

Towards Inclusive Living: A Case Study of the Impact of Inclusive Practice in Neuro-Rehabilitation/Neuro-Psychiatry Services

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Inclusion?

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This report is dedicated to the memory of Lindsay Carter, musician, disabled activist, 'sharp thinker' and service user researcher in this study. She has been sorely missed by her fellow researchers.

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Disclaimer

The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the Department of Health.

GLOSSARY OF TERMS

Action Research: a deliberate, planned process of critical enquiry undertaken by those engaged in and committed to the improvement of the situation. It uses an array of methods, chosen for their appropriateness to the enquiry. It typically proceeds in a cycle of posing questions, generating data and reflecting on that data. It is participatory, critical and educational.

Carer/Family member (CFM): for the purposes of this study CFM is defined as an unpaid person who supports/aides service users, providing practical and/or emotional support to help service users engage in activities of daily living. This does not include those paid as personal assistants to carry out this function.

Co-labouring: defined by Sumara and Luce-Kapler (1993: 393) as a process of engaging in “toil, distress, trouble: exertions of the faculties of the body or mind ... an activity which is at times likely to be uncomfortable” co-labouring is used in this study to reflect the shared aspect of working together to shape treatment and care. In co-labouring, both sides have to work at developing a process. It cannot be confused with consultation.

Communicative space: where people come together to co-labour: in this case to delve into their thoughts and ideas with the aim of constructing new knowings about practice based on both the articulation of their own ideas and those offered by others. It is an active engagement where all parties share responsibility for critical reflection.

Community of inquiry: the grouping together of people in a manner that leads to questioning, reasoning, challenging, connecting and developing new understandings about practice. It is a social and educational group for addressing what is currently understood and using multiple perspectives to improve that understanding.

Consultation: where one party asks the other whether or not they agree with a process/idea that has already been developed.

Facilitator – an independent person who enables people to work more effectively together through advocating fair, open and inclusive communication. They assist people to thinking deeply about their assumptions, beliefs and values and actions and to learn together.

Integration: although debate remains, integration is generally described as the provision of ‘additional arrangements’ to enable settings to admit certain people with particular needs but where the setting itself would remain essentially unchanged. In its most negative connotation this is integration by location, where people attend but cannot participate or the provision of limited access to or a watered-down variant of regular provision. It is characterised by an approach where people may have certain choices but have to fit in, in the best way they can, to regular activities, with the onus being on the person to make accommodations.

Inclusion: conceptualized as more challenging than integration, inclusion is a process that involves society in making changes, both physical and attitudinal, that embrace diversity and enable all people to make choices in relation to the way they live their lives.

Medical model of disability: rooted in an emphasis on individual clinical diagnosis, it identifies the form of impairment as the disabling factor.

Participatory research: a research approach designed to ensure and establish structures for participation by communities affected by the issue being studied. It has particular emphasis on co-learning and reciprocal transfer of expertise by all research partners and mutual ownership of the processes

Pedagogy: the art/approach/method of educating

Person Centred: The concept of person centred practice is now commonly used within health and social care policy documentation. The Modernisation Agency

Action on Neurology: Improving Neurology Services – Practical Guide March 2006 identified a person centred service as one that includes:

- good co-ordination with services planned and delivered in an integrated way around needs of the patient
- an understanding of the skills of different professionals and the role of different agencies
- an integrated assessment of health and social care needs
- up to date information given at appropriate time along patient pathway
- the involvement of patient and carers in the decision making process
- support to help patients manage their condition themselves

Service users: people who use, or have used, inpatient, outpatient or outreach services in relation to their long term condition, provided by Walkergate Park Regional Neuro-Rehabilitation Services.

Social model of disability: this model makes a clear distinction between the form of impairment people have (the individual model) and the way they are treated by the communities in which they live. It identifies the impact of society as the disabling factor.

Staff: for the purposes of this study staff are the people who are employed Walkergate Park Regional Neuro-Rehabilitation Services in any paid capacity.

Symbolic Interactionism: the theory that people create shared meanings through a critical interpretative process: the understandings people attach to their situations are socially constructed and shaped by social interactions.

EXECUTIVE SUMMARY

1. Aims and Objectives

This study set out to:

- explore how feelings of inclusion effect ways in which people (service users and carers/family members) who use neurological/neuropsychiatric services are engaged with the NHS community
- discover whether the way in which people are included in services has an effect on how they are able to understand and use the knowledge from that engagement.

The key objectives were to:

- identify current perceptions of service delivery
- investigate understandings of integrated and inclusive practice
- map what inclusion looks/feels like for people using neurorehabilitation services
- articulate the impact of current forms of inclusive practice on the lives of service users
- identify enablers and barriers to inclusive practice
- provide holistic knowledge and a set of principles to support the development of more person centred, effective service delivery
- develop a body of knowledge on inclusive practice and its impact

2. Findings

- There is general satisfaction with service provision but we must not mistake satisfaction about services for effective services.
- The provision of ineffective services has
 - a high impact on the lives of service users and their families,
 - a high cost to NHS staff in terms of morale and job satisfaction
 - a high monetary cost for service providers.
- Inclusive practice is essential for developing services that are appropriate for service users with long-term neurological conditions.
- Effective communication is at the heart of inclusion. Without it the long-term effectiveness of rehabilitation in practice can be compromised.
- Effective communication needs facilitation.

- Whilst inclusion is individual there are some important common principles for inclusive practice that can be developed.
- Barriers to inclusive practice exist in both personal and organisational perceptions of effective practice. These need to be overtly and systematically addressed as an educational process for all.
- Exclusion is expensive for all.
- Participatory research enables us to delve deeper into conceptualisations of practice: to reach underlying issues in respect of practice that can be masked by common rhetoric.
- The research approach (participatory) offered a model for practice.

3. Background to the Research

3.1 Local

The study arose from discussions with service users during a process of major change in local service provision. The site of the Neuro-Rehabilitation Centre, (Hunter's Moor) was to be closed and services move to a new build (Walkergate Park) joining with neuro-psychiatric and neuro-behavioural services. Whilst engaged in a listening event about the shape of new buildings and services, service users were asked about what they might want to see researched at the new centre. . It was their perception that there might be a link between the way people with neurological impairments are included in the NHS and the way they use treatment knowledge to develop their skills and independence in the community. They therefore wanted to research the notion of inclusion and its impact on the lives of people with Long Term Neurological Conditions (LTNCs).

3.2 National

The research was set against a backdrop of a nation focus on:

- improving practice in LTC through the National Service Framework (NSF)
- service user involvement in shaping services and treatment
- service user involvement in research

4. Study design

The study used participatory action research (PAR). PAR is broadly defined as “the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding” Winter & Munn-Giddings (2001:35). The approach foregrounded in this research drew on the notion of ‘authentic participation’, used by Robin McTaggart (1997) to mean

“ownership, that is responsible agency in the production of knowledge and improvement in practice... Mere involvement implies none of this and creates the risk of cooption and exploitation in the realisation of the plans of others” p28

Service users who raised the initial question were part of the core research team that designed and carried out the study.

Core Research Team
Staff from Northumbria University (two of whom were formerly employees of Northumberland Tyne and Wear (NTW) NHS Foundation Trust)
Service users, carers (non-paid) and family members who used Walkergate Park Regional Neuro-Rehabilitation Centre (Walkergate Park)
Staff from Walkergate Park Services
Representatives from the North Eastern branches of the MS Society, Parkinson's Society and Headway who had involvement with Walkergate Park Services

Participants in the study
Service Users with a range of acquired neurological conditions
Carers/family members (CFMs)
Staff from Walkergate Park Services (including non-medical staff)
Representatives from the voluntary sector who engage with the services of Walkergate Park Regional Neuro-Rehabilitation Centre

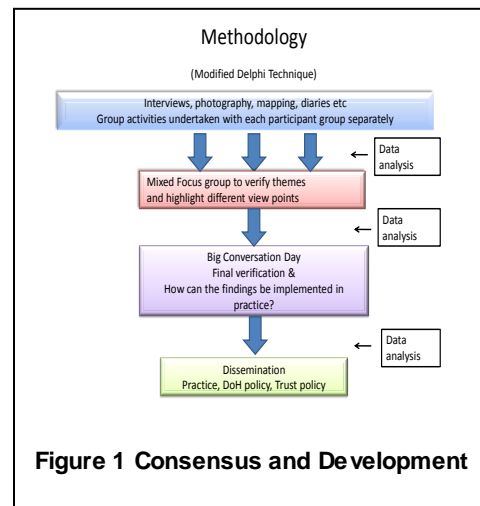
Approaches to data generation were designed to allow participants, some with impaired communication and processing skills, to:

- participate in a way most suitable to their preferences and needs (based on their own choice, not impairment led)
- delve beneath rhetoric, seeking both an appreciation and a critique of practice in the light of current policy requirements
- enable participants to contribute to the analysis of data

Methods
Interviews
Focus Groups (homogenous: ie all participants from same grouping eg all staff)
Focus Groups (heterogeneous: ie participants drawn from across groupings)
Diaries (Written and verbal)
Photography Projects
Blogs

Mapping
Questionnaire

A modified Delphi technique was used both as a synthesis approach to gain consensus, and to develop greater understandings though revisiting synthesised data for further critique.



5. What was learnt from the study

5.1 Perceptions of services

People who use and work in specialised services find a great deal of merit in them. Working at their best, specialist neurorehabilitation / neuro psychiatry services have a profound impact on improving the quality of people's lives. Professionals were praised for their high standard of medical knowledge and whilst people could always point to scarce resources this did not dominate discussions. Service satisfaction should not, however, be confused with efficient and effective services. For a host of reasons, even the most articulate, communicative and confident service users articulate satisfaction with services whilst accommodating, enduring or silently rejecting a range of treatment and treatment process that are incompatible with their daily lives. Services were delivered, over long periods of time, that had little impact and equipment that was not used, or used ineffectively, was maintained at a high cost. This translates into significant costs for the NHS and people and their families.

5.2 Notions of inclusion

Inclusion goes beyond notions of integration, where integration is seen to mean fitting in to what is available. It is a shared endeavour that involves shaping practice based on collaborative critical inquiry into the impact of actions and services. Inclusion involves recognising and respecting contributions from all parties and is the outcome of forging shared understandings. It involves challenging and changing culturally accepted norms of

place and power in engagements. It is demanding of all participants. It is a process, a set of attitudes and communications that go beyond co-producing an agenda and forefronts the importance for service users of owning their physical and communicative spaces. It is hard to grasp, hard to pin down and impossible to frame but inclusive practice has some key characteristics:

- **Active and ongoing communication** - talking and listening, by all
- **Shared decision-making** - which includes taking the lead and stepping back
- Having **real choices** – not just choices from a set menu devised by others
- Having **control** over your own choices
- **Influence and agency** - having your input acted upon
- **Recognition** of your needs and rights - for yourself and by others
- Having **responsibilities** - taking responsibilities and being given responsibilities - not having them delegated or removed
- **Recognition of the person** is at the heart of the process (functionally, emotionally, cognitively, contextually, culturally and spiritually)
- **Respect** for the person
- **Positive** attitudes towards aspirations
- Environmental designs that enable physical **access**
- It is forged through **co-labouring** in a **communicative space** - it cannot be delivered 'to'

Inclusive practice can only be done inclusively. It cannot be an add-on.

5.3 Notions of communication

At the heart of inclusive practice is the development of a communicative space that allows voices to be heard, perceptions to be explored and honest descriptions of practice to be aired. It necessitates that all voices are valued and for the value of perceptions to be agreed, not dictated. It necessitates facilitation. Without a communicative space treatments, processes and procedures alien to the lifestyles, preferences, abilities and characters of people who use the services, are likely to perpetuate. The long-term nature of engagement with services offers opportunities to develop this approach for vital, effective and efficient services.

Communication is seen as secondary to action. Health professionals and managers are encouraged by organisational, professional and bureaucratic imperatives to prioritise 'doing' over 'communicating'. Communication is seen as time consuming and an added extra; even a luxury. This study showed that without effective communication the long-term effectiveness of rehabilitation in practice can be compromised.

5.4 Impact of Inclusion

Services that engaged in developing a communicative space were more likely to develop an inclusive approach to practice. The outcome of inclusive practice was that service provision

(physical or behavioural) was more applicable to the daily lives of users and hence applied more effectively. The cost of not being included is felt socially, emotionally and economically by service users and their carers and family members.

Where a robust communicative space had not been developed this had an effect on the provision of equipment that neither suited a person's personality nor fitted the physical geography of their home. A systematic or bureaucratic (as opposed to inclusive) approach to the provision of technical equipment resulted in expensive resources being delivered to services users but not being used.

Making informed choices about how to be included in services and having that involvement respected and acted upon, leads to improved confidence and motivation for service users.

A greater understanding of the principles of inclusion, that includes developing a communicative space, leads to more successful environments for all. Environments considered inclusive by staff could be considered exclusive by service users.

Effective treatments reduce long-term waste. The cost of repeatedly engaging in services that are not appropriate, either in terms of their content or geography, is particularly high when the conditions in question are by their nature long-term.

Where services are recognised as getting to the heart of the matter they are considered more effective and hence more credible.

When staff feel that they are really making a difference, when they can forge innovative and effective partnerships with service users and see the impact of this, it raises morale. Services led by history, tradition or other frameworks for delivery, rather than being forged by a focus on the needs of service users, can lead to ineffective outcomes and low morale amongst staff as well as the community they serve.

5.5 Enablers and barriers to inclusive practice

Perceptions of who 'knows' and 'what it is important to know about'

Historical weightings of knowledge towards professionals, where contextual knowledge is undervalued, lead to imbalances in communication that affect inclusive practice and effective service delivery. All stakeholders, including service users and CFMs, need support in recognising the importance of in-person knowledge.

Organisational and bureaucratic processes that forefront (and measure) actions above communication are a barrier to developing communicative spaces for inclusive practice.

Communication

The type of communication has an impact on inclusion. Consultation is not necessarily sufficient. The perception that effective communication through reciprocal perspective taking is more time consuming leads people to reject communicative engagement. This perception is not born out by the literature or the long term impact of effective communication.

Understanding and respecting the notion of choice

The notion of choice is not well understood. It is perceived as a luxury. Where people have not been involved in making choices on aspects of services that are important to them, the effectiveness of treatment can be lost. People with long term conditions need to be engaged in developing their lives in a way that makes sense for them. Informed choice is not a luxury, it is a necessity.

Facilitation

The need for two distinct facilitation roles were articulated, facilitator

- as advocate who works on behalf of service users (a model for advocates and self-advocates is available in learning disability practice)
- as a person who opens up spaces to support more inclusive conversations across all parties. Professionals have the technical knowledge and service users and CFMs hold the knowledge about their own lives, preferences, skills and abilities in the everyday situation. These need to be brought together to support the translation of knowledge into effective practice. The mixing of these sets of knowledge is vital for effective treatment but hindered by:
 - Perceptions of the professional/practitioner as the knower - by both professional/practitioners and service users and CFMs
 - Historical perceptions of 'being grateful' for services
 - Deference
 - Difficulties of articulating a position when you are still struggling to come to terms with that position (for example service users coming to terms with their condition, family members recognising themselves as carers)
 - Fear that critical discussion
 - will be misconstrued as criticism that would hinder relationships
 - would lead to cuts rather than improvements in services
 - Inflexible bureaucratic systems
 - The perception that talk is time consuming and unproductive
 - Organisational cultures that prioritise and record actions and not processes that lead to effective outcomes.

