.

**What will happen to my contribution?** Your contribution will become part of the research findings, and these will be presented locally. Beyond [name of Borough], there are many other mental health day services and so it is hoped that the findings will be shared at conferences and published. Wendy also will be writing up the findings for her PhD thesis, which will be available at Brunel University.

Thank you for your interest in this research.

For further information contact

Wendy Bryant  
Brunel University  
School of Health Sciences and Social Care

[contact details]

**Evaluation Form for first Social Networks Day**  
**Social Network Day – July 6<sup>th</sup> 2004**

*Evaluation of the day*

**1. Was it worth coming along to this event?**

<i>Yes</i>	<i>Mostly</i>	<i>No view either way</i>	<i>Not really</i>	<i>No</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Any other comments?** What was useful? What could have been better?  
*(please continue overleaf)*

**2. Would you like to be involved in future developments of day services?**

<i>Yes, I really want to get involved</i>	<i>Yes, keep me in touch with what is happening</i>	<i>No view either way</i>	<i>I'll keep myself updated on developments</i>	<i>No thanks</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Any other comments?** *(please continue overleaf)*

**Thank you for your involvement today. If you want to be involved in future developments, please put your details below. These details will be stored securely by Wendy Bryant at the Department of Health and Social Care, Brunel University, and will not be used for any other purpose other than to inform you about future developments.**

Name:

Address:

## **Evaluation of the social network day: July 6<sup>th</sup> 2004**

Evaluation forms were returned by 31 people.

The overwhelming majority of people attending who returned evaluation forms thought the event had been worth coming along to (97%, n=29), with the remaining person having no view either way. One response to this question could not be categorised.

In terms of involvement in future developments of day services, 8 people indicated they really wanted to get involved (25%). A further 17 people (53%) wanted to be kept in touch with developments. The remaining 6 people had no view either way or said they would keep themselves updated.

There were comments on just over half of the evaluation forms returned. The unexpectedly good turn out on the day meant there were more people than expected, with problems in the organisation of food and refreshments. At first, it was daunting to take part with so many people present and the speed networking exercise was seen as stressful. However, other people thought this was the best bit of the day. It was suggested a PA system would have helped, and another person commented that there was a lot of information to absorb.

There were several comments about it being good to hear users' views, and to meet friends and new people. One suggestion was that more time could have been given to the vision for day services: "I think there could have been greater focus on aspirations for day services in the closing meeting (i.e. what we would like to do with lots of money!)". Another comment was that it was "nice to know people really do care."

It was pointed out that whilst it was good to hear the views of others, it was those who were articulate who tended to speak. One person said "we must ensure that ideas shared and discussed are taken forward." As these ideas are taken forward, listening will be an important role for everyone involved.

Thank you for sharing your views on the day. You'll be hearing more – thanks to those of you who gave your contact details.

Wendy Bryant  
July 30<sup>th</sup> 2004

**CHECKLIST FOR SOCIAL AND RECREATIONAL  
ACTIVITIES**

<u>NAME OF PLACE</u>	<u>LOCATION</u>	<u>DATE OF MOST RECENT VISIT</u>

**1. Is this a place you can go to on your own?**     **No**     **Maybe**     **Yes**

**2. The first time you go, how easy is it to get there?**  
*(give marks out of ten for accessibility)*

By car?     **0**     **1**     **2**     **3**     **4**     **5**     **6**     **7**     **8**     **9**     **10**

By public transport?     **0**     **1**     **2**     **3**     **4**     **5**     **6**     **7**     **8**     **9**     **10**

On foot?     **0**     **1**     **2**     **3**     **4**     **5**     **6**     **7**     **8**     **9**     **10**

**3. Are there accessible toilet facilities?**     **No**     **Yes**

**4. How much does it cost to visit this place?**  
*(Circle the box that applies)*

<u>Free</u>	<u>Under</u> <b>£5</b>	<b>£5-</b> <u>£10</u>	<b>£10-</b> <u>£20</u>	<u>Ove</u> <b>r</b> <u>£20</u>
-------------	---------------------------	--------------------------	---------------------------	--------------------------------------

**5. Can you get refreshments at this place?**     **No**     **Yes**

Your comments (for example, the cost of refreshments, how appealing they are):

**6. Do people talk to you at this place?**  
*(Circle the word that applies)*

Never	Sometimes	Often	Frequently	Usually	Always
-------	-----------	-------	------------	---------	--------

Appendix J  
Checklist, Strand B

**7. Would you feel comfortable starting up conversations at this place?**  
*(Circle the word that applies)*

Never	Sometimes	Usually	Always
-------	-----------	---------	--------

**8. Are there like-minded people at this place? (not just mental health)**  
*(Circle the word that applies)*

Never	Sometimes	Usually	Always
-------	-----------	---------	--------

**9. How does this place affect your mental health?**  
*(Circle the box that applies to you)*

Feel much worse	Feel worse	Feel slightly worse	Feel no different	Feel slightly better	Feel better	Feel much better
-----------------	------------	---------------------	-------------------	----------------------	-------------	------------------

**10. Is there anything you do not like about this place?**

*If yes, specify what it is:*

<u>No</u> <input type="checkbox"/>	<u>Yes</u> <input type="checkbox"/>
---------------------------------------	--

**11. Is there anything you really like about this place?**

*If yes, specify what it is:*

<u>No</u> <input type="checkbox"/>	<u>Yes</u> <input type="checkbox"/>
---------------------------------------	--

**12. Would you visit this place again?**

<u>No</u> <input type="checkbox"/>	<u>Yes</u> <input type="checkbox"/>
---------------------------------------	--

**And would you recommend this place to other service users?**  
*(How many stars would you award it?)*

No star	*	**	***	****	*****
---------	---	----	-----	------	-------

Thank you for your time. Please return this checklist to a member of Day Services staff or Wendy Bryant at the research group meetings or to Wendy Bryant, Brunel University, [contact details]

# Getting better by going out

## Introduction

The current emphasis on helping people become more included in life beyond mental health services has had an impact on day services. Service users and staff are being encouraged to explore resources for social and recreational activities in the local area.

There are many resources but it is difficult to know which are good to go to. Choosing a social or recreational activity depends on a individual's interests and needs. But everyone can use information about activities, such as cost, location and opening hours.

However, to become socially included, people also need to know whether a social or recreational activity is welcoming. If there is a friendly welcome, then a feeling of being included or belonging is more likely to follow.

This research, carried out by service users in partnership with a researcher, aimed to check local social and recreational activities known to mental health day service users. The research was co-ordinated by a research group which met at Alder House, [name], for eight sessions. The members were four service users, a member of staff and the researcher from Brunel University.

This group designed the checklist and collected and analysed information. The checklist was also distributed amongst other day service users to get as many responses as possible. There were 45 responses, covering 38 places. There were 2 checklists covering mental health resource centres in general terms, - they were not used, as were 2 checklists covering seaside towns which were thought to be too far away.

## What the research group did

After giving signed consent to take part, the group spent the first week discussing what was involved in the research. We used the BITRA, a local index of activities, to identify which places could be included.

The second meeting involved designing the checklist. The next week everyone filled out and discussed the checklist, agreeing changes. This was the piloting stage of the research. By week four, we had some completed checklists and discussed how to manage the information we had gathered. Some of the group members organised a joint trip to check the Odeon in [name]. By the time we met again, we had a good number of checklists and discussed how the findings could be presented to other service users and staff. We agreed that a poster was the way forward.

During this week, we also paid a visit to Oasis, a group which meets at Elm Lodge, and filled out a checklist with them. At the next research group meeting, we agreed the basic content of the poster and started to organise the information needed. We continued doing this the next week before sharing thoughts about the experience of the research as a whole. We met one final time to agree the layout for this poster.

## The research group:

[names]



**Places which are free to visit**  
[name] Nature Reserve, [name]  
St Peter's, [name]  
[name] Lock  
[name] Shops  
[name] Park, [name]  
Greenwich Observatory  
Kensington Gardens and Hyde Park  
[name] Lake, [name]  
Natural History Museum  
[name] Cow Byre Gallery  
[name] Lido  
[name] Manor Library  
[name] Woods  
Oasis, Asian Group, Elm Lodge  
[name] Church, [name]  
Social Activities Group, Alder House  
[name] High Street  
[name] Library  
[name] Town Centre  
V&A Museum, Kensington  
[name] Harlequin  
Wyevalde Garden Centre, [name]

**Places costing more than £10 to visit**  
[name] Shopping Centre  
Kew Gardens  
London Zoo



**\*\*\*\*\*Five star places to go to\*\*\*\*\***  
Bingo, [name]  
St Peter's, [name]  
Compass Theatre, [name]  
[name] Pizza Hut  
[name] Swimming Pool  
[name] Church, [name]  
[name] Town Centre  
V&A Museum, Kensington

**Places that are not very easy to get to without a car**  
[name] Nature Reserve, [name]  
[name] Lock  
[name] Museum  
Kensington Gardens and Hyde Park  
[name] Lake, [name]  
[name] Woods  
[name] Harlequin

**Places it might be difficult to visit alone**  
[name] Museum  
[name] Shopping Centre  
[name] Woods  
[name] Harlequin

**Places with cheap refreshments**  
Bingo, [name]  
St Peter's, [name]  
[name] Bowls  
Oasis, Asian Group, Elm Lodge  
Social Activities Group, Alder House

**Places without refreshments**  
[name] Nature Reserve, [name]  
[name] Lake, [name]  
[name] Manor Library  
[name] Woods  
[name] Library

**Places without accessible toilets**  
[name] Nature Reserve, [name]  
[name] Lake, [name]  
[name] Manor Library  
[name] Woods

**Places which affect mental health for better or much better**  
[name] Nature Reserve, [name]  
St Peter's, [name]  
[name] Lock  
[name] Park, [name]  
[name] Museum  
[name] Pizza Hut  
[name] Swimming Pool  
Kensington Gardens and Hyde Park  
London Zoo  
Oasis, Asian Group, Elm Lodge  
Social Activities Group, Alder House  
[name] Library  
[name] Odeon  
V&A Museum, Kensington  
[name] Harlequin  
Wyevalde Garden Centre, [name]



**Places where there are always likeminded people, not just in terms of mental health**  
Bingo, [name]  
Compass Theatre, [name]  
[name] shops  
[name] Bowls  
[name] Lido  
Oasis, Asian Group, Elm Lodge

**Places which do not affect mental health for better or worse**  
Compass Theatre, [name]  
[name] Shopping Centre  
Trader Post/Use Group  
Kensington Gardens and Hyde Park  
[name] Cow Byre Gallery  
[name] Manor  
[name] Manor Library  
[name] Woods  
[name] Odeon

**Places where people always talk to you**  
[name] Shopping Centre  
Oasis, Asian Group, Elm Lodge  
[name] Town Centre

**Places where it's comfortable to start conversations**  
Bingo, [name]  
[name] Bowls  
Trader Post/Use Group  
Kensington Gardens and Hyde Park  
[name] Cow Byre Gallery  
[name] Manor  
Oasis, Asian Group, Elm Lodge  
[name] Church, [name]  
Social Activities Group, Alder House  
V&A Museum, Kensington  
Wyevalde Garden Centre, [name]

**Places where people usually talk to you**  
[name] Museum  
Kensington Gardens and Hyde Park  
[name] Church, [name]  
Social Activities Group, Alder House  
V&A Museum, Kensington

**Places where it's never comfortable to start up conversations**  
[name] Lock  
[name] Shopping Centre  
[name] Lido  
[name] Manor  
[name] Manor Library  
[name] Woods  
[name] Odeon

**Places where people never talk to you**  
[name] Lido  
[name] Woods  
[name] Library  
[name] Odeon

## Discussion

This information, gathered by the research group, extends the BITRA (Borough Index to Recreational Activities), which was launched in [name] in 2005. Service users within and beyond the research group were involved in selecting activities and gathering information.

Personal opinions were central to this research: the findings reported here might stimulate discussion and new ideas. There are many places and activities which were not considered in this research. It is hoped there will be further initiatives to build on the work of the research group.

Whilst the local places and activities are an important subject, service users and staff could also consider the specific qualities of a welcoming place to go and belong to.

In particular, it is important to consider what scope there is for social contact within a social or recreational activity. Meeting or being with likeminded people is important. This research did not distinguish between those places which offer opportunities to meet new people, and those which do not. Future research could address this gap.

The research group believed that being involved in this research was a very positive experience, and hope that more opportunities of this nature will arise in the future.

**Conclusion** Information about social and recreational activities was gathered by a research group and mental health day services in the London Borough of [name], using a checklist. The findings were put together to provide an information resource, this poster, for day service users and staff. It is hoped that these findings will form the basis for future initiatives.



## Evaluation form, Day Services Forum

March 20<sup>th</sup> 2007

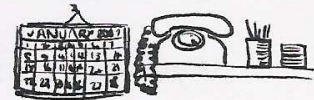
## Day Services Forum: Evaluation of research

This questionnaire is designed to give you an opportunity to give feedback about the research conducted by Wendy Bryant, in collaboration with people involved in mental health day services in <name of borough>

Please feel free to write any additional comments you feel are relevant and/or helpful. You do not have to give your name.

Wendy will store all the responses securely at Brunel University to use to evaluate the research only, and for no other reason.

## Question 1



When did you find out about this research? (please circle)

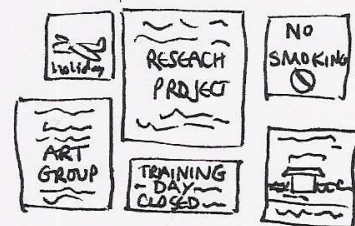
2002      2003      2004      2005      2006      2007

Today      Can't remember

## Question 2

If you knew about the research before today, how did you find out about it? (please tick)

- Heard about it at a meeting
- Saw a poster or display about it
- Read about it
- Other (please specify)



Please turn over for Question 3

*Thank you for filling out this questionnaire.*

Question 3

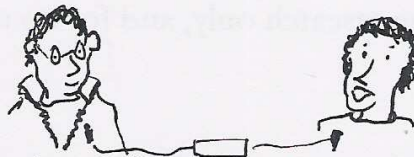
Did you get involved in the research in any way? (please tick)

Yes (please go to Questions 4 and 5 below)

Not sure (please go to Question 7 over the page)

No (please go to Question 6 over the page)

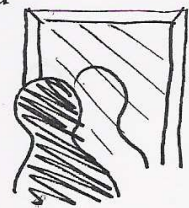
Question 4



If you put yes for Question 3, how did you get involved?