6. Impact of research design

The research process modeled a form of communication that used a facilitated, recursive approach to shape a communicative space. This communicative space created opportunities that gently prodded people into critiquing both their own articulation and those of others. It got beneath rhetoric and common understandings. There was evidence of this in the design of the project, that was influenced by the interchanges within the core research team and the quality of the data generated. Repeatedly revisiting both data and analysis of that data with participants resulted in new approaches to understanding, new meanings being articulated and analysis being verified. It needed time and facilitation.

Data analysis and triangulation
1 st level - researcher analysis – taken back to participants in focus groups
2 nd level - researcher/participant analysis taken to heterogeneous focus groups
3 rd level – researcher analysis using Nvivo as data storage and sorting/sifting mechanism
4 th level – confirmation and development of themes and concepts through a 'Big Conversation Day' for all participants.

7. Difficulties in embedding the learning from the project

The low priority given to 'soft' aspects of both practice and research into practice may have had an impact on the ability to recruit managerial staff into the project. Staff who engaged with the communicative space afforded by the project experienced its potential to affect their thinking and hence future actions. Taking the learning beyond practitioners and engaging senior managers proved more intransigent. This is a challenge if we are to affect cultural change.

Policy and practice in the NHS now forefronts the importance of communication and a more inclusive approach but the recording processes still prioritise measurable actions. There is a need for a re-conceptualisation of practice and the monitoring of practice in LTNC that advances the development of an inclusive approach through a communicative space. Considerable work is needed to develop this in practice. Inclusion cannot be fitted in when other activities allow, it has to be central and requires an overt space in practice which is not currently recognised.

8. Summary

This study has highlighted the unacceptable cost of practices that exclude the very people they are there for. Whilst for the NHS the burden of this is financial, service users and CFMs shoulder a shocking cost in relation to their health and life choices. Directors of services and commissioners need support to understand why and how to set priorities towards inclusive practice and to have this overtly legitimised. The challenge is to conceptualise services for people with long term conditions that move from a delivery model to a model with co-creation at its centre.

CHAPTER 1: THE CASE FOR RESEARCHING INCLUSION

The Department of Health (2005) reported that approximately 10m people in the UK have a neurological condition, with 350k people needing help with daily living. There are approximately 850k people caring for someone with a neurological condition. They account for 20% of acute hospital admissions and are the third most common reason for seeing a GP. For most people the illness/injury has life-long consequences (DH, 2005 p10).

People with neurological conditions access a variety of inpatient, outpatient and community services. From these services they receive up to date scientific treatment, functional assessment and support. The people who carried out this research believed that there might be a link between the way people with neurological impairments are included in the NHS and the way they use treatment knowledge to develop their skills and independence in the community. Much has been written about types of medical treatment people receive but we have found nothing about the effect of feeling included and its impact on the ability of people to use hospital-based and community services. Over the past decade community neuro-rehabilitation has emerged as an extension of neurological rehabilitation (Barnes & Radermacher, 2003) but critical gaps exist in understanding how this should be carried out (Chard, 2006).

Cott (2004) highlighted the need to improve the relationship between treatment and community. She identified the importance of the subjective understandings that people attach to situations as drivers for participation. This study sought to find out whether there is a link between the way people with neurological impairments are included in the NHS community and the way they use knowledge from treatment to develop their skills and independence. As such, it directly addressed one of the key threads running through legislation in respect of long-term conditions (LTCs), that of improving the quality of life of service users through a more patient-centred, inclusive, approach.

It is a key tenet of policy initiatives that people with differing needs and from different communities and social groups should be meaningfully involved in the development

of their own services and be able to make choices about the way in which these are embedded in the way they lead their lives. This approach necessitates a move to a more inclusive philosophy by service providers. There is an aspiration for sustained inclusion and participation (DH 2007c:46) but sparse literature on the development of a more inclusive approach to treatment and how this affects those with neurological conditions in their daily lives. Very little is known about what service users experience in relation to engaging with services and embedding those services in their daily lives to enable them to be more independent: even less is known about the experiences of carers (Baxter et al, 2001).

Lord Darzi (2007b:6) reported that people still feel alienated from the system, and that patients “still feel like a number rather than a person ... [they] lack ‘clout’ inside our health care system”. The DH Impact Assessment (2007c:30) identified that stroke survivors leaving hospital could still feel forgotten by services and did not feel part of decision-making processes. In addition, in daily life, 'social exclusion', where social isolation occurs for reasons that are beyond the control of the person involved, has been identified by numerous studies as a common outcome of traumatic brain injury (Callaway et al, 2005).

Dr Colin-Thomé (formerly National Clinical Director for Primary Care), when introducing action to implement the Government's priority to improve care for people with LTCs (2007), highlighted the need to move away from reactive care, based in acute systems, towards a systematic, patient-centred approach. He stated that the latest evidence continues to support the clear messages that people with LTCs are the most intensive users of the most expensive services. As they are also long-term users of social care and community services, Dr Colin-Thomé argued that there would be benefits to the population and financial savings if health and social care communities invest in effective management that takes a more person-centred approach. Some of the costs of social exclusion, both personal and economic, have been highlighted in the Social Exclusion Unit Interim Report (2005). It is therefore reasonable to expect that reducing perceptions of exclusion would have a positive effect on people's lives and affect their need for further support and intervention services.

Questions have been asked about whether participatory philosophical/theoretical underpinning about service delivery may lead to more effective life-enhancing outcomes. Studies have cited the importance of strengths-based practice (Rowlands, 2001), of friendships (Callaway, 2005) and for models of rehabilitation that include opportunities for users to be incorporated into communities (Condeluci, 1997), but most tend to refer to an integration approach, finding where people might fit, rather than making broader changes to precipitate inclusion.

Being part of the treatment process for service users has been articulated through recent policy initiatives as a key element of more effective practice. The White Paper Equity and excellence: Liberating the NHS (July 2010) set out the Government's vision for people with long-term conditions to be at the centre of decisions about their care and support - "no decision about me without me". The generic LTC model places the emphasis on engaging the individual in making shared decisions about their care. What this looks like in practice, and which elements of the engagement process are necessary for it to be effective, is not well understood.

Using the social model of disability as its driver, the study is framed by the notion that integration and inclusion are mutually exclusive, integration being defined by a process of fitting into a location or event, changing buildings, bringing in people who 'know'. It can be delivered and is underpinned by dominant values of what is normal (Swain, 2003). Inclusion is conceptualized as more challenging and is characterised by recognising diversity, including race, gender and disability, and based on the positive valuing and celebration of difference. Inclusion is partnership-led through negotiation and demands change for all. It is a Government policy commitment that "By 2025 disabled people in Britain ... will be respected and included as equal members of society" (PMs Strategy Unit, 2005) but processes for developing communities of practice (including the NHS community) for this to happen remain unspecified.

This study focused on:

- What is inclusion
- Enablers for and barriers to inclusion

- The impact of inclusion and exclusion on both the users of services and services themselves

It sought to tease out how neurological rehabilitation services are experienced and understood by service users and carers and family members (CFMs), how people perceive such services in terms of feeling included and how daily lives are affected by feelings of inclusion. In other words, the researchers wanted to find out whether there is a link between the way people with neurological impairments are included in the NHS community and the way they use knowledge from treatment to develop their skills and independence.

ORIGINS OF THE RESEARCH QUESTION

Northumberland Tyne and Wear (NTW) NHS Trust has an active Patient and Public Involvement (PPI) group and in 2005 it funded a review to look at the lives of service users from their perspectives. The agreed priorities for change included the need for service users to be involved in major decisions about their lives and to be visible and included in local communities. This raised questions about what 'being included' might mean.

A group of people, mainly service users, who thought there might be a link between the way people with neurological impairments are included in the NHS community and their motivation to use knowledge from treatment to develop their skills and independence in the wider community, instigated this study.

In 2008 a 'Listening Event' was held in Hunter's Moor Neuro-rehabilitation Centre. The building was being closed down and the whole service moving to Walkergate Park Neuro-rehabilitation Centre under a PPI new build initiative. The 'Listening Event' was instigated to consult with people who were users of services about the shaping of the new Walkergate Park Regional Neuro-rehabilitation Services. As part of this there was an opportunity for people to discuss what kind of research they thought would help future service delivery. A number of topics were suggested, one of which was about the impact of feeling alienated from service delivery, or conversely the impact of being more included in the ways services are shaped and

delivered. Service users suggested that neurological rehabilitation could be more effective if it was embedded in communities of practice that include the users: that it might be more effective when based on the real and complex lives people live rather than on a clinical model of effectiveness.

RESEARCH AIMS AND OBJECTIVES

This study investigates how service users, carers and family members and staff understand integrated (fitting into a system) and inclusive (making the system suit the person) ways of working. It describes what inclusion looks and feels like for people with neurological impairments using neurological rehabilitation services, and other health services in the North East of England. The aim of this study was to find out whether there is a link between the way people with neurological impairments are included in the NHS community and the way they use knowledge from treatment to develop their skills and independence in their daily lives.

It sought to:

1. identify current perceptions of service delivery
2. investigate understandings of integrated and inclusive practice
3. map what inclusion looks/feels like for people using neuro-rehabilitation services
4. articulate the impact of current forms of inclusive practice on the lives of service users and CFMs
5. identify enablers and barriers to inclusive practice
6. provide holistic knowledge and a set of principles to support the development of more inclusive and effective service delivery
7. develop a body of knowledge on inclusive practice and its impact

The research also considered the perceptions of service delivery from:

- i) the perspective of staff who work in the services
- ii) CFMs of users of Walkergate Park Services

iii) voluntary services who engage with service users, CFMs and Walkergate Park Services

The study was framed within the context of symbolic interactionism i.e. that the understandings people attach to their situations are socially constructed and shaped by social interactions. It addressed some of the key themes in the LTC (Neurological) National Service Framework (NSF) (2005)

- Person-centred approaches
- Care planning around the needs and choices of the individual
- Joint working

This NSF is set against a backdrop of similar Government policy initiatives towards more inclusive practice in other arenas e.g. *'Valuing People: a new strategy for learning disability for the 21st century' White Paper* (2001); the new *Commissioning Framework for Health and Wellbeing* (2007a) which proposes to help people stay healthy and independent, provide choice in care services, deliver services closer to home and tackle inequalities; the *White Paper Our health, Our care, Our say* (2006) and the *NHS Improvement Plan: Putting People at the Heart of Public Services* (2004) which offers a model for management of LTCs through self care, disease management and case management. *The Impact Assessment: a New Ambition for Stroke* (2007) raises issues about continued care and how this might be more effective with *The National Stroke Strategy* (2007c) putting particular emphasis on the involvement of people in care planning.

CHAPTER 2: LITERATURE REVIEW

This chapter informs the search for a link between the way people with neurological impairments, specifically acquired or traumatic brain injury, are included in the NHS and the way they use treatment knowledge to develop their skills and independence in the community. Much has been written about types of medical treatment people receive but there is little about the effect of feeling included and its impact on the ability of people to use hospital-based and community services.

This overview draws from published peer-reviewed journal articles and reports written in English pertaining to the topic of inclusive practice from the perspectives of service users, family and carers, and health care staff. Relevant items were identified by examining references retrieved from:

- searches conducted in electronic bibliographic databases provided by the University of Northumbria (AMED, ASSIA, CINAHL, PsycArticles, Web of Science, ZETOC) initially using subject terms and keywords (and variants where appropriate) taken from the project proposal, such as inclusion, exclusion, service users, carers, professional-patient relationships, involvement, neurological, brain injury and rehabilitation;
- resources provided by the research team, advisors to the project, and subject specialists in the field;
- hand searches of reference lists provided to the research team by The Kings Fund and the Department of Health, and also of the bibliographies of relevant items retrieved as above.

The chapter begins by outlining some key terms (personalisation, person-centred planning, participation, co-production, and inclusion) before discussing patient-centred, and inclusive, practice. Two elements, relationships and decision-making, are explored with reference, respectively, to Bourdieu's theory of practice and Habermas' theories of democratic communicative action and life world. Findings from studies of the experience of neuro-rehabilitation from the perspective of

patients, families and carers, and therapists, are summarized. Finally, the social policy context for inclusion in health care in England is outlined in a table.

TERMINOLOGY

'Personalisation', "the process by which services are tailored to the needs and preferences of citizens" (Great Britain Prime Minister's Strategy Office, 2007, p. 33), is a central feature of the government's agenda for public sector reform. Participation, choice, control and empowerment are key concepts for personalisation and have their origins in the independent living movement and social model of disability. The idea of starting with the person, rather than the service, was announced in *Putting people first: a shared vision and commitment to the transformation of adult social care* (2007). Authored by Ministers, local government, the NHS, social care, and professional and regulatory organisations, this concordat documents the shape of a personalised adult social care system, where people have maximum choice and control over the services they receive through the development of individual budgets, direct payments and 'person-centred' approaches to planning and care.

'Person-centred planning' was formally introduced in 2001 for people with learning disabilities in the Command paper *Valuing People* (Great Britain. Department of Health, 2001). Its central tenet, "rather than fitting people to services, services should fit the person" (Valios, 2008, p. 36), gives it similarities to personalisation and inclusive practice.

'Participation' and patient participation, at both individual and national levels, have an array of interpretations and lack clarity. Hammel et al (2008) sought to gain an insider perspective from 57 disabled people, a third of whom had a traumatic brain injury, in understanding what participation means, how to characterize it, and the barriers and supports to participation. The participants defined participation as a "multifaceted, transactive process . . . predicated upon access, opportunity, respect and inclusion." (p. 1458-9)

'Co-production' is another term used in recent discussions about personalisation. Co-production, also called 'co-creation' or 'parallel production', describes direct participation and community involvement in social care services, and can be seen as a way of building social capital (Valios, 2008). Dunston et al (2008) theorise and detail co-production and health system reform in an Australian context. In the UK, one view of the overall aim of the co-creation concept is to reduce the pressure on the health system by preventing people from needing traditional health care altogether (Lynch, 2005). In 2002, *Securing our future public health: taking a long term view* (Wanless et al, 2002) showed the potentially massive growth in health costs if we did not invest in reducing demand for, as well as improving supply of, services. It also argued that the future of health care in an era of chronic, rather than infectious, disease would hinge on the 'full engagement' of people in their own health care (Lynch, 2005; Cayton, 2006). A fully-engaged person is "one who looks after themselves and makes choices with responsive health services to take responsibility for and to maintain and improve their own health" (Cayton, 2006, p. 288).