Question 5

If you put yes for question 4, did anything change for you personally as a result of getting involved?



Please go to Question 7

*Thank you for filling out this questionnaire.*

## Evaluation form, Day Services Forum

## Question 6

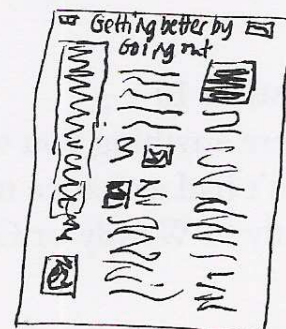
If you put no for Question 3, please tick the main reasons why you didn't get involved.

- Personal reasons
- Not enough time
- Not a priority
- Didn't know how to get involved
- Didn't see how I could get involved
- Not invited to get involved
- Other (please specify):

## Question 7

Are you aware of any of the findings of the research? (please tick)

- No
- Not sure
- Yes : please give details

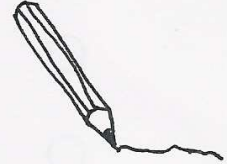


*Thank you for filling out this questionnaire.*

## Evaluation form, Day Services Forum

## Question 8

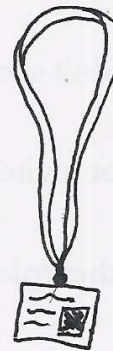
Do you have any ideas for research projects in the future?  
Please write them here.



## Question 9

What is your role in day services? (please tick)

- Service user
- Ex-service user
- Volunteer
- Staff
- Manager
- Other: please specify



## Question 10

Is there anything you would like to say about the research that you haven't had a chance to so far? If so, please write here or speak directly to Wendy or Geraldine Vacher.

*Thank you for filling out this questionnaire.*

Appendix M

Sample spreadsheet for final analysis

number	2003	2004	2005	2006	2007	WHO					WHAT			RESEARCH						
						Staff	NGO	User	Career	other	Mail	Email	Telephone	Other	Notifying	Shaping	Doing	Reflecting	Reporting	
C1																				
C2																				
C3																				
C4																				
C5																				
C6																				
C7																				
C8																				
C9																				
C10																				
C11																				
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C25																				
C26																				
C27																				
C28																				
C29																				
C30																				

# [Elm Lodge] Day Service Users



*You are invited to take part in a*

## **RESEARCH PROJECT**

on social networks  
in the Social Lounge at [Elm Lodge]

This research will involve eight project group meetings on Wednesday afternoons, starting on December 7<sup>th</sup> 2005 from 2 - 3.30pm. The meetings will be led by Wendy Bryant from Brunel University and [Sian] from [Elm Lodge].

### **Find out more:**

- Come to the first meeting of the project group on Wednesday December 7<sup>th</sup> at 2pm
- Contact the researcher, Wendy Bryant, from Brunel University on 01895 268746 (24 hour answer phone)

**User involvement in mental health day services**

**Participant Consent Form: Strand A/The Social Lounge**

	Yes	No
Have you read the Participant Information Sheet for Strand A?		
Have you had the opportunity to ask questions and discuss this research?		
Do you understand that you will not be referred to by name in any report on the research?		
Do you understand that you will have the final say on the use of any photographic images of you?		
Do you understand that you are free to withdraw from this research at any time?		
<i>And</i> without having to give a reason for withdrawing?		
<i>And</i> without affecting your future care?		
Do you agree to take part in this study?		

Signature of participant.....Date.....

Name in capitals.....

I have given a clear explanation of the study to the participant and I am satisfied that they have given informed consent.

Witnessed by .....

Name in capitals .....

**Withdrawing from the research**

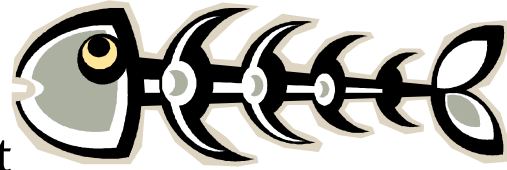
If you wish, you can use this section to inform us that you wish to withdraw from the research.

I wish to withdraw from the research

Signature of participant.....Date.....

Name in capitals.....

Please send to Geraldine Vacher, Day Services Development Manager,  
[contact details]



# Bare bones of a report

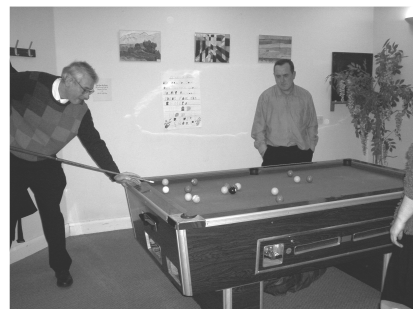
## Why the research was done



## How it was done



## What was done

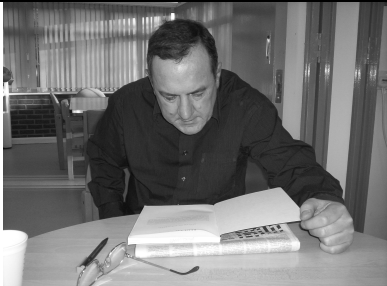


## Why it is important

[photo removed]



**How the findings could be used**



**What the next steps could be**



**Who are we? And who is this report for?**

Wendy Bryant would like to thank

**[name]**

For getting involved and making much  
valued contributions to the  
**RESEARCH PROJECT**  
**“The Social Lounge and beyond”**

In particular for [specific details of their  
contribution]

Wendy Bryant, MSc, DipCOT, PGCertHE  
February 7<sup>th</sup> 2006

Details of development work, Strand A

**Proposed day support service for people with severe and enduring mental health problems in [name of Borough].**

The Adult Social Care Health and Housing Department of the London Borough of [name of Borough] has identified funding for a day support service for people with severe and enduring mental health problems to be provided by a voluntary sector organisation. This service is being proposed in response to feedback from service users and to national and local guidance on mental health day services. As highlighted below, the drafting of the service specification has been based on research and reviews into the needs of people with persistent mental health problems and long-term support needs.

The proposal is for a day opportunities facility that promotes mental well-being, service user involvement, peer support and engagement with the wider community. The service should increase choice for service users, make effective use of current resources and develop partnerships with statutory and non-statutory mental health services and with generic services such as libraries, community centres etc.

The service would deliver on national and local priorities for mental health day services. However in developing this service it will be important to be clear about what it is, and is not, expected to achieve in relation to the care and support needs of the individual service user and also in relation to how the service fits into the overall provision of care and support in [name of Borough].

Two qualitative studies undertaken with service users in [name of Borough] by Wendy Bryant, Department of Health & Social Care, Brunel University - *Perspectives of day and accommodation services for people with enduring mental illness*<sup>1</sup> and *The Social Lounge and Beyond* a research project on social networking - have influenced the development of the service specification. The approach to the involvement of service users that was taken in these studies provides a model for the design and proposed delivery of this service. In line with this approach, a focus group of service users was asked to comment on specific aspects of the draft service specification. This group has agreed to meet again to discuss amendments to the draft following a period a wider consultation.

[name]  
Project Manager  
London Borough of [name of Borough]

23<sup>rd</sup> January 2008

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<sup>1</sup> Journal of Mental Health, Volume 14, Number 2 April 2005, pp 109-120(12)

Dear all,

**Research into user involvement in mental health day services**

Thanks for your continuing interest in the research. I'm writing to keep you in the picture on how things are going.

**Strand A – The Social Lounge at [Elm Lodge]**

Five people worked with me, and [Sian] from [Elm Lodge], from December to February. We took lots of photographs and have selected the best ones to use in the report on the project. This should be finished in April: copies will be available via [Elm Lodge] and the Day Services Forum. Let me know if you want your own copy – I can send it to you.

**Strand B: COMING SOON!!**

This strand is where we're gathering information on how accessible local social and recreational activities are. I've attached the information sheet for the strand for your information [Appendix E]. There will be a weekly group which will meet for 8 weeks, starting on Tuesday May 16<sup>th</sup> until Tuesday June 11<sup>th</sup>, with a break for the Whitsun Bank Holiday week. The group will meet at [Alder] House, in the craft room, from 10.30-12.

I'm planning to come over to [Alder] House to the user/staff meeting on Friday 7<sup>th</sup> April at 1.45pm, so do come along if you want to find out more. Alternatively you can turn up for the first meeting of the group on Tuesday May 16<sup>th</sup> at 10.30 – there'll be a chance to discuss the research then without any commitment on your part.

As always, you can always contact me directly for more information – leave a message and I'll get back to you.

**Day services forum**

Don't forget the next day services forum will be on

**Tuesday April 11<sup>th</sup>, 2-4pm, [Alder] House.**

Many thanks

Wendy Bryant

Lecturer in Occupational Therapy  
Brunel University  
School of Health Sciences and Social Care  
<address>

[Wendy.bryant@brunel.ac.uk](mailto:Wendy.bryant@brunel.ac.uk)

# Day Service Users

*You are invited to take part in a*

## RESEARCH PROJECT

on social networks

### What is this research all about?

- Getting involved in finding out how to develop social networks in mental health day services
- People have social networks for support and enjoyable times with other people.
- This research involves exploring whether activities in the community can make social contact easier.

### What would I have to do?

Join the project group and then it's up to you. We will be meeting:

**Tuesday mornings, starting on May 16<sup>th</sup>  
from 10.30-12 at [Alder] House**

The meetings will be led by Wendy Bryant from Brunel University, with [Sally] from [Alder] House.







### Find out more:

- Come to the first meeting of the project group on Tuesday May 16<sup>th</sup> 2006 at 10.30am at [Alder] House
- Contact the researcher, Wendy Bryant, from Brunel University on 01895 268746 (24 hour answer phone)

### CHECKLIST: PILOT VERSION

<u>NAME OF PLACE</u>	<u>LOCATION</u>	<u>DATE OF MOST RECENT VISIT</u>
<b><u>1. Is this a place you can go to on your own?</u></b>		<div style="display: inline-block; width: 20px; height: 15px; background-color: red; margin-right: 5px;"></div> <div style="display: inline-block; width: 20px; height: 15px; background-color: yellow; margin-right: 5px;"></div> <div style="display: inline-block; width: 20px; height: 15px; background-color: green;"></div>
<i>(Mark on the traffic light spectrum: green for go/yes, amber for wait/maybe, red for stop/no)</i>		
<b><u>2. How easy is it to get there?</u></b> <i>(give marks out of ten for accessibility)</i>		
<u>By car?</u>	<u>0</u>   <u>1</u>   <u>2</u>   <u>3</u>   <u>4</u>   <u>5</u>   <u>6</u>   <u>7</u>   <u>8</u>   <u>9</u>   <u>10</u>	
<u>By public transport?</u>	<u>0</u>   <u>1</u>   <u>2</u>   <u>3</u>   <u>4</u>   <u>5</u>   <u>6</u>   <u>7</u>   <u>8</u>   <u>9</u>   <u>10</u>	
<u>On foot?</u>	<u>0</u>   <u>1</u>   <u>2</u>   <u>3</u>   <u>4</u>   <u>5</u>   <u>6</u>   <u>7</u>   <u>8</u>   <u>9</u>   <u>10</u>	
<b><u>3. Are there accessible toilet facilities?</u></b>		<b><u>No</u></b>     <b><u>Yes</u></b>
<b><u>4. Is this place affordable?</u></b>		<div style="display: inline-block; width: 20px; height: 15px; background-color: red; margin-right: 5px;"></div> <div style="display: inline-block; width: 20px; height: 15px; background-color: yellow; margin-right: 5px;"></div> <div style="display: inline-block; width: 20px; height: 15px; background-color: green;"></div>
<i>(Mark on the traffic light spectrum: green for go/yes, amber for wait/maybe, red for stop/no)</i>		
<b><u>5. Can you get refreshments at this place?</u></b>		<b><u>No</u></b>     <b><u>Yes</u></b>
<u>Your comments (for example, the cost of refreshments, how appealing they are):</u>		
<b><u>6. Do people talk to you at this place?</u></b> <i>(Circle the word that applies)</i>		
Never	Sometimes	Often
Frequently	Usually	Always

Appendix V  
Pilot checklist, Strand B

<b><u>7. Would you feel comfortable starting up conversations at this place?</u></b> <i>(Circle the word that applies)</i>						
Never	Sometimes	Often	Frequently	Usually	Always	
<b><u>8. Are there like-minded people at this place?</u></b> <i>(Circle the word that applies)</i>						
Never	Sometimes	Often	Frequently	Usually	Always	
<b><u>9. Does this place make you more aware than usual of mental illness?</u></b> <i>(Circle the face that applies)</i>						
						
<b><u>10. Is there anything you do not like about this place?</u></b>				<b><u>No</u></b>		<b><u>Yes</u></b>
If yes, specify what it is:						
<b><u>11. Is there anything you really like about this place?</u></b>				<b><u>No</u></b>		<b><u>Yes</u></b>
If yes, specify what it is:						
<b><u>12. Would you visit this place again?</u></b>				<b><u>No</u></b>		<b><u>Yes</u></b>
<b><u>And would you recommend this place to other service users?</u></b> <i>(How many stars would you award it?)</i>						
No star	*	**	***	****	*****	

Thank you for your time. Please return this checklist to Wendy Bryant at the research group meetings or to Wendy Bryant, Brunel University, School of Health Sciences and Social Care, [contact details]

**Appendix W**  
**Recruitment letter, Strand C**

Dear

**[Traders Post] Group, [name of place]**

I am writing to ask if you would be willing to be interviewed about the [Traders Post] Group. I understand that you used to come along to the group. I would be interested to hear your views on how the group was then. This is part of my research towards a PhD.

The interview would be held on a Monday at [Traders Post] or the [Larch] Centre, at a time to suit you. The interviewer, [Ken], is independent of mental health services. Your contribution to the project would remain anonymous and it would not have any effect on any services you are in contact with.

I hope you will be happy to take part. If so, please ring me (01895 268746) or [Ken] [contact details].