This new approach to designing service is illustrated by the Design Council's involvement in co-creating services for diabetes management in Bolton and Kent (Lynch, 2005) and by Hyde and Davis' (2004) examination of mental health service design, culture and performance. In 2010 the Department of Health produced '*A guide on co-production with older people*' to help local authorities and their partners, including local communities, work together and improve older people's influence at all levels of service commissioning and delivery. Seven principles are identified: older people are involved throughout the process, from the beginning to the end; older people feel safe to speak up and are listened to; older people's skills and experiences are used in the process of change; we work on the issues that are important to older people; it is clear how decisions are made; meetings, materials and venues are accessible for older people - they can get there, prepare, be heard and follow progress through reports and minutes; and, progress is evaluated through looking at the actual changes in older people's lives.

In terms of neuro-rehabilitation, locational access is also an issue. Improvements in locational access, such as ramps and wider doorways in city centres, are viewed by many as a way of being more enabling to those using wheelchairs, but such

environmental improvements are not sufficient to overcome a 'user's' understanding of inclusive access (Bromley, 2007).

Inclusion in health service planning and delivery is described by a number of different terms, sometimes interchangeably. In areas where it is difficult to find good examples of 'inclusive practice' inclusion is often described by what it isn't, as in Wilkinson and McAndrew's (2008) phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings entitled "I'm not an outsider, I'm his mother!" Inclusion may also be confused with integration: to clarify, 'integrated' is about the person fitting into the system, whereas 'inclusive' is about making the system suit the person.

'Inclusive practice' is an overarching term that may feature processes such as partnership, participation and collaboration. What all of these processes have in common is that they each have the potential to change the traditionally asymmetric relationship between doctor and patient, shifting the balance away from 'doctor-led' towards 'patient-led' or 'patient-centred' care. This shift is important, not only because it reflects social, cultural and political changes since the 1960s together with demands for increased autonomy and choice, but also because improving communications between patients and professionals has been assumed to improve health outcomes and have benefits for both parties by reducing the stress caused by unbalanced power and knowledge relationships (Hughes et al, 2008). Patient-centredness in itself a "slippery concept" (Mayes, 2009, p.484) and, indeed, only one of several notions of 'centredness' evident in health care settings (Hughes et al, 2008), provides a useful starting point for framing this exploration of inclusive practice within neuro-rehabilitation.

PATIENT-CENTRED PRACTICE

NHS 2010-2015 from good to great: preventative, people-centred, productive (Great Britain. Department of Health, 2009) identifies that carers and patients want to be recognized as expert partners in their care, and notes:

“This aspect of quality has been neglected or seen as less important in the past. If we are to realise the vision of a people-centred NHS, with quality at its heart, then this has to change. Patients and their carers have a right to be treated equitably, whoever or wherever they may be.” (p.30)

The shift towards the ‘patient-centredness’ in the NHS can be evidenced through government records. For example, a Select Committee on Education and Science in 1968/69 acknowledged that:

“. . . medical practice frankly recognises that some doctors are patient-centred and accommodates them in general practice, pediatrics, psychiatry and similar fields that require a feeling for the patient as a person; but it recognises, too, that many doctors are ‘disease-centred’, uninterested professionally in people, and a little irritated that diseases usually come with people wrapped around them.” (Great Britain. House of Commons, 1969, p. 265)

The term was subsequently used in connection with midwifery training in the *Briggs Report* (Great Britain. House of Commons, 1972, p.87) and appears infrequently in other documents. One of the first occurrences in UK government documents of the term ‘patient involvement’ is reference to the popularity, due to the friendly atmosphere and patient involvement in the running of the centre, of a psychiatric unit at the Croxteth Day Hospital (Great Britain. House of Commons, 1980). It is not until the 1990s, in connection with breast cancer services, that we see a repeated reference to ‘patient-centred care’ (Great Britain. House of Commons, 1995). The mid-1990s also saw the publication in the UK of *Patient-centred medicine, transforming the clinical method* (Stewart et al, 1995). The launch of *The NHS Plan* by the Department of Health in July 2000, with its vision of a “health service designed around the patient” (p.17), featured the term ‘patient-centred care’ five times.

A systematic review of involving patients in the planning and development of healthcare by Crawford et al (2002), found 42 studies, out of 337 papers, describing ‘involvement’. Involvement was defined as “the active participation in the planning, monitoring, and development of health services of patients, representatives, and wider public as potential patients.” The authors conclude that involving patients had

contributed to changes in service provision, but the effects of these on the use of services, quality of care, patient satisfaction and patient health had not been reported. Of interest to this review, where we are looking for examples of going beyond a 'choosing from the menu' approach, is the reference to a small study concerning user-focused monitoring in a neurological disorder unit where patients and staff found user-involvement rewarding: MS Society volunteers, many of whom have MS, were trained to make sure that self-audit assessments were fair. As well as increasing their knowledge about MS and service provision the volunteers said that "the experience also helped their sense of self-worth." (Poole, 2000. p. 15)

A global definition of patient-centred care is proposed by Stewart (2001), and within general practice by Little et al (2001). Patients view patient-centred care as that which:

- a) explores the patients' main reason for the visit, concerns, and need for information;
- b) seeks an integrated understanding of the patients' world—that is, their whole person, emotional needs, and life issues;
- c) finds common ground on what the problem is and mutually agrees on management;
- d) enhances prevention and health promotion; and
- e) enhances the continuing relationship between the patient and the doctor. (Stewart, 2001, p.445)

Stewart goes on to explain that patient-centred practice is not a process, but rather "a holistic concept in which components interact and unite in a unique way in each patient-doctor encounter"; and that it is not about sharing *all* information and *all* decisions but rather ". . . taking into account the patient's desire for information and for sharing decision making and responding appropriately" (p. 445). This can create tension, as we see in Slade et al's (2009) qualitative study of partnership in care for people with non-specific chronic low back pain, between patients' wanting a genuine voice and also wanting a care-provider to give explicit diagnosis, neatly encapsulated as 'listen to me; I know my own body: tell me; explain it to me'.

The use of patient narratives to explore patient-centred care further confirms that patients may be reluctant to participate in their care, viewing it as interfering, or may feel uneasy about breaking out of traditional professional-patient relationships: “If patients were to be encouraged to take a more active role in their care, this gratitude at being cared for and the deference to medical authority needed to be supplemented with a greater sense of ownership in their care . . .” (Blickem and Priyadharshini, 2007, p. 623)

Mead and Bower’s (2000) review of empirical literature for patient-centredness captures the lack of consensus surrounding patient-centredness, citing, for example, early initial definitions from the 1960s stemming from general practice of “understanding the patient as a unique human being” to a later style of consultation emphasizing communication and relationship (see also Hughes et al, 2008), originally seen in client-centred psychotherapy. This review also provides a conceptual framework identifying five dimensions of patient-centredness - biopsychosocial perspective, the ‘patient as person’, sharing power and responsibility, therapeutic alliance, and ‘doctor as person’ - that make it different from the traditional ‘biomedical model’ that focuses on the clinical diagnosis and treatment of illness.

Lepelge et al (2007) provide conceptual and historical perspectives on person-centredness in relation to rehabilitation where the concept of person-centredness has multiple meanings, including addressing the person’s specific and holistic properties and difficulties in everyday life, respecting the person ‘behind’ the impairment or disease, and acknowledging the person as an expert regarding their own situation and needs. Gzil et al (2007) question why rehabilitation is not yet fully person-centred and whether it should be more person-centred. This study articulates the challenge of finding ‘inclusive practice’ and ‘person-centred care’ in rehabilitation practice that is framed within a medical model.

At practice level, a guide to improving neurology services defines a person-centred service for people with long-term neurological conditions as “seeing the right person at the right time in the right setting with the right information to help make informed decisions” (NHS Modernisation Agency, 2005, p.14). This guide states that an effective person-centred service needs:

- good co-ordination
- services planned and delivered in an integrated way around the needs of the patient
- an understanding of the skills of different professionals and the role of different agencies
- an integrated assessment of health and social care needs
- up to date information given at the appropriate time along the patient pathway
- involvement of the patient and carers in the decision-making process
- access to general and specialist advice as necessary
- support to help patients manage their condition themselves
- encouragement to the patient to join any of the support groups relating to their condition

Services were not, however, always delivered in a person-centred way. For example, issues regarding information provision and co-ordination of services meant that: “Some did not feel involved in decisions about their care and treatment and were left feeling isolated and confused, lack of information and co-ordination.” (NHS Modernisation Agency, 2005, p.14)

Hammell (2001) argues that person-centred, or client centred practice, emanating from the client’s perspective, needs to incorporate a philosophy of respect for the client that is characterised by partnership approaches to practice that encourage choice and control. She draws on both rehabilitation and disability studies literature to challenge traditional views of rehabilitation and client-centred practice (Hammell 2006, p.147-163) and to argue that power and control issues have not been adequately addressed to facilitate a more client-centred approach. She draws on the work of Oliver (1996) who suggests that ‘within rehabilitation there is a failure to address the issue of power and acknowledge the existence of ideology’. (p.104) Professional groups espouse collaborative working and realignment of power (Law et al, 1995) and when a collaborative approach is used in practice, service users report positive benefits in terms of outcomes (Ford et al, 2003) and relationships (Marquis and Jackson (2000). Hammell (2006) suggests however, that professional rhetoric does not match the reality of practice in part due to ‘an unwillingness to

relinquish professional power and a conflict of accountability.’ The latter finds professionals ‘serving two “masters” – the system in which they are employed, and their clients.’ (p162).

Many of the above points are vividly illustrated by Nieuwenhuijsen (2009), a rehabilitation specialist of more than 30 years, who presents her observations of the person-centred medical and rehabilitation services her husband received after a ruptured abdominal aortic aneurysm. Nieuwenhuijsen identifies two further issues: the role of the environment in the rehabilitation process and the need for transparency, for example, in communication. The theme of communication occurs elsewhere, not only as a mechanism for information-exchange (Nieuwenhuijsen, 2009) but also as a mechanism for empowerment, by enabling the patient to ‘tell their story’ (Mayes, 2009). This link between the ‘complementary’ concepts of patient-centredness and patient empowerment is discussed by Holmstrom and Roing (2010) who view patient empowerment as a broader concept that can be achieved by patient-centredness, but nevertheless note that patients can also empower themselves.

INCLUSION

The terms integration and inclusion are often used interchangeably. Increasingly, however, differences between the two are being articulated within academic writings (Thomas 1997, Reiser & Mason, 1992, Oliver, 1996). Although debate remains, integration is generally described as the provision of ‘additional arrangements’ to enable settings to admit certain people with particular needs but where the setting itself would remain essentially unchanged. In its most negative connotation this is integration by location, where people attend but cannot participate or the provision of limited access to, or a watered-down variant of, regular provision. It is characterised by an approach where people may have certain choices but have to fit in, in the best way they can, to regular activities, with the onus being on the person to make accommodations. Inclusion is conceptualized as far more challenging than integration. It is a process that involves society in making changes, both physical and attitudinal. It embraces diversity. It enables people be in control of their lives and the choices they make in relation to their lives.

INCLUSIVE PRACTICE

Inclusive practice is an overarching term, often seen in reference to including groups. For example, the *NHS East Midlands Inclusion Strategy 2010-13*, discusses inclusion at the level of commissioning and staffing from a general point of view. Workforce capabilities for socially inclusive practice were first developed in 2004, for mental health practice. These were subsequently developed by the Department of Health to produce best practice guidance, *Capabilities for inclusive practice* (National Social Inclusion Programme, 2007). The NHS Education for Scotland has produced an online training document, *Developing socially inclusive practice*, exploring the link between the *10 Essential Shared Capabilities* (Hope, 2004) and developing socially inclusive practice.

This work on capabilities (Hope, 2004; National Social Inclusion Programme 2007) subsequently informed the Royal College of Nursing's *10 Principles for inclusive practice*. In terms of providing 'person-centred care' in nursing, the RCN principles appear to encapsulate a person-centred nursing framework (McCormack et al, 2010), stating that:

- nurses work collaboratively to establish goals and outcomes which are from the perspective of the individual.
- nurses are highly skilled to build trusting relationships with individuals which elicit 'what matters' to them.
- nurses create relationships with a wide range of community services to facilitate matching of opportunities to unique needs.

Other principles relevant to providing individual, inclusive care are those of 'promoting recovery':

- nurses respect that recovery is what people experience themselves and is not a health 'intervention'.
- nurses support individuals to make their own choices and decisions – demonstrating hope and optimism towards recovery.
- nurses are creative in promoting opportunities for people to achieve a valued and positive lifestyle.

And of 'identifying people's strengths and needs':

- nurses use advanced assessment skills which focus on the strengths and needs of individuals and their support networks.
- nurses are able to work with complexity, recognising the holistic needs and individual situations of people.
- nurses appreciate and respect that people have a right to make choices and manage their own recovery.

Glasgow Association for Mental Health (GAMH) (2006) defines inclusion as an approach applicable to individuals that can contribute to challenging inequalities and the social inclusion of people who experience mental health problems in our communities.

“Inclusive Practice is about participation, collaboration, and including people: where individuals are fully involved in choices and decisions that affect their lives and in the matters that are important to them.”

In doing so the Association captures two key elements of inclusive practice, relationships and decision-making, and these are explored further below with reference to Bourdieu's theory of practice and Habermas' theories of democratic communicative action and life world, respectively.

GAMH (2006) principles for Inclusive Practice in the arena of mental health include:

- Valuing people as experts in their own mental health.
- Valuing and promoting diversity and equality.
- Challenging stigma, prejudice and discrimination in all its forms.
- Upholding and promoting the legal and civil rights of people who use our services.
- Promoting choice.
- Working collaboratively with individuals, and groups, to agree goals, actions and solutions.
- Working in a way that enables people to have as much control as possible over the decisions and matters that affect their lives.

- Services which offer safe environments, are welcoming, and respect, value and reflect our diverse identities.
- Being open and honest about boundaries and any limitations.

PROFESSIONAL-PATIENT RELATIONSHIPS

In neuro-rehabilitation, goal-setting is a core element. Holliday et al (2007) used focus groups to explore how 28 inpatients with neurological impairments experienced two different types of goal setting and identified the issues that underpin individuals' experience of goal setting. This study illustrates the complexity of patient understandings of goal setting and whilst involvement may be important it is challenging in practice. The findings suggest that the quality of the relationship with the key worker was important. As in previous studies, effective communication, time spent establishing rapport and discussing priorities "had significant consequences for the way in which rehabilitation was perceived." (Holliday et al, 2007, p. 393)

Another qualitative study of perceptions of goal setting in a neurological rehabilitation unit from the perspectives of patients, carers and staff (Young et al, 2008) identified the goal-setting process as "a collaborative endeavour between the patient and the clinical team" with various benefits for the patients, but also the triangulated approach revealed that goal setting may also be important for the psychological well-being and future role of carers: "The goal setting process benefited carers as well as patients by fostering relatedness with the clinical team and providing some achievable short-term treatment aims. In addition, carers used the goal setting meetings as a coping strategy, allowing them to compartmentalize and defer future anxieties." (Young et al, 2008, p. 194)

These two studies begin to illustrate the complexities of the professional-patient/family/carer relationships within the rehabilitation setting. A further layer of complexity was uncovered by Bertram and Stickley (2005) in their exploration of what inclusive practice means in day-to-day service delivery. They examined whether mental health nurses were 'promoters of inclusion or perpetrators of exclusion' by consulting focus groups in a residential rehabilitation unit.