Many thanks

Wendy Bryant



Appendix X

Topic list for interviews, Strand C

<i>Tell me, how long have you been a member of &lt;name of group&gt;?</i>
<i>When did you first think of joining it?</i>
<i>Tell me about the first time you attended the group.</i>
<i>Have things changed in the group since you first joined? If, so, how?</i>
<i>At the moment, what part does the group play in your life?</i>
<i>Do you see this changing in the future?</i>
<i>Is there anything else you would like to share with me about the group?</i>

**Appendix Y**  
**Sample transcript, Strand C**

K do you have anything to do with the running of this group

C no I think [name] manages it so

K when you say [name] do you mean [name] or [name] or both

C erm ... [name] with the glasses

K ok yeah so [name] who was putting stuff out at the beginning

C yes

K what do you think are the benefits for yourself in going

C as I say it gets me out for the afternoon there's absolutely nothing on the telly in the afternoon erm then from here I go shopping and that I'll go home and have something to eat and then sit and watch the television or my friend came round this morning bit anxious so I might go round to her this evening

K what about the particular activities that you actually do

C erm I've done a bit of art work which I've never done in my life before I used to watch my little grandson do it when we looked after him and I actually did it myself and as I said we talk erm and as I say I'm getting better at scrabble heheheh still one of the lowest one of the lowest erm scorers so heheh

K how did you take to the art work

C er there weren't enough of us to play scrabble so you know they said would I like to join in so yes you know erm

K and how was it

C oh quite relaxing and as I said we talked and you know erm er ...

K when you talked I assume that's in a completely unstructured way yes

C mmm yes yes I mean I first knew [name] heh with glasses heh erm from the anxiety management no from capital volunteering last year [[name]

K [that group

C [[name] said would I like to go bowling with what I call the youngsters from here I mean that was my first time since the nineteen seventies heh heheh we went over to the [name] bowl and that ... er she was one of the people there so I did know her sort of roughly ... there was another young girl who used to come but she's now managed to get a job [details] ... another

**Appendix Y**  
**Sample transcript, Strand C**

lady comes [name] sometimes there's another boy [name]  
sometimes

K do you (8:40) tend to talk about problems that you've  
had or just or not at all or is it just sometimes

C sometimes yes sometimes it's about children and  
grandchildren about our animals heh it's sort of just  
off the top of your head you know erm

K did you ever go to drop in centres previously

C no ...

K is that because you didn't know about them or  
C didn't know anything about them no I would just sit in  
a ball with the door open with the cat you know ... it  
lasted four years I suppose er [name] managed realised  
how much money I was spending on bus fares to get  
everywhere and she managed to get me a [bus] pass so  
that's really opened everything up for me means I can  
get over to [name] it means I can go over to [names]  
on the [number of bus] take about twenty-five hours  
then we get there heheheh

K and that's another way I suppose of avoiding isolation

C yeah it gets me and I see my little grandson he's two  
now I'm able to help my daughter out I'm able to  
babysit with him like that and erm

K have you got to know the people in the group yet

C yes yes I have

K and do you ever see them outside

C well [name] funnily enough said today said you know  
would I like to go round her house sometime and play  
scrabble you know and erm she says she lives in [name]  
so the [number of bus] takes me to [name]

Question for Standard 'D'... 6.8.07

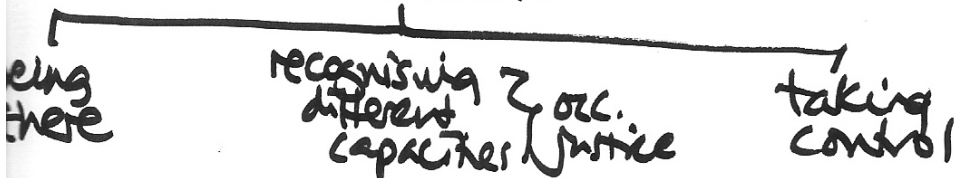
What impacts on user involvement?

- the details of the factors
- the impact - to what degree
- the impact - quality

user involvement :: in this research ::

What impacted on service user involvement in this research?

- the methods of recording & assessing impact
- the multiple timescales
  - short term
  - long term
- what defined user involvement?
  - continuum



→ ~~how~~ how did the process of involving service users influence the outcomes of the research?

→ involving service users — process-oriented here  
dynamic  
experiential  
occupational  
holistic

→ assumption that their involvement did influence outcomes of the research.

→ balanced against my own influence + agenda (getting the work done, occupational)

→ assumption that the outcomes can be identified and recognised → limitation to this in complex situation. Distinguish between steps + leaps??

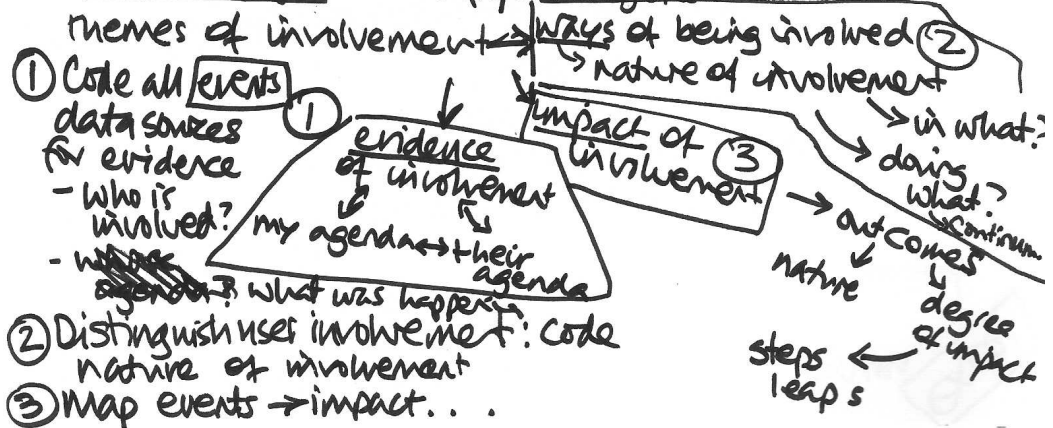
→ what would have been different if their involvement had been different?

↙ continuum of involvement ↘

KEY: COLLABORATIVE project.

→ consider COLLABORATION in terms of empowerment.

Steps of analysis: identify, Categorise



**Events** are (A) meetings e.g. Day Service Forum Excel  
 where: I was present  
**Code**  
 Include **MEET**: the research was discussed  
 Exclude (B) mail outs / correspondence / discussions  
**Date**  
**Who** - GV  
 (number) - Staff / Mgr: (C) strategy / documents where: proposed  
 - NGO - user → policy ~~change~~ <sup>was</sup> announced  
 - carer **POU** → for day services in relation to:  
**Where**  
 - social networking, contact  
 - recreational, leisure, support, self help, drop ins  
**Research**  
 - informing / notifying  
 - shaping  
 - doing  
 - evaluating  
 - reporting  
 - buildings  
 - ? user involvement  
**User Involvement** - which events were users involved in?  
 Filter events (A) how were they involved?  
 (B) which events were they not involved in?  
 - why weren't they involved?  
**Impact / Outcomes** Map or link key events.  
 Discuss implications.

large volume of data  
 had to organise it  
 had to examine & ~~do~~ categorise each.