“The literature identifies that mental health services and those individuals working within them have the potential to facilitate inclusion for their client group, because of their power to initiate potential inclusive opportunities. However, evidence suggests that service users themselves perceive many aspects of mental health services as contributing to the problem of exclusion. This has been attributed to an accumulation of messages, attitudes and disempowering practices that have emanated from mental health care providers over a long period.” (Bertram and Stickley, 2005, p. 387)

Discussion of the findings highlight how, in spite of alleged inclusive practices, the reality was quite different:

“. . . the attitudes held by members of the unit team could impede the clients’ opportunities to become socially included, as a result of defensive practice, paternalistic attitudes, expectations of the local community upon the team and the stagnant views that are embedded in the culture of mental health services.” (Bertram and Stickley, 2005, p. 387)

Understanding how nurses view and react to their patients, both implicitly and explicitly, may allow us to unravel such apparently contradictory care practices. Rhynas (2005) explores nursing interactions at a theoretical level using Bourdieu’s theory of practice. Bourdieu’s work incorporates both ‘biomedical’ objectivity and ‘compassionate’ subjectivity to create a framework that explains individual and group actions in a social world defined through the three concepts of ‘field’, ‘capital’ and ‘habitus’ (Rhynas, 2005 p.181).

Within the field, according to Bourdieu, the primary area of importance is the study of the relationships, rather than the individuals. For example, the hospital care of patients with traumatic brain injury will be influenced by the organizational structures of the hospital and staff.

Capital, for Bourdieu, highlights the power of a person and how this can be used to change their position in the field. In a neuro-rehabilitation setting, a patient with severe injuries will usually have less opportunity to contribute to decisions about their care, thus reducing their power to influence their situation.

Habitus is used by Bourdieu to explain features of social life that are often unconscious or unquestioned, perhaps influenced by tradition or custom. For example, in neurological rehabilitation, a nurse's attitudes may be shaped by observations of colleagues' approaches, say, in dealing with communication difficulties. Note that "people will also use their personal history and experiences to shape their responses and feelings within the workplace" (Rhynas, 2005, p.182). Whilst not explicit, the interplay between these responses, relationships and structures could influence care and practice. This is well illustrated in McKeever and Miller's (2004) Bourdieusian interpretation of mothers' accounts of raising severely disabled children. The authors further the use of Bourdieu's three concepts by presenting mothers' responses to exclusionary practices. Knowing that parent-professional interactions greatly influence the quality of children's care, McKeever and Miller observed that mothers learned 'the rules of the game' to facilitate services for their children and, in doing so, often demonstrated contradictory behaviour.

A study of patient-centred care in stroke rehabilitation exploring the potential of using patient narratives for 'patient-centred' inter-professional learning identified the same issue, that once patients and carers try to 'play the game' in order to 'fit in' the likelihood of receiving patient-centred care decreases: "once they try and play the game, they're fitting in with the hospital, rather than the hospital working around them." (Blickem and Priyadharshini, 2007, p. 627)

And again, in a study of perceived service and support needs during transition from hospital to home following acquired brain injury, participants consistently expressed frustrations at what they referred to as 'the system': a term used to collectively describe the issues impacting upon access to and utilization of rehabilitation and other support services. Participants, 20 individuals with acquired brain injury and 18 family caregivers, were seen to either attempt to work with the system or struggle against it and the findings suggest that

"the complexity and rigidity of service systems can significantly . . . amplify the difficulties individuals with ABI and their family caregivers experience with respect to adjustment and integration." (Turner et al, 2011, p.828)

Gravois Lee et al (1999) draw on Bourdieu's work in their detailed study of improving

health service encounters in a rural Appalachian community through resource sensitivity. Descriptions of staff members ensuring they understood about the lives and families of people and expressing genuine concern demonstrate “egalitarian, personalized, and client-centred interactions” where “consumers were given as much time as they needed, service encounters were not rushed, and informants did not feel ‘pushed aside’” (Gravois Lee et al, 1999, p. 242). Pertinent examples of models of healthcare, driven as much by ‘caring’ as ‘curing’, appear in *Now I feel tall* (DH/RAW/PPI, 2005). This report demonstrates the importance of improving patients’ emotional experience and the relevance of this to creating a patient-led NHS. It cites examples such as a reception nurse in the Newcastle, North Tyneside and Northumberland Mental Health NHS Trust who was “a friendly face to meet them [patients] on admission and stay with them until they are settled”, and states that this “makes a patient feel cared about and this is really important.” (DH/RAW/PPI, 2005, p. 52)

DECISION-MAKING

Improvements in health outcomes occur when patients are better informed and more engaged in treatment decisions because they select treatments that fit better with their values and lifestyle, which improves their ability to adhere to treatments (King et al, 2011). There is evidence (Robertston et al, 2011) that patients want to be offered choices and that doctor-patient collaboration correlates positively with health outcomes.

The accounts of experiences of neuro-rehabilitation demonstrate that patients do not like the idea of having no say at all in their treatment. Many patients want to have some say in their treatment, but, for various reasons, do not want to take full control of decision-making. A continuum of shared decision-making, where patients have knowledge about treatment options, and where clinicians may participate in, but do not dominate the decision-making process, is a useful resource for creating a middle ground and is particularly applicable in situations where there are several valid treatment options and patients want a real choice. It is also a challenge against the traditional asymmetry of doctor-patient relationships.

Research conducted in the 1990s, at a time when shared decision-making was increasingly advocated as an ideal model of treatment decision-making, showed a lack of clarity about what shared decision-making really means, both for clinicians and patients. Charles et al (1997) describe the origins of, and models of, shared decision-making and identify key characteristics: shared decision-making involves at least two participants – the physician and the patient; both parties take steps to participate in the process of treatment decision-making; information sharing is a prerequisite to shared decision-making; and a treatment decision is made and both parties agree to the decision (Charles et al, 1997, p. 685-688). These characteristics have been questioned as to how far they describe a real choice, as opposed to a choice from a pre-set menu. For example, Sandman and Munthe (2010) present the 'shared' model alongside other models of decision-making, such as 'paternalism' and 'patient choice'. Thus a continuum of shared decision-making models is presented, including 'informed patient choice', 'interpretive patient choice', 'and advised patient choice'. The fourth and fifth options, 'shared rational deliberative patient choice' and 'professionally driven best interest compromise', differ in that they present a dynamic process for 'taking sharing all the way', where, for example, "the professional and patient both engage in a rational discussion or deliberation, trying to get all the relevant preferences, facts and reasons relating these aspects together on the table. In the end the patient decides what option to choose." (Sandman and Munthe, 2010, p. 73)

Such models of effecting change through dialogue draw from Habermas' theories of communicative action and life world (Habermas, 1984; Habermas, 1987) as a tool in medical lifestyle interventions. Returning to the options described above, 'shared rational deliberative patient choice' exemplifies 'communicative action', that is, interaction that aims to achieve a consensus between participants; and 'professionally driven best interest compromise' exemplifies 'strategic action' that aims to achieve a predetermined goal. Walseth and Schei (2011) give a detailed discussion of how communicative action can be implemented in decision-making processes in general practice, and practical guidelines – what to talk about and how to talk about it - that bring together the patient's 'life world' and the doctor's 'system world' experiences in consultations. Note that for a decision to be rooted in a patient's everyday life it has to take into consideration the patient's practical

circumstances, feelings, preferences and so on, as demonstrated in a study entitled *Giving voice to the lifeworld* (Barry et al, 2001).

Returning to the practicalities of how communicative action can be implemented in decision-making, Walseth and Schei emphasize that “The aim is a balanced conversation, demonstrating respect, consistency and sincerity, as well as offering information and clarifying reasons”(Walseth and Schei, 2011, p.81). This is illustrated through a case story illustrating the importance of detail, time, trust, and the delicate use or non-use of power, in a patient’s increasing ability to make independent decisions over a prolonged period of interaction with her GP:

“The doctor’s enduring interest and engagement in seemingly trivial aspects of the patient’s life contributes to a powerful therapeutic alliance, which has a strong empowering effect . . . at the same time, a practical understanding of the situation is produced through a reflection focusing on the particulars and wholeness at the same time.” (Walseth and Schei, 2011, p. 88)

The authors conclude “When challenged to help patients adjust to illness or change lifestyle, doctors need to take an active interest in the patient’s everyday life, and seriously explore the conscious and unconscious complexity that precedes, constitutes and results from behaviour” (Walseth and Schei, p. 89).

In practice this does not always happen. A Cochrane Review (Legare, 2010) noted the potential of shared decision-making but that it had not yet been widely adopted in clinical practice and found a paucity of evidence regarding interventions for improving the adoption of shared decision-making by health care professionals. In the Netherlands, van Til et al (2010) explored professionals’ perceptions of barriers to and facilitators of shared decision-making, and the use of decision-making aids in rehabilitation, and saw great potential for shared decision-making in that setting. Barriers included the patient receiving conflicting recommendations from specialists and the patient’s difficulty in accepting, or misconceptions about, treatment/condition. Facilitators included the patient’s trust towards the professional, and the patient having emotional support from family, being knowledgeable about treatment and wanting to participate in shared decision-making. Robertson et al (2011) use a discourse analysis of decision sharing in general practice to argue that shared decision-making is not yet embedded into routine practice and that “notably, decision

sharing does not happen with the ease implied by current models . . .” (Robertson et al, 2011, p.91)

A recent study in the United States, *Improving Patient Decision-Making in Health Care* (Brownlee et al, 2011), confirmed that “clinicians’ opinions and personal beliefs often dominate decision-making” (Anon., 2011). Also in the United States, the Centre for Shared Decision Making in Dartmouth, New Hampshire, is empowering patients with knowledge about treatment options and developing the doctor-patient dialogue.

Biley (1992), writing when nurses in the UK were starting to be encouraged to promote the inclusion of patients in decision-making, identified three situations that effect patient choice and participation in decision-making about their nursing care. Firstly, 'if I am well enough...' describes the states of 'being too ill' to be involved in decision-making and 'being well' which allows greater involvement. Secondly, 'if I know enough...' describes situations that require technical knowledge, or where patients prefer to take a passive role in decision-making for whatever reason, or an 'I know best' situation where patients prefer to be actively involved in activities of living. The third category, 'if I can...', describes the organizational constraints or freedom that can either restrict or encourage choice and participation in decision-making.

Verkaaik et al (2010) take a theoretical stance to develop the ‘productive partnerships framework’ that aims to facilitate robust, harmonious and productive relationships in health care that harness patient knowledge and autonomy to create successful outcomes. The framework, based on the metaphor that ‘power shared = power squared’, is particularly relevant in the context of rehabilitation where there is significant patient-professional contact. The framework begins in the context that ‘it is as important to know the patient who has the disease, as it is to know the disease that the patient has’ and balances desired knowledge and autonomy levels on behalf of the patient with the degree of outcome alignment between the professional and the patient. While the framework is still to be tested in practice, it could be viewed as an opportunity for creating a ‘communicative space’ for patients and professionals within the rehabilitation relationship.

NEURO-REHABILITATION SERVICE DELIVERY

A focus towards community-based rehabilitation, rather than it being a hospital-based specialty, was evident in a review summarizing models of community rehabilitation and the evidence for their effectiveness (Barnes and Radermacher, 2001). The study found that, although there is a reasonable body of evidence for both the acceptability and effectiveness of community rehabilitation, there was a clear need for further research. More recently Halting et al (2010) refer to the increasing awareness that rehabilitation should be patient-centred and this interpretative phenomenological study shows that social relationships, encapsulated as 'belonging', are an important component of patient-centred rehabilitation. The participants identified different themes of belonging: through cheerfulness and informal settings; through dialogue, shared understanding and fellowship; through professional care and competence. The authors comments that "informal behaviour, participation and trust in patients' resources appeared to increase the participants' feeling of belonging and of being valued as individuals" (Halting et al, 2010, p. 1278) and draw comparisons with other studies where 'family-like relationships' and informal commonplace situations with staff were shown to be valuable. An exploration of the lay person's perspective on the rehabilitation process focused on the individuals' own stories and experiences of factors that promoted or hindered the rehabilitation process. The results vividly demonstrate how the interviewees focused mainly on the socioemotional aspects of the treatment where the most important factor in rehabilitation was finding supportive relationships in the process: "they spoke of *how* they had been treated and *by whom* rather than about what kind of rehabilitation programme they had participated in" (Ostlund et al, 2001, p.287). The interviewees described supportive and non-supportive qualities in encounters with staff, enabling the authors to present a model featuring the roles of 'professional mentor', 'distant technician', 'empathic administrator' and 'routine bureaucrat'. Above all interviewees wanted to meet "one specific person . . . a professional who combined caring and trust with competence." (Ostlund et al, 2001, p. 290)

Regarding neuro-rehabilitation in particular, several articles describe the experience of living with brain injury. The "individual and invisible" experience of surviving traumatic brain injury as narrated by 60 individuals with a median age of 35 years

one year after injury is described by Chamberlain (2006). The narratives were classified into five categories: 'regret and grief within self', 'insensitivity of health professionals' particularly regarding a lack of empathy towards 'invisible' symptoms, 'invisibility of self', 'stranded self' and 'recovery in self'. These narratives show that recovery from traumatic brain injury is a complex and individual process, requiring hope, empathy and holistic care: "Survivors expressed that hope was often all they had and the insensitivity of health professionals at times diminished it." (Chamberlain, 2006, p, 413)

Haggstrom and Lund (2008) describe the complexity of participation in daily life in their qualitative study of the experiences of persons with acquired brain injury. Pryor's (2004) study to determine the environmental factors nurses identify as being irritating to people with acquired brain injury, identified many factors including too much stimulation, too many restrictions, and interactions with staff, other patients, and family and carers. A report of an explorative, descriptive study conducted to determine how people who suffer from head injuries perceive respect for their dignity, discovered what some patients mean by the concept of dignity. Patients experienced their dignity as maintained when they were taken seriously, and received appropriate information, and as violated if they had been neglected or had encountered healthcare staff that lacked knowledge, were skeptical about their stories, or were mistrustful. The participants emphasized the importance of adequate information: "head injuries do not show up on the outside and people with head injuries do not have a high status in society". (Slettebo et al, 2009, p. 2426)

These findings are in line with previous studies such as Mangset (2008) who found that 'to be treated with respect and dignity' was identified as a core factor contributing to elderly stroke patients' satisfaction with rehabilitation services. "The findings illustrate that trivial daily care activities influence the patients' global assessment of health care services. Patients seemed to perceive subtle signals that made a significant contribution to their evaluation and emotional response" (Mangset, 2008, p. 832). This point is vividly illustrated in Chamberlain's study (2005), as previously detailed:

"My outpatient visits are awful. The docs [doctors] who see me are only fill-ins and don't seem to understand what I am going through . . . I wait for half a day

to see them only to get strange looks when I try to ask for advice . . . even the waiting around to see these guys is exhausting. My brain feels like it's 'popping out of my head' from all the concentrating I have to do.”
(Chamberlain, 2006, p.412)

A metasynthesis of qualitative research regarding the lived experience of recovery and outcome following traumatic brain injury (Levack et al, 2010) identified eight themes describing the enduring experience of traumatic brain injury: mind/body disconnect, pre-injury identity disconnect, social disconnect, emotional sequelae, internal and external resources, and reconstruction of self-identity, of a place in the world, and of personhood.

PERSPECTIVES OF LONG-TERM CONDITIONS

Within the setting of neuro-rehabilitation services there appears to be limited literature directly reporting the experiences of patients, their families and carers, and professional staff. In contrast, a series of studies by Hemsley, B. et al (2008a, 2008b, 2008c) explored the views of six adults with cerebral palsy, exploring how and why family carers become involved in care in hospital, what this care involves, and how this impacts upon themselves as patients and on their family carers; the views of hospital and disability service staff on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital; and the views of six family caregivers of adults with cerebral palsy and complex communication needs on their roles in the hospital setting and what would help them in these roles on the hospital ward.

The findings reveal the interplay between the different participants in care. Carer involvement is a complex issue and that although such patients depend upon others for communication support, they wish to be included in decisions about their healthcare, to be involved in the education of the hospital and to communicate directly with hospital staff. Family members and carers described being involved in supporting communication and providing valuable information and guidance to hospital staff. Hospital staff highlighted the family carers' expertise and roles in

emotional and communication support, advocacy, protection, information exchange, and direct care. They also acknowledged that there is a gap between the ideal of hospital staff being able to provide all necessary care to the patient and the reality of hospital staff relying upon family carers for their expertise and provision of patient care. These studies revealed that family carers with a high level of expertise in providing care may need support in adapting to the culture of care on the ward and in transferring their roles and expertise in direct care to hospital staff. In addition, they need emotional and practical support through the stressful experience of having a family member hospitalized.

THE PATIENT

A study of 51 patient perceptions of practitioners following brain injury entitled *Tears in my eyes 'cause somebody finally understood* (Darragh et al, 2000) identified that beneficial practitioner roles included advocate, friend, mentor, and team member, while perceptions of helpfulness of the services included relevance, meaningfulness, practical application, skill development potential, and feedback on progress. Personal characteristics valued by the participants were clear and honest communicator, supportive, respectful, good listener and understanding. In practice these personal characteristics were described in terms such as

“. . . whenever I go to see her, I always leave feeling better, and she's totally in tune to me" or "he listens to my perception about all of it . . . I can sense that he is not . . . not looking down on me." (Darragh et al, 2000, p.196)

Suggestions to professionals who work with persons with brain injury included not just sharing information but learning how to time giving information. A vignette describes how one participant was coming to the realization that she would not be able to continue as a dentist: "the timing was essential, and the therapist was in tune enough with the client to know that she was ready to hear the difficult news." (Darragh et al, 2000, p. 198)

A qualitative investigation of patient experience of neurologic rehabilitation (Wain et al, 2008) developed four themes of person-centredness: ownership, personal value,

holistic approach, and therapeutic atmosphere that “reflected patients’ perceptions of choice and control and feelings of personal respect and self-worth.” In practice the factors that created a positive rehabilitation experience appeared to be

“the understanding and friendly nature of staff and other patients, physical improvements, psychologic gains . . . as well as the unit’s informal, relaxed environment.” (p. 1366)

Blake and Redfern (2010) describe how the experiences of service users throughout the neuro-rehabilitation pathway were used to help develop and shape service delivery in a community team working within a time-limited (8-14 week), goal-focused, holistic theory of neuro-rehabilitation. The study found low levels of community integration, wide variation in needs, with two-thirds of the sample reporting ongoing physical, cognitive, communication and psychological difficulties. Whilst rehabilitation care was rated as excellent, many users reported experiencing difficulties at transition points such as discharge, and concerns regarding loss of confidence and motivation post-discharge: “users wanted more collaborative preparatory discharge planning” (Blake and Redfern, 2010, p.50). As a result of this study discharge planning meetings and packs were re-developed.

THE FAMILY/CARERS

Considerable attention has been given in recent years to the needs of family caregivers of patients with acquired brain injury. A recent summary of the literature (Kleinstaub and Gurr, 2011) identifies different issues of the impact of living with an acquired brain injury survivor, including depression, anxiety, reduced life satisfaction, the role of family functioning, and the needs of care givers and ‘carer burden’. There appears to be little in the literature examining or reporting the experiences of families/carers involvement in using neuro-rehabilitation services. Jumisko et al (2007b), in a phenomenological hermeneutic interpretation of the data collected from qualitative interviews held with eight family members’ living with an individual with moderate or severe TBI, reveal relatives ‘struggling to be met with dignity’ and

highlight that professionals should pay more importance to the suffering of close relatives:

“Close relatives felt that health care personnel did not have enough knowledge about caring for people with TBI and therefore felt insecure . . . Close relatives felt that various professionals treated them with indifference and impatience when they advocated for the ill person. They expressed fear of the power of professionals because they felt they were subject to their control and in a weak position. Being controlled and being met with nonchalance and disbelief was frustrating and insulting.” (Jumisko et al, 2007b, p. 361)

Turner et al (2011) draw attention to such findings (Jumisko et al, 2007a, 2007b) in their study of perceived service and support needs during transition from hospital to home following acquired brain injury noting that “authorities should seek to promote inclusiveness and dignity by carefully considering the needs of individuals and their families.” (Turner et al, 2011, p. 828)

THE THERAPIST

A systematic review examining the influence of the therapist-patient relationship on treatment outcome in physical rehabilitation found, on the whole, that “the alliance between therapist and patient appears to have a positive effect on treatment outcome in physical rehabilitation settings” (Hall et al, 2010, p. 1099). Thirteen studies were considered, including patients with brain injury, musculoskeletal conditions, cardiac conditions, or multiple pathologies. Three of the studies included patients who were participating in brain injury rehabilitation involving a multidisciplinary team working with the patient on achieving goals of improved physical, cognitive, and social function. The results were inconsistent, with only two out of the three studies indicating, for example, that alliance is positively associated with depressive symptoms in patients with brain injury. A qualitative investigation of therapists’ perspectives on achieving optimal functional outcomes in community-based rehabilitation following acquired brain-injury emphasized the need for

treatment and care to be environment-focused and contextually appropriate, collaborative, and goal-directed and client-centred; also that creativity does not go amiss in engaging patients: “the therapist asked him to review a booklet that she was editing that had been written by people with brain injury about their experiences . . . he liked having his opinion asked rather than me sitting there and asking him questions.” (Doig et al, 2008, p. 366)

CHAPTER 3: RESEARCH DESIGN

3.1 PHILOSOPHY AND CONCEPTUAL UNDERPINNINGS

This research project is grounded in a theory that uses a symbolic interactionist/social constructivist approach¹ (i.e. that the understandings people attach to their situations are socially constructed and shaped by social interactions) and based on Freire's (1972) belief that pedagogy to improve peoples' lives must be forged *with* them not *for them*. In recent years an approach to research that embeds active participation by those with experience of the focus of that research has been championed both from the human rights perspective, that people should not be excluded from research that describes and affects their lives, and from a methodological perspective in terms of rigorous research.

“...knowledge constructed without the active participation of practitioners can only be partial knowledge” (Somekh, 2002, p.90).

The impact of not asking disabled people for their views, and taking them seriously, has meant that policies and services have been built and delivered in inappropriate ways (Hunt, 1966, 1981; Barnes and Mercer, 1997). As subjects, not active participants in shaping the research, they were less able to influence the research to enable it to reflect the issues that they felt most constrain or eradicate their potential. If marginalised, less powerful voices are eclipsed by historical and cultural dominant voices, and then the course of action will be based on partial knowledge. To reset the balance we need to use our energies to find effective means of giving audience to all voices. The rationale for doing this is ethical, political and methodological, as illustrated below:

Ethical: because to exclude the voices of those with lived experience in relation to the issue or practice being researched challenges our notions of the moral, the fair and the just. If authentic voice is not afforded to the currently marginalised issues

¹ See glossary of terms

relating to their lives, they are over-shadowed by the voices of others who may have different experiences, needs and interests.

Political: because even when the project is not political in itself, asserting a right to be heard is a form of social justice. Who decides on the meaning drawn from research, and how it is disseminated, distributes power. Being excluded from knowledge production reduces opportunities, and power, to inform, shape and transform practice for improving lives.

Methodological: because the way we hear what is said decides on what it means in a given situation, and how what is heard is acted upon is dependent on the way in which we choose to do research, its conceptual and theoretical underpinnings. Knowledge can only ever be partial if it is constructed without the authentic voice of those with lived experience.

Using the social model of disability as its driver the study is framed by the notion that integration and inclusion are mutually exclusive, integration being defined by a process of fitting into a location or event, changing buildings and bringing in people who 'know'. It can be delivered to people. Inclusion is conceptualized as more challenging and is characterised by recognising diversity, including race, gender and disability and based on the positive valuing and celebration of difference. Inclusion is partnership-led through negotiation and demands change for all.

In January 2006 the goals for health research and development in England for the next five years were set out in a Department of Health (DoH) publication entitled *Best Research for Best Health: A New National Health Research Strategy* (DoH 2006). The Strategy included the recognition that members of the public and patients/users of services can play an important part in the research process and make research "more relevant to people's needs and concerns, more reliable and more likely to be put into practice" (DoH, 2006, p34). The policy on public and patient involvement (PPI) in research was founded on the principle that people who are affected by research have a right to have a say in what and how research is undertaken (Staley, 2009).

The ways in which people are involved in research covers a wide spectrum of types of engagement. PPI and ‘user involvement in research’ have become used almost synonymously in the UK as umbrella terms for all types of user involvement. The UK National Institute of Health Research (NIHR) defines three categories of user involvement with consultation² at one end of the continuum, to user led³ at the other. Collaboration is sandwiched in the middle⁴ (<http://www.nihr.ac.uk/research/Pages/default.aspx>).

The participatory approaches in this study draw on a notion of ‘authentic participation’, used by McTaggart (1997, p.28) to mean

“ownership, that is responsible agency in the production of knowledge and improvement in practice... Mere involvement implies none of this and creates the risk of cooption and exploitation in the realisation of the plans of others”

Participatory research does not merely ask people to comment on what ‘is’, but challenges them to work together to delve into the understandings they hold that underpin their assumptions about practice. Meanings are forged through critical discussion rather than captured using single event data collection methods. It involves participants in co-labouring to forge new approaches, methods and outcomes for the research. Co-labouring, described by Sumara and Luce-Kapler (1993, p.393) as an activity that involves “...toil, distress, trouble: exertions of the faculties of the body or mind”, goes beyond consultation where patients / the public act as referees, reviewers, panel members, where they sit on committees or are invited to comment on drafted proposals. It seeks to build, through what Etienne Wenger (1998) calls ‘communities of practice’⁵, positive working relationships and productive communication to harness the dynamic interchange of knowledge and understandings. What is important in participatory research is not existing

² Researchers ask members of the public about the research e.g. through individual contacts, one-off meetings.

³ Members of the public lead the research and are in control of the research. This is often, through a community or voluntary organisation led by service users.

⁴ This includes active, on-going partnerships between researchers and members of the public e.g. involvement of members of the public on the project steering group, or as research partners on a project.

⁵ Communities of practice: groups of people that share concerns and passions about a topic

“hierarchies of credibility” (Winter 1998, p57) but mutual learning and emergent knowledge. It seeks to break down the barriers between ‘scientist’ and ‘subject’ found in traditional forms of data collection and interpretation (Wright et al., 2010a) and work towards creating knowledge through bringing together contextualised understanding, practical experience, wisdom, and reasoning. This dynamic and democratic approach is designed to challenge and disturb current understandings for practice. Change in how practice is conceptualised and carried out is an expected impact.

Participatory research holds the possibility of having a direct effect on:

- participants, by shaping their thoughts, knowledge and practices
- researchers, by affecting the theories they draw from the research for practice
- rigour and trustworthiness of the research process
- knowledge about practice

These aspects of participatory research, core to making it worthwhile and powerful, are so often lost if consultation is seen as the watch word for participation. This is not denying the important role that consultation and other forms of involvement play but participatory research is generally conceptualised as more radical than this.

3.2 THE RESEARCH TEAM

“user involvement in the development of a research bid provides a key opportunity for shaping a project around the perspective of users, at a point where aims and methods may not be decided and so involvement can have most impact” (INVOLVE, 2006, p.6)

The researchers in this study brought a distinctive combination of expertise as people who use or have used the services, including CFMs, staff who deliver services, managers who shape service delivery, representatives from external agencies and expert researchers in the field of participatory action research and disability.

The group, who became the core researchers in the study consisted of: those who used, or had used, the services of a regional neuro-rehabilitation service in the North East of England (3); unpaid carers or family members of those who used the services (1); people who worked with voluntary agencies, e.g. the MS Society (3); a member of staff (1) and an academic researcher⁶ (1). The academic researcher, formerly a member of staff of NTW NHS Trust has considerable experience in developing participatory research with service users, including those with disabilities. The member of staff (now working part-time at the University as a researcher on this project) has a strong background in service user involvement and in-depth knowledge of current policy and practice as well as bringing her clinical expertise. The service users, CFMs and volunteers brought their expert insider knowledge of service provision and its role-out in practice. They also have their own specific knowledge and interests beyond their knowledge of services, for instance one member has considerable in-depth and practical experience of designing and conducting surveys as well as being an ex-service user, while another has in-depth knowledge of the disability rights movement, and two are connected to voluntary agencies (Headway and MS Society). All became co-researchers, although the level of their involvement differed across researchers and also changed over time.

The team was guided by a steering group, the membership of which can be found in appendix 1. Monthly management meetings were held by the core team to discuss what had been achieved in the previous months, next steps, and to provide each other with support and guidance in taking our roles forward.

3.3 DEVELOPING THE RESEARCH

This group of prospective researchers worked for two years to transform the original thought/idea into a research proposal. The guiding principles for the work were that it would be collaborative and that it would make a difference. People were clear that they only wanted to be involved if it made a difference to practice. Faulkner and Morris (2003), writing about user involvement in forensic mental health research,

⁶ I had also previously worked in the organisation supporting research and development and so was aware of many of the issues and had previous working connections with a number of people in the project.

reminded us that:

“...one of the main reasons for service users/survivors wishing to be involved in research is to make a difference”. (p.33)

The process for designing the study took a democratic, participatory approach framed by the concept of symbolic interactionism, i.e. that the understandings people attach to their situations are socially constructed and that people create shared meanings through a critical interpretative process (Blumer, 1969). In order to shape the design the core researchers had to learn about asking researchable questions and about methodological approaches that might enable them to find and address the issues they wished to research. It meant learning about how to phrase questions, how to share and critique ideas, ways of generating and analysing data, writing for an audience and supporting each other during difficult times. It meant building sufficient rapport and trust between the members of the group to enable them to work productively at the edges of knowing, to deal with uncertainty, disappointment (and even bereavement) and to celebrate successes.