## Sample report from NVivo, final analysis

## Coding Summary Report

**Project:** Final analysis  
**Generated:** 12/03/2008 09:45

<b>C3 form</b>			<b>Document</b>
<b>Nodes Coding</b>	<b>References</b>	<b>Coverage</b>	
Cases\C3 form	1	100.00 %	
Results\3 dimensions of form RRN	1	13.41 %	
Results\4 dimensions of form	1	13.41 %	
Tree Nodes\day services\outcomes of research	1	23.90 %	
Tree Nodes\form\fixed	1	2.68 %	
Tree Nodes\form\novel	2	42.60 %	
Tree Nodes\form\recognisable	2	37.15 %	
Tree Nodes\form\responsive	2	31.38 %	
<b>Total References</b>			

<b>C3 function</b>			<b>Document</b>
<b>Nodes Coding</b>	<b>References</b>	<b>Coverage</b>	
Tree Nodes\function\explicit	1	75.31 %	
<b>Total References</b>			

<b>C3 meaning</b>			<b>Document</b>
<b>Nodes Coding</b>	<b>References</b>	<b>Coverage</b>	
Free Nodes\It is almost as if he is experimenting with different communication forms within the letter, there is a playfulness which was characteristic of the research and him. It was possible to be playful, to be creative, in the research, and it generated more oppor	1	11.97 %	
Tree Nodes\day services\outcomes of research	1	3.96 %	
Tree Nodes\day services\service user experience	4	55.20 %	
Tree Nodes\form\novel	1	2.79 %	
Tree Nodes\meaning\negotiated agreements	1	10.48 %	
Tree Nodes\meaning\open dialogue and occupation	1	10.48 %	
Tree Nodes\my experience\transforming me	1	4.90 %	
<b>Total References</b>			

## Social Networks Project



### Agenda

January 28<sup>th</sup> 2005

1.45-2.30 at [Alder] House  
2.45-3.30 at [Elm Lodge]



Led by: Wendy Bryant  
PhD student  
Brunel University  
[contact details]

[Wendy.bryant@brunel.ac.uk](mailto:Wendy.bryant@brunel.ac.uk)  
[contact details]



## Agenda



The Social Networks Day  
(July 2004) and beyond

**Research:** what is happening,  
why is it happening, why is it  
important?

- Something new
- Something established
- Something which could  
change

**Organising** the research



## Appendix AB

Leaflet, M18.

*An occupational perspective*

Or

*What do people do all day, and  
why?*

In occupational therapy, there is  
great interest in what people do all  
day, and why.

Theories are being developed to  
explain why doing something can  
benefit health. It's also recognised  
that not everything a person does is  
good for their health, and often  
people don't have a choice about  
what they have to do.

The word occupation is used to  
describe everything a person does,  
not just what they are paid to do.

So some of the outcomes of this  
project could be used to add to the  
knowledge we already have about



occupation, social networks and mental health.



**Appendix AC**  
**Letter to user group, M24**

July 12<sup>th</sup> 2005

Dear [user group] members,

Thank you for including me in your recent meeting on June 15th. I've attached the draft Information Sheet about the research for your information. As some of you already know, the research has grown out of the Day Services Review in 2002, and as well as contributing to the development of the services, is also a means for me to study for my PhD. Here are some of the questions you asked, and my response (as far as I can remember, sorry if there are any inaccuracies).

**Users are leading groups already – did you know that?** Yes and no, and it's very useful for me to meet with you to find out what is going on in [name of Borough].

**Will we have to read your PhD thesis to find out the results?** Not unless you want to, and you don't mind waiting until 2008.... But I'm hoping there will be at least two short reports over the course of next year. The people involved in the research will be involved in producing the reports. In addition to this I'm happy to send you copies of the journal articles we have written about the 2002 review.

**Who is the research targeted at?** It is widely recognised that day services involve many different groups of people with different needs. Again this was a really useful question: the answer is people with long established contact with services, rather than people who are acutely ill. But beyond that, anyone who uses day services or has used day services recently can be included.

**What are your views on current day services policies?** In essence I am concerned to take into account the different needs people have within day services. Not everybody can keep a paid full time job, and our research has shown that many people really value the opportunity to get support from each other in group and social settings. Yet these settings can be the hardest places for staff to be, because of the concern with minimising risk and the informality. I am also concerned that sometimes the efforts to minimise risk undermine efforts to improve services.

**One of the biggest problems we face is loneliness.** Yes, and I hope the research will shed some light on what helps people in this situation.

**What are you doing at the moment?** I'm currently waiting for confirmation of ethical approval from [name of Borough] Local Research Ethics Board. Since I met with you, I have attended the Board meeting on July 5<sup>th</sup>, and there were more questions to answer, which I found useful and helpful. I've got approval from Brunel University Ethics Committee now.

**My current plan** is as follows:

**Appendix AC**  
**Letter to user group, M24**

Strand	Timing	Question	Method
A	Autumn 2005	Are social networks being formed and sustained in the Social Lounge?	An 8 week research group, taking and analysing photographs. Based at [Elm Lodge]
B	Spring 2006	How accessible are local social and recreational activities to people with enduring mental health problems?	An 8 week research group, visiting and rating local social and recreational activities. Based from [Alder] House.
C	Summer 2006	What do people do to initiate and sustain a user-led social group?	Agree which user-led group will participate in consultation with Day Services Forum and [User Group]. Individual interviews by external interviewer.

The next day services forum will be concerned with Social Networks: if you have any thoughts on key issues for this, let me or Geraldine know. The details are

**Tuesday August 30<sup>th</sup>, 2-4pm, [Alder] House.**

I always welcome your comments and suggestions. Once I have ethical approval for the research I will be in touch again with those people who have already indicated an interest in the research. If you would like to be included, then send me your details to the address below. I will be in touch with [you] again and hope that you will have a slot free for me later in the year.

Many thanks

Wendy Bryant

Lecturer in Occupational Therapy  
Brunel University  
School of Health Sciences and Social Care  
[contact details]

[Wendy.bryant@brunel.ac.uk](mailto:Wendy.bryant@brunel.ac.uk)

**Report on second Social Networks Day, M41**

**Social Networks Day: 1<sup>st</sup> November 2005**

We met in [St Peter's hall] for a second Social Networks Day for day service users, staff and other interested people. The day was attended by 49 people, half of whom were service users. We were pleased with this response, given that the day coincided with Diwali and no transport was arranged for people to get to [name].

We had two ice-breaker activities which gave a chance for people to meet each other, and there was plenty of time to enjoy the food and drink provided. Organisations, including [Health Promotion team], [Oak Foundation], Capital Volunteering, [Employment team] and [National Mental Health helpline] had displays about their services. There was an opportunity to hear briefly about what was on offer, and then people were invited to participate in discussions about the services.

A special guest, [Lou] from [project elsewhere], spoke in the afternoon about the challenges in user-led groups. [The project] was established in 1990 and is entirely user-led, providing social and recreational activities particularly in the evenings and at weekends. They have been very successful in getting Lottery funding.

[Emma], the Capital Volunteering Co-ordinator, invited people to come up with ideas for user-led projects which could be funded by small grants. Ideas were shared, and there was support for a self-help group and an optimism group.

The feedback from people indicated that it was useful and helpful day, for getting more information about what's happening in [name of Borough]. People appreciated having the opportunity to discuss how to get involved and everyone felt they had a chance to share their views.

Not all views were positive: there is still lots of work to be done. In particular, information needs to be more accessible to users. People who lead services should be going directly to service users to share information and take action to address access issues. This was raised in particular by the [Oak Foundation group]: it was good and very useful to have their contribution.

Whilst the food was appreciated by some, the presentation of it posed difficulties for vegetarians. It was a long day for some and it was good to see that people were happy to pop in and out during the day.

The Social Networks Day was organised on behalf of the Day Service Forum. You are invited to the next meeting to share your views.