Finding out about and debating different types of research, purposes and practice is crucial to enabling prospective researchers to debate the means by which new knowledge might be developed. This participatory approach shaped the research design in unexpected ways. For instance, the inclusion of a questionnaire as a method for data collection was entirely down the voice of one service user. Writing about the study, Hutchinson et al. (2010) explain the importance of this.

“Everyone had different knowledge and skills that they brought to the table. We then began the process of working together to find a clear focus for our research that we all thought was important enough to commit a considerable amount of time to and held the possibility of improving practice. The discussions were about the difference between integration and inclusion, what we meant by the NHS ‘community’ and the way that we would go about doing the research. The process of doing this, of listening to others, debating and then finding a clear focus, has been lengthy but necessary. We all learnt a lot from the process itself”. (p.8)

Time needed for developing this study in a collaborative manner, especially when working with people who are new to research (and who may also have memory and/or cognitive difficulties) was lengthy. Mittlemark et al. (1998 p.192) found that no less than and sometimes more than one year was needed to carry out successful planning for participatory research. For this study, the preparation time was over two years. The long development time was only possible due to the good will of all participants, including the academic researcher who had no time allocation for this. This is fairly typical for participatory research with authentic involvement at its centre. The need for a considerable allocation of time before research is funded has implications, however, for the viability of participatory research if it has to depend on so much on good will and we are danger of replicating the historical reliance on good will and charity that has marked the lives of many marginalised people and limited their access to change mechanisms.

In addition, there were institutional barriers to taking the research forward. For the host organisations, the notion of services users, CFMs and volunteers as researchers severely challenged local systems for supporting research. For instance, all researchers needed honorary contracts with the NHS Trust. This necessitated police and occupational health checks. Many hours were spent on such processes which tested the systems in place in the NHS and the patience of some of the core researchers. In addition, support services such as IT and finance were designed for other purposes. This led to significant barriers to effective communication and responsive remuneration for researchers and research participants, some of whom were on very low incomes. The unwieldy (and sometimes unnecessarily intrusive) nature of the rigid application of practices not designed for purpose meant some of the participant researchers considered leaving the project after we had received funding but before the practical research started.

Organising people with disparate lifestyles, experiences and needs necessarily leads to complications but time-consuming aspects peculiar to participatory studies were found not only in the needs of the participatory researchers and participants. The host organisations found this new way of researching tested their systems. Examples where extra time was needed in this project are:

- time for discussing, explaining and planning meetings if the notion of a meeting is an alien concept to core researchers and participants
- practical help and support for people to attend meetings or research activities
- the necessity of sending out information in a variety of formats when not all people had e-mail, could read or could concentrate on written information
- practical help to enable people to remember what they had to do, and in some cases, help and support to carry out their responsibilities
- keeping everyone feeling involved over the length of a study when there might be long gaps between engagements was very necessary, but very time consuming.

3.4 RESEARCH DESIGN

The approach was predominantly qualitative, using a form of participatory action research (PAR). PAR is broadly defined as “the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding” (Winter & Munn-Giddings, 2001, p. 35). It aims to get “sufficiently close to the underlying structure to enable others to see potential similarities with other situations” (Winter, 2000, p. 1) and at the same time to develop solutions, grounded in the emerging evidence, to improve practice at the host site.

This project was committed to enabling participants to participate fully in the activities of the research programme and was therefore multifaceted in terms of its approach to recruiting participants and the methods used.

The collaborative research approach chosen for this study lent itself to the forging of meanings in respect of inclusion through critical discourse rather than captured using single event data collection methods. The study used of an array of methods (See appendix 4) to allow participants, some with impaired communication and processing skills, to:

- i) participate in a way most suitable to their preferences and needs rather than their impairment
- ii) delve beneath rhetoric, seeking both an appreciation and a critique of practice in the light of current policy requirements.

A validated questionnaire, the Client-Centred Rehabilitation Questionnaire (CCRQ) was also used alongside PAR. The basic premise of CCRQ is that a key component in assessing the performance of rehabilitation services is the client's perspective: that client-centred rehabilitation encompasses much more than goal-setting and decision-making between individual clients and professionals (Cott et al 2006). This questionnaire provided further means of identifying and analysing current notions of service delivery and implementation was taken forward by one of the service user researchers. Due to the low number of participants choosing to participate in this way, it was used to triangulate data rather than scored.

The methods used in the research were embedded in a recursive design (Figure one) that draws on the concept of the Delphi process. Participants and researchers revisited data generated from previous cycles of the research to critique and develop understandings and to clarify the meanings being deduced from the data (data analysis). A recursive approach reduces opportunities for building practice on rhetoric and builds in fought-for interpretations that go beyond the individual, lending both triangulatory (the need to bring together different data, methods and theoretical schemes to contest knowing) and construct validity (the way in which the research recognises the perspectives of the participants as opposed to importing predetermined frameworks) to the process. If research merely describes what we already know, rather than revealing what we nearly know, or could learn about together, it is likely to restrict programme development to what is rather than what could be.

The fluid and emergent nature of recursive enquiry makes the distinction between data gathering and analysis far less absolute (Patton, 2002, p. 436). Ideas for making sense of the data, and the identification of key themes, emerge whilst in the field. This was often the case in this project. Patton goes on to say that, as long as researchers do not allow the overlapping of data collection and analysis to overly confine analytical possibilities, such overlapping improves the quality of both the data collected and the analysis (Patton, 2002, p. 437).

Methodology

(Modified Delphi Technique)

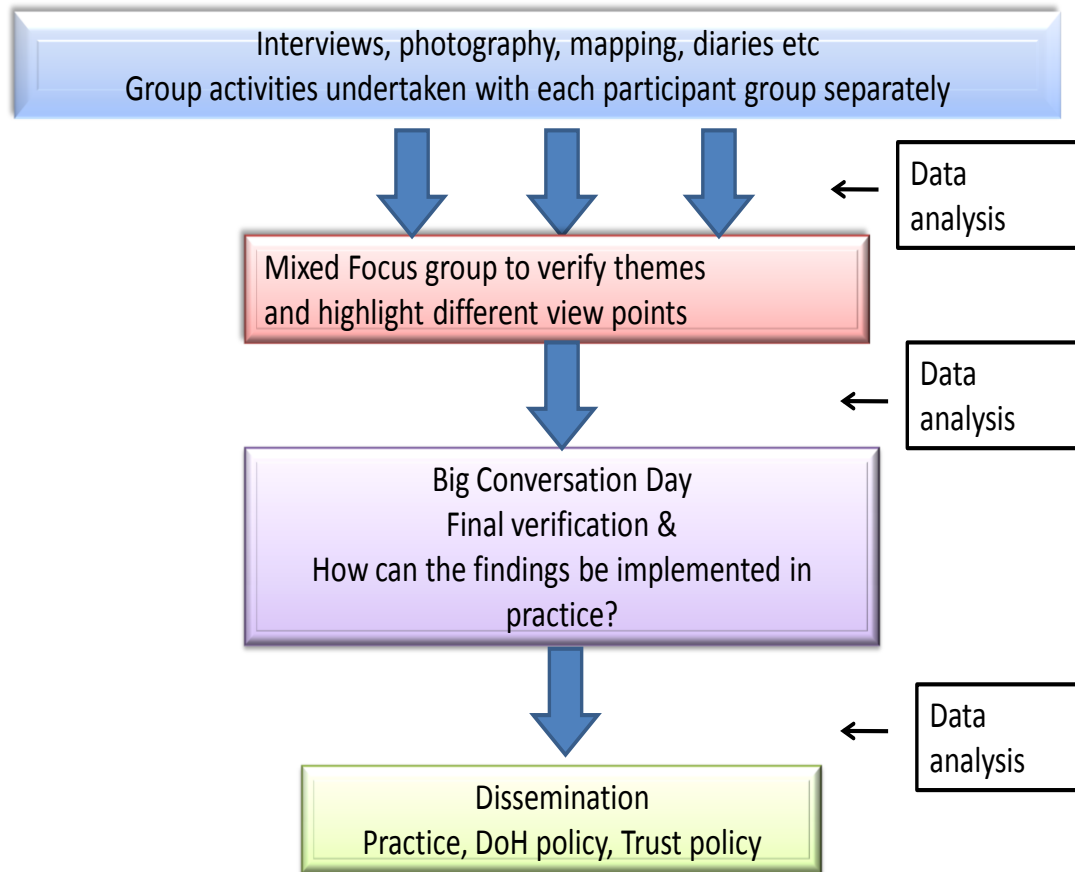


Figure 1: Overarching Design of the Study

Traditionally, one indicator of rigorous research has been the distance between the interpreter and their subject. Talking about the use of investigator distance in evaluations, Scriven (1997) argues that when the evaluator is distanced from participants in a project, and not drawn into the complexity of their discussions, their perceptions and formulations about what constitutes programme quality are less likely to be distorted towards those of the participants. If the researcher remains aloof their judgements are characterised as being untainted by participants who are perceived as necessarily biased towards their own particular beliefs and ways of working. Building participative communities of inquiry is, however, considered to be central to an effective action research approach (Reason and Bradbury, 2001; Reason and Torbert 2001). Stakeholders are not separate from reality; their reality is the dynamic part of the picture and it is their notions of reality that ultimately shape

practice. It is argued that claims for accountability that use predetermined preconceptions and standardised external measures are not always helpful in making judgements about the relative merits of programmes and practices. Blumer (1969) warned that remaining aloof as a so-called 'objective' observer, refusing to take the role of the acting unit is:

“...to risk the worst kind of subjectivism – the objective observer is likely to fill in the process of interpretation with his own surmises in place of catching the process as it occurs in the experience of the acting unit which uses it”.

(Blumer, 1969, p86)

Capturing and negotiating personal realities within a discursive milieu provides a communicative and argumentative engagement that allows understandings of philosophies, principles and practice to surface. The mix of methods and the recursive process used in this study were designed to prompt further discussions, to develop arguments and capture agreements.

3.5 RECRUITMENT

Northumberland Tyne and Wear NHS Trust is home to one of the largest neurological rehabilitation services in the UK, The Regional Neuro-rehabilitation and Neuropsychiatric Service based at Walkergate Park (referred to in this report as Walkergate Park). Approximately 70% of service users use the neurorehabilitation services and 30% neuropsychiatric services. In the period 2002-2007 there were approx 400 inpatient placements (commissioned mainly from the North East but including patients from North Yorkshire, Cumbria and southern Scotland⁷) and 10000 outpatients.

Sample: Identification of possible participants was through

⁷ Whilst Newcastle, the main centre of population, as a more mixed population, service users of Walkergate Park are predominantly from an area that is not multi-cultural. Figures for this can be found in appendix 21

- Service users: a sample from the Trust electronic database. Each sample was randomised across services (inpatient, outpatient, community, based on the percentage size of that service) ⁸
- Walkergate Park staff: through the Trust staff database
- Carers: through voluntary sector and carers' support organisations and through the invitation letter to services' users. This had an enclosed letter for any CFMs who may be involved with the service user
- Voluntary sector staff: through North East Neurological Alliance

Inclusion criteria:

- Over 18 years of age. Young people under the age of 18 were not included as, whilst some of the issues they face in relation to their diagnosis are similar to adults, there are elements of their circumstance and experience that differentiate them from the adult population.
- Staff currently employed within Walkergate Park services
- People who have used Walkergate Park services in the last six months: male/female
- Users of inpatient/outpatient/community, long-term/short-term, who have used services in the past year, even if they are now discharged.
- Service users who are able to understand the information about the project and consent for themselves
- Carers and family members of people who have used Walkergate Park services
- Members of staff or volunteers from voluntary organisations who support service users and carers who use Walkergate Park services

Exclusion criteria:

- Under 18 years of age
- NHS staff who work in the area of neuro-rehabilitation but do not work under the auspices of Walkergate Park services
- Service users who have a neurological condition but do not use Walkergate Park services

⁸ We did not fully meet our recruitment targets from this, and a secondary process of voluntary recruitment was instigated using poster displays.

- Service users who are unable to understand the information about the project and hence are unable to make an informed decision about participation in the project.
- Voluntary sector organisations who do not actively support the service users with an acquired neurological impairment and their carers who are users of Walkergate Park services

Participants of all ethnicity, gender, religion, sexual orientation and neurological condition would be included in the research. It should be noted however, that the North East of England has a relatively small black and ethnic minority population compared to the rest of the country.

<http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=14238>

Data on demographics was collected from service users based on their own perceptions and only if they wished to divulge that information. This research was not, however, looking to isolate particular types of practice to be homogeneously applied, but to identify underpinning principles for practice that enables inclusion based on the positive valuing and celebration of difference and the diverse needs of all service users. Having this type demographic information did offer opportunities at a later stage to consider whether certain populations might be more included than others as a basis for further research. Demographic information for service users can be found in appendix 2.

Researchers were guided by the tenets of the Mental Capacity Act 2005 and acted in accordance with the guidance from this Act. Where there was a question in relation to capacity to consent, advice was sought, in the first instance, from personal (unpaid) consultees who knew the person well. Whilst the researchers were guided by this act, it should be noted that where access to patients was reliant on gaining permissions, if professionals used a more generic approach and felt that groups of patients/CFMs should not be approached with information about the study, researchers were unable to do so.

The researchers regret not being able to engage directly with people deemed unable to do so. This was entirely due to the timescales for the research and the complexities of navigating the ethical processes necessary for working with people who may not have capacity to consent where the study is also being carried out with those who do have capacity. This raises ethical issues that go beyond the remit of this research, but were keenly felt by the core team.

Recruitment Approach: Given that some participants would have more complex needs, very careful consideration was given to recruitment. The researchers met with a range of services and committees to seek advice on how to take this forward. Suggestions made at these meetings were incorporated into the recruitment process which was undertaken in the following manner.

- i) *Raising awareness:* General awareness about the nature of the project was raised across Walkergate Park services and associated voluntary sector organisations. Meetings were held with various sectors to be involved to outline the study and prepare the ground for recruitment. Posters (see appendix 3) were displayed within Walkergate Park Centre at various strategic places. The first posters advertised that the study was about to happen, the second phase of posters were used for recruitment.

Recruitment of participants (which included invitation letters, information about the project, the ways in which data would be collected and consent procedures) was also designed to address a range of needs, abilities and preferences and included a reading of all the information by a service user researcher (See appendix 4). This was recorded on DVD and sent out with the information packs

- ii) *Invitation Letter:* A letter of invitation was delivered to all prospective participants. Methods of delivering this letter and the information contained within this letter were tailored to the expected needs of certain groups of participants and are described in more detail below.

- Inpatients: due to the particular nature of inpatient services, the information letter was only sent to people who had the possibility of being able to consent.
- Outpatients and community patients received an invitation letter that included one to CFMs.
- Staff from Walkergate Park Services, including domiciliary staff, and staff and volunteers from Voluntary Sector Organisations received an invitation letter.

iii) *Information and consent procedures:* Using previous experience in similar research (Cook and Inglis, 2008) the importance of a communicative opportunity in helping prospective participants understand research and the implications of participating in research was given full consideration. The process of gaining informed consent included opportunities for collaborative, recursive engagement that instigates a learning process about the nature of research. To this end, the interpretation of the information sheets was offered with support personnel rather than leaving people to interpret written material without help. People could choose whether they wanted someone to come out to visit them. This approach was chosen over simplifying information as whilst words can be reduced and simplified, conceptually qualitative research is a complex concept for those who have not previously been engaged in research. This is especially so when, as in this project, multiple methods to aid inclusion may make the project appear more difficult to understand at first. The opportunity for prospective participants to revisit the information in their own time (read it and/or watch the DVD) and to ask questions of a 'real person' as many times as needed was seen as the key to understanding. For inpatients, identified staff on wards were briefed to be able to present the information and were there to discuss it with patients. Outpatients and community patients received the information either by post with an invitation to contact the research team for further help, or by a personal visit. The approach was determined by their response on the invitation letter. Staff from Walkergate Park services, including domiciliary staff, and staff/volunteers from Voluntary Sector Organisations, received the information through the post. These steps were taken to help people understand the nature of the research

and to enable them to make an informed decision in respect of their participation. Consenting to participate was an iterative process with opportunities for participants to learn, incrementally, about the research and any implications for themselves of participating in this research.

This array of approaches was very labour intensive but necessary if the study was to include people who needed more support to make informed decisions about their participation. The Local NHS Research Network, DeNDron, supported the core research staff recruitment. Two student researchers and volunteers who currently work in the Trust to support service users supported the process.

NUMBERS OF PARTICIPANTS IN THE STUDY

43 service users consented and took part in the study. A further 6 service users gave their consent but subsequently did not take part in the study (2 people died, 1 person withdrew and 3 were did not respond when contacted)

24 staff took part in the study. On further person consented but then decided not to continue due to work pressures.

23 family members/carers took part in the study

8 voluntary sector representatives took part in the study.

3.6 METHODS

The study used a range of methods designed to allow choice of types of engagement for participants. These methods are described in detail within the information sheets for participants (see appendix 4). To broaden the choice and avoid participants being guided towards a means of engagement on the basis of their impairment, support was available both in terms of adaptive equipment (easy press cameras, voice activated digital recorders, etc.) and personal support delivered by a person of their own choosing.

The aims of the research were gathered into three strands:

Strand 1 investigated understandings of integrated and inclusive practice, identified current perceptions of treatment and clarified enablers and barriers to embedding treatment programmes into daily lives. Data were generated through individual interviews and four focus groups, one for each set of participants (service users, carers and family members, staff from Walkergate Park Services, and voluntary sector representatives). This segregation was to allow full and frank discussion. After the first interview/focus group, data were analysed into key themes and then original participants were invited back to engage those themes. This overlap stage, where themes came together to be articulated and discussed was where inclusion began to be articulate, new ideas for principles and practices for improved service delivery began to be developed, and participant-validated data analysis took place. Most participants chose to engage through this strand.

Strand 2 mapped what inclusion looks like and where it might be found in relation to treatment and daily life. There will be two streams of data collection on the topic of inclusion (as detailed above) but in this strand there were a number of ways of generating data.

- Photographic project: participants took photographs of where they see inclusive practice during a one week period. They were then interviewed about their photographs and the meaning they attached to them. The aim of the interview was to discuss what makes the subject of their photograph inclusive, what enables that inclusion to happen, barriers to it happening, and the effect of inclusive practice on their lives.
- Diaries: these were kept for a week and recorded either verbally into an MP3 recorder or in written form.
- Blogs: blogs were offered to allow people who wished to use IT to engage with the study. Nobody chose this option initially, but supported access to computers offered to participants during the Big Conversation Day made this viable. People engaged in conversations about inclusion online, in a password protected site and using a pseudonym.
- Mapping: people were asked to map areas where they see inclusive practice occurring, to identify what made it inclusive and why, and to articulate their perception of how treatment received through a more inclusive approach effects daily lives. The mapping exercise took place during interviews and focus groups.

Strand 3 Client Centred Rehabilitation Questionnaire (CCRQ) which studies client perspectives of client-centred rehabilitation (See appendix 5). This questionnaire uses seven domains of client centre rehabilitation, participation in decision-making and goal setting; client-centred education; evaluation of outcomes from the clients' perspective; family involvement; emotional support; coordination and continuity and physical comfort. The questionnaire was delivered by a service user researcher who also used it as a basis for discussion in line with suggestions for such an approach made by Cheryl Cott herself.

Participants chose which method they preferred and whether they would like help in the task. These strands then funnelled synthesised data through the stages for further critique and converge in the Big Conversation Day (BCD).

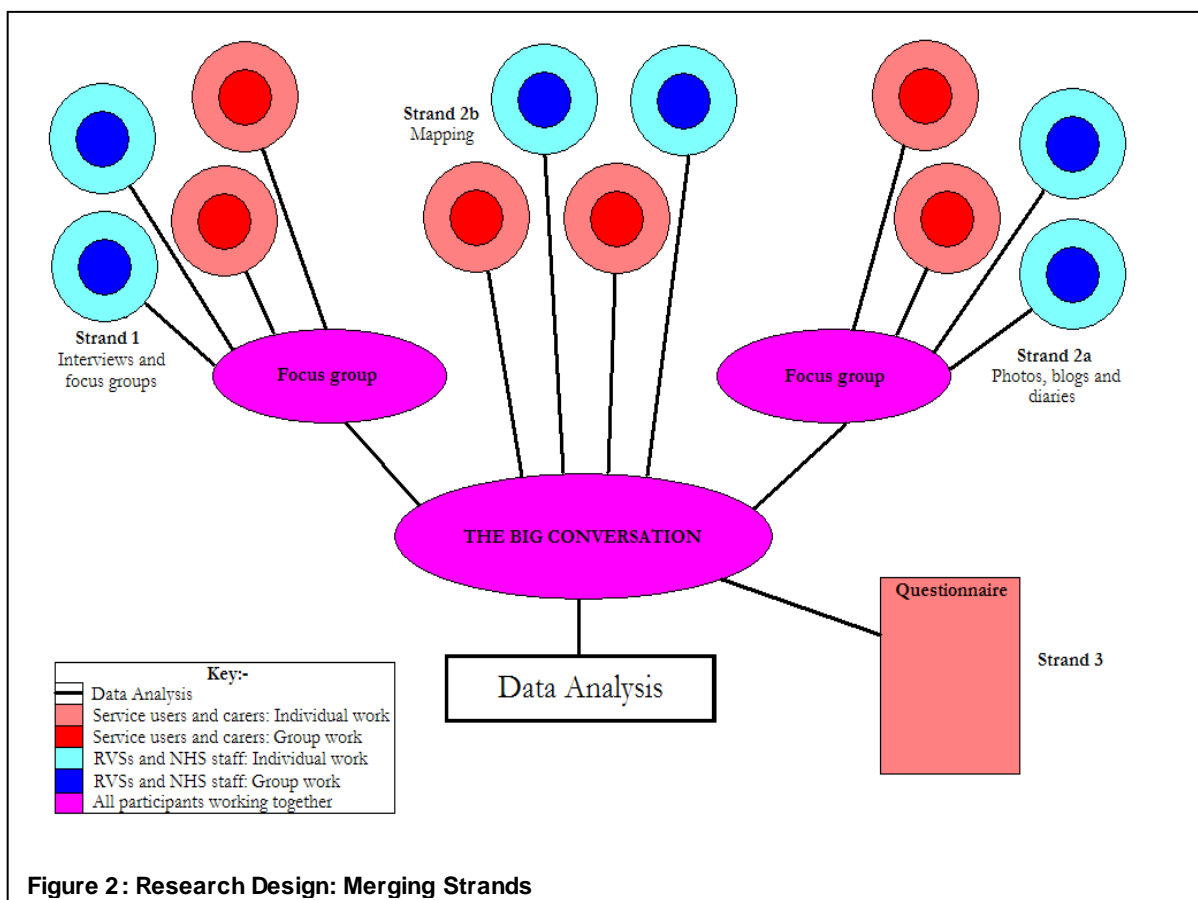


Figure 2: Research Design: Merging Strands

Big Conversation Day (BCD): The final part of the data gathering process was a conference, or day of conversations, to which all participants (service users, carers

and family members, NHS staff and representatives from the voluntary sector who had registered an interest were invited. The day was designed to be a relaxed space for further critique and discussion. Analysed findings of the research were presented to participants in a number of different formats to enable people to validate themes generated from all the synthesised data. Some themes were confirmed and new ways of seeing were offered to further develop our combined knowledge. This way of analysing the data was in keeping with a research approach that had, as one of its key aims, the facilitation of authentic voice.

i) *DVD*: Explaining how the key themes had been developed from data was a challenge for the core research team. Making a DVD of the data and showing it to participants alongside the themes drawn from that data seemed one way of achieving this. Five scenarios that reflected the key themes from the data were acted out by drama students from the University. The student scripts incorporated, almost in their entirety, whole sections of anonymised data. These were then shown to participants who discussed the key issues they considered emanating from the data and commented on the themes being presented back to them. The aim of revisiting the data was to critique the meanings being drawn from that data as opposed to the stories themselves. This way of revisiting their own data through a new lens, as an external watcher, in the company of others who had participated in the project, led to much interesting and animated discussion

ii) *Inclusion Factor*: People were invited to work in groups to consider scenarios and the themes that had been drawn from those scenarios. Any new themes discussed were noted. Group members were then asked to vote, on a 0-5 scale, how closely the principles for inclusion drawn from the data reflected their perceptions of the data

ii) *Absolutely Inclusion* – People were invited to work together to explore some of the key assumptions underpinning inclusion that had been drawn from the data. Group members were asked to rank the assumptions in order of importance. Taking the two most important assumptions, the group discussed the change that needs to take place in order to develop a more inclusive culture in practice.

iii) *Inclusion Café*: tables were set out cafe style, where people could get together with a researcher and discuss issues that were arising during the day.

iv) *Blogs*: computers were set up with blogs that were security protected though a closed University site, and people were invited to develop threads of conversation

about inclusion, inclusive practice and the impact of inclusive practice as they perceived it.

v) *Wall of photographs*: photographs taken during the photography project were displayed on one wall with captions drawn from the original discussions with the participant who took the photographs. People were invited to view the photographs and comment on the captions.

vi) *Themed Graffiti wall*: Key themes from the data were used as headings on large sheets on the wall. People were asked to make comments on these themes by writing on a piece of card that was then attached to the relevant theme.

vii) *Roving Mike*: an MP3 player was used, reporter style, to capture comments and discussions on the day. This was especially useful where people had sudden inspirations in terms of their own understandings brought about by the discussions around them, and wanted to add to their contribution.

As well as being a test of the face validity⁹ of the themes, the BCD was particularly relevant in developing an outline for principles to support the development of a more inclusive and effective service delivery approach and in providing a body of knowledge on inclusive practice and its impacts.

3.7 DATA ANALYSIS

There is limited literature on participatory involvement in data analysis. Beresford and Turner (1997) describe a collaborative approach to data analysis in their work with the Citizens' Commission and Cook and Inglis (2008) used an integrated, recursive approach to data analysis with participants with learning difficulties. The key reason for adopting an approach for including participant involvement in data analysis is to enable in-depth and robust critique to take place that mitigates the dominance of a single view, particular the researcher view, on claims for knowing from the data. Analysis of data that is re-visited and critiqued by participants is likely to be closer to participants' experiences and concerns.

⁹ Face validity: where participants recognise and agree with assumptions and themes drawn from the data : explanations and descriptions make sense to participants

Data analysis was integral to the research process and used multiple perspectives to locate and clarify key themes and concepts. The recursive design allowed researchers to analyse the first stage of the work as an initial step and return the themes back to participants for further discussion and critique (a modified Delphi technique). The strands of data collection, in particular the BCD, were designed to allow for synthesised data to be returned to participants for interpretation and further synthesis with the crossover of data between strands allowing participants to act as inter-raters¹⁰. Each stage of the research had, therefore, an initial researcher analysis of the data followed by a check for face validity. This was a way of both legitimising and developing the themes. This also developed construct validity¹¹ as it allowed researchers to track how original themes were altered by participatory engagement. In addition the academic researchers used NVivo (qualitative data analysis software) for thematic storage and analysis of data.

Analysis took a cyclical approach based on three key stages: data reduction, data organisation and interpretation of themes (Miles and Huberman, 1984).

¹⁰ Inter-raters: when research participants work as moderators across understandings

¹¹ Construct validity: the aspect by which theories have been altered through data collection and critique

CHAPTER 4: FINDINGS

This chapter describes the key themes underpinning inclusion and inclusive practice as generated through the data and confirmed by participatory data analysis. In keeping with the philosophy of this research the voices of participants are used to unpick and reveal the experiences behind each key theme¹².

4.1 UNDERSTANDINGS OF INCLUSIVE PRACTICE AND WHAT IT LOOKS/FEELS LIKE

Inclusive practice

- starts from valuing people
- is about recognising what is important and for whom
- is about learning together, not one-sided delivery
- involves challenging within a supportive environment
- involves change and willingness to change
- is about making choices based on shared perceptions of the bases for that choice
- is about giving and taking responsibility
- is based on attitudes
- is about getting it right for people

Inclusion is:

‘having a space in a system, having a role in the system, being part of it, you know, you know being part of the jigsaw or something like that or not just turning up and forcing you're way in but turning up and being welcomed or being, feeling that you belong’ (SU50-M-I)¹³

‘it’s a feeling of warmth and acceptance. Of people being prepared to listen to what I have to say and going along with it ... or not! Disagreement is ... can be inclusion as well can’t it?’ (SU25-M-I)

¹² NB: The data does not just refer to Walkergate Park services: participants talked about their experiences across the whole region, both in the NHS and in the community.

¹³ For an explanation of referencing for data please see appendix 6.

'enmesh[ing] together well. I suppose that's also a definition of inclusion isn't it, where other people concerned feel they have a contribution to make and they are to make it, but up to the point that they're not actually going to jeopardise the treatment by saying stupid things' (SU25-M-I)

'Oh, everybody in the... not just me...everybody in the..... "Pass the biscuits over. And can I have another cup of coffee, please?" And that sort of thing and everything. And you can say what you like. You don't have to bite your tongue'. (C13-F-I)

'[needing] to feel I can add or contribute something and that what I had to add or contribute would be worth adding or contributing. I would have to feel that for myself and then, if I felt that, I would then need to feel that, maybe, that what I was doing or my presence was appreciated' (S10-F-I)

'a bunch of people all pulling on a rope with a place for you to pull' (SU50-M-I)

Inclusive practice can only be done inclusively. Knowledge constructed without the active participation of those who have lived experience can only be partial knowledge.