**Tuesday 20<sup>th</sup> December, [Alder] House, 2 - 4pm**

Geraldine [surname] and Wendy Bryant  
November 4<sup>th</sup> 2005

Dear [name of project lead],

### **Day Services Review**

Thank you very much for inviting me to contribute to the review. My comments are drawn primarily from the experience and findings of my PhD research, which focused on involving service users in investigating aspects of day services. My membership of the Day Services Forum and occupational therapy background obviously also influence my views.

### **Findings of research**

The research is not yet complete, so many of these findings are provisional. However it seems appropriate to make the following observations at this stage.

#### **Strand A focused on the built environment as a focus for day services, with service users gathering and analysing data which offered their perspective.**

1. A safe place within day services is fundamentally important to day service users, before they can become involved in other aspects of day services or think about moving on from day services
2. Service users have experienced many changes to services over the years, especially in terms of staff approach, available resources and expectations of their own involvement. It is very important that future developments occur in continuous consultation with long-term service users, to ensure their needs are fully considered.
3. Whilst there is currently an expectation that people will move on from day services, in reality for many people this is a difficult and fragile process.

#### **Strand B focused on mainstream community resources which were accessible to mental health service users for social networking.**

1. A key discussion for this strand was to consider what makes a place or group accessible to someone with enduring mental health problems.
2. Many places were considered appropriate for one-off visits, but a more critical issue was finding places to go which were accessible on an ongoing basis.
3. Most of the places which did offer such ongoing accessibility were those specific to people with mental health problems, organised by [Oak Foundation] and statutory services. Churches were also recognised as an important resource for social networking and support, but did not appeal to everyone.
4. Aspects of accessibility for people with enduring mental health problems have some common features, for example, whether there is an opportunity for social contact or a friendly welcome, but individual needs are equally important. For example some people are happy just to be in the company

Letter for Day Service Review, C45

of other people, whereas others are looking for opportunities for more interaction. This echoed the findings of Strand A.

5. The posters for this strand have been welcomed as an accessible resource for staff and service users: it has been suggested that an ongoing project could be devoted to sustaining this initiative.

**Strand C focused on three user-led social groups, and analysis is still in progress.**

1. So far it seems clear that these groups require some service users to take an active leadership role, which is not readily perceived by other group members who assume the groups run themselves.
2. The groups face similar issues with recruitment of new members, publicity and supporting existing members as any other group in day services, but with much more varied levels of support and links with the statutory services.
3. The groups face ongoing uncertainty over funding, locations and existence.
4. It seems to be appropriate for these groups to be perceived as a specific aspect of day services, requiring ongoing support and input from statutory services. This would involve intensive involvement with groups that are just starting and groups that are not surviving, and less intensive support for groups that are ongoing, with attention directed to the user/leaders. It is important to recognise that these groups will be in a constant state of flux, reflecting the changing lives and priorities of service users.

**The Day Services Forum**

The forum has become an established space for staff and service users to discuss key issues in service development. As such it has also been a significant source of support and point of reference for my research. However service user participation in the forum is variable, depending on the theme of the forum meeting and their investment in the issues. It seems to be worth considering whether themed meetings are the priority or whether it is possible to establish a group of service users with a commitment to the forum, and a specific role. This in itself would be dependent on how powerful the forum is perceived to be in the wider context, and to what extent the service users can determine the themes of the forum. It does appear that the forum is largely acting in response to externally generated agendas, which may or may not be meaningful to service users.

**Key issues for day services**

The research has given me an understanding and knowledge of not only of current policy and its impact, but also how day services have evolved since the 1940s in the UK. It does seem that the current emphasis on individualised packages of care and specialist teams undermines the role of day services, which have evolved to offer a collectivised approach from a generic team with a holistic range of approaches. The original day services emphasised an

## Appendix AE

### Letter for Day Service Review, C45

occupational perspective to mental illness, which embraced every aspect of occupation not just paid employment.

It seems that the challenge for you in putting together a new strategy is to reconcile the current political preferences with the benefits of conventional day services. A collective approach enables service users to establish supportive networks with each other and gain access to staff informally. A generic team can be responsive to a wider range of issues and can offer a service which can be holistic, through a flexible and person-centred approach. Many long term day service users often have multiple problems and experiences, not neatly fitting into a 'pathway of care', and it seems appropriate to propose that day services are best placed to offer professional support to this group to facilitate their recovery. Similarly, by offering shelter, a safe place and a structure for the day, day services can be an essential element in people who are recovering in a more straightforward way.

I do hope these comments are helpful to you and of course would be happy to comment on the strategy as it evolves.

Wendy Bryant  
Occupational therapy lecturer

Cc: Geraldine [day services development manager].  
[Andrew], [User Group]



**Core values of day services**

**Core Values**

*(as agreed by the membership of the Day Services Forum)*

Mental Health Day Services core values are to:

- Work in partnership with service users, their families and carers focusing on the individual's strengths and interests.
- Provide an effective and safe care pathway, from pre-discharge through to living in the community that focuses on recovery and activity.
- Work together with community providers to promote and develop a range of community opportunities for service users.
- Promote meaningful occupation and social inclusion through the provision of supported employment and access to training, leisure activities, further education and voluntary work.

[from Pring and Vacher 2004)

**PROGRAMME DETAILS**

**1. Reception:**

People to write their first names on labels and to complete register.

**2. Ground Rules:**

- No mobile phones
- If you have to leave let someone know
- Clear cups away yourself and keep venue tidy

**3. Speed Networking: Exercise 20 mins**

**Aim:**

- Ice-breaker
- Introduce self to others

Move around room. Find a partner, talk to them for 2 mins, find out something about them you didn't know. When whistle blows, move on.

**Rules:** What you discuss stays with the person you shared discussion with.

**4. Mapping Exercise: 30 mins**

**Aim:**

- Sharing information
- Mapping of social opportunities

Flip chart sheets with areas identified inside and outside [name of Borough].

Maps of [name of Borough]

People to write down on post-it notes social activities, clubs etc. they are unsure of and attach them to area sheet where activity takes place.

This information will be put together in a format that can be distributed to users and staff.

**5. Group Exercise: Changing Networks - 1 hour**

**Aim:**

- To share information
- Support change
- Encourage social contact
- Confirm what people do

Divide up into 6 groups, 2 groups for each theme. All groups facilitated by organisers.

Each group to produce top ten tips.

**6. Reflection time: 20 mins**

**Aim:**

- Answer questions
- Feedback

**7. Group Exercise: What can we do? – 1 hour, 20 mins**

**Aim:**

- Identify Next Steps
- Action Plan

Divide up into 6 groups, 2 groups each theme. All groups facilitated by organisers.

Exercise time – 25 mins  
Feedback time – 10 mins max each group

4 before tea, 2 after tea.

**8. Next Steps:**

- General information
- Making connections
- Developing the Social Network

Appendix AH  
Flyer for exhibition

Brunel  
UNIVERSITY  
WEST LONDON

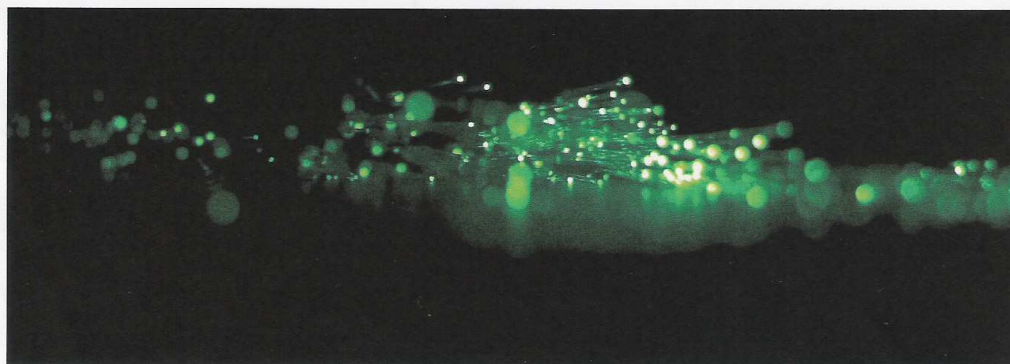
2006

THE ARTS  
CENTRE  
at Brunel

# MOVING FORWARD

Brunel research projects showing together with the work of Arts Centre staff: cosmic-ray particle detectors, diamond-like carbon, painting, social studies, sculpture, laser creations, ceramics, cell and chromosome biology, textiles, prints, 2D and 3D digital models.

**INCLUDING:** **MICHAEL AJERMAN** Painting • **Prof TONY ANSON** Diamond-Like Carbon (DLC) • **LINDA AUSTIN** Painting & mixed media • **HELEN AYRES pg** "Doctor-on-a-Chip" • **ALAN BENNETT** Painting and Drawing • **VAL BENNETT** Ceramic Jewellery • **DANIEL BISHOP pg** Effects of Music...on Tennis Performance • **Dr JOANNA BRIDGER, Dr IAN KILL, MARTIN FIGGITT, Dr SABRINA TOSI, ERICA BALLABIO, Dr RHONA ANDERSON, Dr DAVID TREE, Dr GUDRUN STENBECK, ISHITA MEHTA, EDWIN ODOEMELAM** "Unlocking the Cell" • **WENDY BRYANT** Mental Health Service users • **Dr WILLIAM BROWN** "Fearful symmetry" • **Dr PETER BURROWS** CLEAPSS reports • **JULIAN COOKSEY** Sculpture, Digital Prints • **DAVID COWLEY** Sculpture and Drawings • **LAURA FURLONG** Ceramics • **Dr GEORGE GHINEA, Dr SIMON KENT, Prof LORRAINE DeSOUZA, Dr ANDREW FRANK** "Pain Drawing Vizualisation" • **Prof PETER HOBSON & DR PAUL KYBERD** Fluorescing fibres • **USMAN KHAN pg** Freeform Surface Induction...via Neural Networks • **CAROLA KOENIG** Computational Fluid Dynamics • **ANNE LIGHTWOOD** Wall panels & Prints • **CHENG MAO pg** Sketch-based Virtual Human Modelling... • **Dr KYOKO MURAKAMI** Ethnographic partnerships • **TIMOTHY NOAD** Calligraphy & illumination • **VERITY PARKER** Electro-textiles • **LUCY PERKINS** Glass • **EMMA PICKERING pg** New Usability...in computing • **Dr IVAN REID**, Particle physics – live from CERN and interactive • **Dr HAN-KYUN RHO** Textual Messages • **GIDEON RUBIN** Painting • **BERYL SEDGWICK** Ceramics • **Dr. ROB SHAVE** Cardiac ultrasound imaging • **MATT SHERRATT** Ceramics • **Dr SARAH SILVE** Laser forming • **PREDRAG SLIJEPCEVIC** Imaging of Telomeres



Prof Peter Hobson & Dr Paul Kyberd: FLUORESCING FIBRES

## BELDAM GALLERY

**BRUNEL UNIVERSITY** (WILFRED BROWN BUILDING)  
CLEVELAND ROAD, UXBRIDGE, MIDDLESEX UB8 3PH

**26th JUNE – 8th SEPTEMBER 2006**

Monday - Friday, 9.30am - 5.30pm Admission Free  
Closed Bank Holidays

Enquiries to: Brunel University Arts Centre  
E.mail: [artscentre@brunel.ac.uk](mailto:artscentre@brunel.ac.uk)

Tel: 01895-266074  
[www.brunel.ac.uk/artscentre](http://www.brunel.ac.uk/artscentre)

<b>2002</b>	
May	Focus group review of day services
<b>2003</b>	
June	Preliminary meeting with Day Services Development Manager
July	First day services forum
October	Day services forum
	Meeting with Day Services Development Manager
November	Met Peter, supervisor
December	Day services forum
<b>2004</b>	
January	Met with School head
	User involvement conference
February	Meeting with Day Services Development manager
	Day services forum
March	Meeting with Day Services Development manager
	Day services forum
April	Meeting with Day Services Development manager
May	Day services forum (not present)
June	Meeting with Day Services Development manager
July	Social networks day
	Meeting with [Maneesha, Oak Foundation]
August	Meeting with service users
	Day services forum
September	Met [Ken], oral historian
November	Day services forum
<b>2005</b>	
January	Day services forum (not present)
	Meetings with service users
February	Present proposed design at school research day
	Meeting with service users
March	Day services forum
April	Meeting with Day Services Development manager
	Joint presentation of project with Day Services Development Manager at Association of OTs in Mental Health conference, Stockport
May	Day services forum
	Presentation of project at Canadian Association of OT annual conference, Vancouver
June	Joint meeting with Peter, Day Services Development Manager and Commissioner for Mental Health services
	Meeting with user group
	Day services forum
July	Meeting with Day Services Development manager
August	Meeting with [Health Promotion Team]
	Day services forum
September	Meeting with Day Services Development manager

October	Meeting with Day Services Development manager
November	Social Networks Day
	Meeting with service users
December	Strand A starts
	Meeting with Day Services Development manager
	Day services forum
<b>2006</b>	
January	Meeting with user group
	Oral history training day
February	Strand A ends
	Day services forum
March	Qualitative data analysis course
	Presentation of project to MSc students, University of Limerick
April	Meeting with service users
	Day services forum (not present)
	Meeting with service users
	Meeting with Day Services Development manager
May	Meetings with service users
	Presentation by Day Services Development Manager to BSc OT students, Brunel University
	Strand B starts
June	Day services forum
	Meeting with Day Services Development manager
	Presentation of Strand A at College of OT conference, Cardiff
	Received Institute of Social Psychiatry Award to fund Strand C
	Exhibition of research including Strand A starts at Brunel University
July	See play written by [Ken]
	Day services forum
	Presentations of Strand A and project at World Federation of OTs Congress, Sydney
August	Meeting with Day Services Development manager
	Strand B ends
September	Presentation of overall research design at Occupational Science Symposium, Northampton
	Exhibition of research including Strand A ends at Brunel University
	Meeting with day services development manager
	Day services forum – presentation of findings of Strand A and posters from Strand B
October	Preliminary meetings with [Ken] re Strand C
	Service users contribute to MSc and BSc teaching programme at Brunel University
	Announcement that funding for some Oak Foundation day services to be withdrawn by PCT from 2007
November	Strand C starts

	Day services forum
	Visit to student on placement in day services in another area which were about to be closed and converted to Personality Disorder Service
December	Presentation of Strand B at College of Occupational Therapists Specialist Section in Mental Health annual conference, London.
	Presentation of researcher and service user co-researchers to HRH Princess Anne at conference in London (see above)
	Meeting with day services development manager
2007	
January	Day services forum
February	Strand C data collection ends
	Research methods workshop for staff
March	Day services forum