4.2 PERCEPTIONS OF SERVICE DELIVERY

The immediate rhetoric of service users tended towards one of satisfaction in relation to the overall experience and involvement with neuro-rehabilitation services. Many could not speak highly enough of their experiences within the system. They recounted how parts of the service provision, particularly the neuro-rehabilitation centre, had 'saved my life'.

'I always think if I hadn't found [the neuro-rehabilitation centre], I don't even know that I would still be alive.' (SU9-F-I)

'I feel valued. I think that's a very important feeling' (SU37-M-FG)

'I feel respected as an individual.' (SU3-F-MFG)

'They treat you like a person. They remember who you are. They remember all about you, and they take an interest...it makes such a big difference... you feel included.' (SU9-F-MFG)

4.2.1 SERVICE USERS AND CFMS VALUED

a) Good quality medical treatment

- access specific medical and therapeutic treatments: e.g. physiotherapy, occupational therapy, speech and language therapy, botulinum toxin treatments, wheelchair clinics, drug treatments
- access the knowledge and expertise of professionals who work in this specific area and the reassurance of knowing that there are people they are familiar with that they can engage with in a flexible manner

The importance of having an interaction which is based on a trust in the specialist knowledge of the professional resulted in a positive emotional impact of feeling a part of treatment and being understood. When there is a lack of confidence then service users can experience difficulty.

'I don't think my GP has ever treated someone with one [sub arachnoid haemorrhage], which is why I think that he's been very negative whereas the doctor I saw in Occupational Health, I got the impression that she had. I had more faith in her than I did anybody else, because she talked to me as though she knew the experiences of what I was going through' (SU23-F-I)

Where practitioners are less experienced, if they take time to find out, and shared learning takes place, service users recognise that commitment.

'it's having someone and he's took the time to get to know about the condition'(S4-F-I)

'if you have to go and see somebody out of that system, you're that person and therefore you're an idiot. Or that's what they class you as. That's their box. You've had a head injury, or a brain injury, or whatever. They're not quite sure where to put you. Everything else is fine. And I'm just using a GP for an example, and that's when it can be a problem' (SU-BCD)

b) Opportunities to

- engage with peers
- engage with the local community
- give something back
- work together in a relaxed manner

Engage with peers: Service users and CFMs identify the importance of engaging with each other to receive and offer advice and experiences. Peer support can help in the early days of being diagnosed with a neurological condition.

'I mean, in our case we know that the MND [Motor Neurone Disease Support Group] meet the first Friday of every month, and so, I mean, often, throughout the month, if something happens, we say, "Oh we'll ask them that at the next meeting" you know. And we do. You know, so we always have a little thing – "Oh by the way, such and such happened during the month, what do you think that was?" And so we get advice back and yes... So I think it's good. That you know that you've got this advice there and it's always good advice'. (C19-M-MFG)

Recognising the value of that support, this carer went on, in time, to become a volunteer herself. Supporting other people with the same condition is valued work and provides people with a sense of purpose. Volunteers and the voluntary sector play a significant role in developing peer to peer engagements and support.

'It was the volunteers when I first went [that supported me]. When I think the first day I went I was sat with a cap on and big sunglasses and crying-terrified thinking I had something really badly wrong with us. After coming out and then

sitting chatting having a cup of coffee with this woman and she was just marvellous and within a year I was that woman and you would sit and you could just see them coming in and the terror on their face.’ (SU24-F-P)

For some people, peer support can move beyond the pure medical exchange to one of sharing wider human interest:

‘I think you know the layout of the building and the fact that it’s new and quite a nice place to visit. It’s not one you know, not a ‘hospital’ [it is a Centre] and you know peer support, people get to meet each other and share experiences and share what’s going right and what’s going wrong and the important things like what’s happening on the X-Factor as well (laughter). That’s an important thing, you know, but it’s not all about the condition’ (V3-F-I)

However for some service users meeting with others who share the same condition is not something that is supportive or helpful for them, but they have a choice as to whether they want to do this, and can make that choice for themselves.

‘it’s like I get a letter that says do I want to go to the MS Society Christmas party? Do I want to go to a Christmas party where the only thing I’ve got in common with people is a disease no!’ (SU9-F-I)

Engage with the local community: Belonging and being part of everyday activities, something which many service users called ‘normal’, was an aspiration.

‘it [inclusion] means feeling normal’ (SU-21-F-1)

‘Just in general, what makes me feel included would be things like, say, for instance going to a regular shop and the people there saying, “Hello, how are you? It’s nice to see you again.” Making it clear they actually recognise me. That makes me feel included in the community, for example.’ (SU31-F-M)

‘I feel included pretty much everywhere I go- in my church activity, just locally at the church mothers’ club, at the library where I can go by myself. We go out

in the car nearly every day – to the coast or to the theatre. I've been to the Sage but usually go to the People's Theatre nearby or to the Whitley Bay Playhouse. I don't go to the corner shop anymore and Y (husband) does most of the shopping along at Morrison's. The odd time I do go to the supermarket with him, I am always treated very well and made to feel welcome. People ask if they can do anything to help me. My chair helps me around and I can participate in groups like I always did. I enjoy the [condition specific] support group meetings and feel a part of that group and I ask questions and meet others.' (SU49-F-I)

This service user talks about going with her daughter to a local collage and the importance of this to her life. She places importance on identifying with other people who share a similar identity that is not based around her disability.

'that's where most of my social life takes place...sitting with other mothers and we can often have nights out as a result of that. So that's quite an important part of my life.' (SU24-F-P)

Engaging with their local community is equally important for CFMs who want to access their hobbies and pastimes with their partners. This CFM identifies the importance of accessible space.

'I feel included... My main hobby is bowling and I feel included at the bowling club. The bowling club is a fairly new building which was built in 2000 and has disabled features, so I'm able to take my wife there without any worries. Disabled toilet – no ramps, no steps to get in and out. And that is very good. I also feel included at the local church, which we attend regularly. Again, they have facilities for disabled people. They've built a ramp. They've built places in the pews for her wheelchair to go and they have a disabled toilet in the building. So those, I would suggest, are the main places I feel very included.'

(C11-M-I)

Give something back: for instance to be part of the Service User Forum or volunteer in some way. Giving something back to the service, making a difference for others,

has been identified as an important role for participants and part of feeling included. This service users benefitted from and enjoyed the experience of being useful.

‘Even though it’s [the accident resulting in her head injury] so long ago, I still haven’t accepted that I’m different. Because I know I’m different. In my head I know I’m different. I react different. But I love to participate and put in. If there’s got to be a reason for being head injured I want to be included to try and put something back in for me being as I am ... You feel as though you’re important and you’re part of the team. And you work together. And it makes you feel important that you’re putting back in on a different level to beforehand’. (SU38-F-FG)

Work together in a relaxed manner: to have time invested in building relationships. The importance of being in an atmosphere where you are recognised and where staff show a genuine interest made a positive difference to people’s experience of using services.

P: 1 ‘...If you’re talking about [this Centre] the attitude is totally different to every other hospital in Newcastle. Or, in my experience.

P: 3 I think it’s a lot more relaxed.

P: 1 It is. They treat you like a person. They remember who you are. They remember all about you, and they take an interest.

P: 3 When I first went there I was very impressed by the receptionist. Because I was going to speech therapy, and after the first week he remembered my name and who I was going to see.’ (SU9 & SU23-F-MFG)

Relationships take time and a commitment to building understandings. This is particularly so when service users have communication impairment.

‘my son has got speech problems. He gets by, put it that way. But when you’ve met him for the first time you probably wouldn’t be able to

communicate with him. Understand everything – what he’s saying. But if you saw him persistently you would, you know.’ (C8-M-MFG)

This highlights the importance of continuity of practitioners and practitioners investing in relationships, believing in the right of individuals to have a voice in their own care. Staff members do reflect on the range of service user voices they hear. This staff member suggests that the majority of people she is involved with value a long-term relationship with their practitioner and feel safe with a high level of familiarity. They link the sense of certainty and familiarity with who they are seeing with feelings of support and care.

‘I just find people very much like to establish a relationship with a professional. When they’ve got a long-term illness it seems really important to have an established relationship with a professional who they feel they can trust and approach. When people are speaking to me, they’ll speak about the other therapists, you know, using their Christian names. And how important that is. That they know who they’re going to see – who would be treating them.’
...Support, continuity of care and... I think it’s somebody who knows me [is important]. I haven’t got to go through everything all over again. You know, they know me and they care.’ (S10-F-I)

c) Being treated as a person who matters

Relating to a person in a way that demonstrates they matter and are more than just their component parts is reiterated by this service user. They have a clear perspective of the person as a whole being central to inclusion.

‘You get the impression he’s [practitioner] always interested to know what you’ve been doing recently and what’s going on. I mean he doesn’t go straight in by saying, you know, where does it hurt this week or...He sort of deals with you as a whole person to start with and I think inclusion probably has quite a lot do with being treated as a whole person.’ (SU25-M-I)

The importance of being seen as a person and not a number and part of a purely

systematic approach is recognition of your value.

'You never feel that you're just being... "Oh, you're number 16 today, so get him in and get out there." You know. No, that's excellent.' (SU49-F-I)

'You feel you're a person, you're somebody. You're not just a name or...And you're somebody they know because they've remember little things about your life from last time or they chat to you about their life. You get to know...And they get to know... And it's a totally different feeling here, isn't it? You can go in all cheerful and relaxed. You feel you can ask things. It's lovely.' (SU9-F-MFG)

'It gives you more confidence, doesn't it? Instead of sneaking out like a humble little mouse, you come out thinking, "Oh yes." And as you say, it does carry on into other aspects. Which is what inclusion is, I would think, because you're actually including your whole life.' (SU9-F-MFG)

'It's looking at the whole person and not just the physical factors or the physical impairment, it's looking/treating the whole individual as a person. Someone who is unique and looking at, their cognition, their emotional [needs] rather than just concentrating on the physical side of it. ... It's more kind of let's look at this holistically and try and treat the whole. You know, the whole individual and work on it from there rather than just breaking it down into a component part.' (SU3-F-FG)

Reciprocal relationships are part of being included and having your input valued. Service users find it important for their clinical encounter to recognise the humanness of practitioners in times of pressure. They both hope, and also find, that practitioners respond with equal humanness to them. It requires noticing the situation for the other, putting themselves in others shoes and then responding.

'it's back to the adage: 'wear my shoes' (SU5-M-I)

Reciprocal understanding and exchange creates the potential for stronger

partnership working. In this case below, the impact was that the service user felt understood and that they really mattered and were important.

'But the previous appointment – 3 months before that – he'd asked me if I would like to consider some surgery and I went with the intention of asking him lots of questions about that. And I did say to him, I said, "Look, I know... I can see you're busy, would you like me to leave these questions until the next time?" And he said, "Absolutely not." He said, "You take as much time as you need and you can ask all the questions you need to...he made me feel like he was listening to me and not thinking about his packed waiting room full of patients and he was really taking proper notice of me.' (SU31 -F-M)

Reciprocal means that those who use services have to recognise and work within limitations, be those financial or human. There was significant evidence that service users wished to engage with staff on a human level. In this situation the service user felt that, whilst she mattered, the doctor also mattered. Her approach was to recognise that a previous situation was acknowledged as a basis for starting communication.

'When you go through the door sometimes you're not sure what sort of day have they had already...the last clinical appointment I have had with a consultant, the patient before me came out in a rage and was screaming and yelling and shouting, and really, really upset with him [consultant] and vowed never ever, ever to go back in and see him and I thought 'thank you very much, I've got to go in now'. When I went in, he was clearly upset. And I thought 'I'm not going to sit here and say you know, here I am, you know, sort me out', he just needed to be asked if he was alright because he was clearly shaken by that woman's reaction. I think it's a partnership and sometimes the partnership will be skewed, sometimes I've got more responsibility than the, the provider of the service. But its working out together what that's going to mean; having the confidence and courage sometimes to say 'hang on a minute, can we, you know, just cut to the chase here and let's get down to what this is about' (SU-BCD)

When practitioners make the space for service users it makes a difference to being seen not as a wheelchair or an object that is difficult and gets in the way, but as a person in their own right. This service user articulates the value of that in enabling her to contribute and be a part of things within the community.

'So now they just space is made for me and that helps me to feel that I am part of what's going on and that I'm not just a tag on or I don't stick out or I don't have to be walked around or treated like a roundabout but I can be part of of whatever gathering it is,' (SU32-F-I)

This service user describes the impact of not being valued.

'A doctor was coming to visit me [on the ward], but then something else had cropped up and so when I finally saw her at, like, 5 o'clock in the afternoon, I'd had an appointment with her at 10 o'clock in the morning. And I had to say to her something – I said, "I know you're very busy." But I said, "Well I felt that... I felt so low in priority that you knew I was always going to be here, so ... you could delay my appointment by 7 hours, just like that. And because you were busy with something else." I said, "It made me feel so unimportant to you." And I said, "And all it would have taken..." I said, "To make me feel a lot better about this was if you've just phoned up and said to me, "Look, I'm really busy with such and such, and I just can't come... Can you just tell and apologise to SU29?"'" And it was that non-verbal communication, that she was so much more important than I was that made me feel very, "urghhh...", you know. And after she explained to me I could understand that she was thinking, "Yeah, but SU29 is always going to be there. And so I did understand it eventually, but I sort of... And I think it was a good lesson for her to realise that... Popping out to see me., that was my whole...that was the big event in my day, you know. And so that, like, that, to her, was just like, "Yeah, popping along to see SU29 I'll just go and do that later." But to me it was like the big event of the day and so it felt very... she just sidelined that. (SU29-F-MFG)

4.2.2 PRACTITIONERS VALUED

- Teamwork – where service users and CFMs are identified as part of the team.
- Time to build relationships
- listening to service users and CFMs
- Where possible, including service users and CFMs in discussions about the way forward
- An accessible environment
- Being friendly and enabling people to relax

The concept of the team was really important to staff as part of an inclusive approach. Their understanding of the position and role of service users and CFMs within the team did, however, vary. Some members of staff were quite cautious about having service users and CFMs involved and feel that meetings with service users were often used to air complaints.

P: 'I suppose we should be discussing with them all the time when we're you know, making the care plans for them and stuff, they should be included in that.

I: Do you think they feel included in it?

P: The feedback that we get is not always positive, I think... it's sometimes they're having a go at the medical staff or the therapist...' (SU17-F-I)

The discussion between staff and service users at the Big Conversation Day identified the importance of service users and CFMs being a member of a team and being able to influence actions and outcomes.

S:1 'They [service users and CFMs] have a role in the team, because then you have...you put your thoughts forward to the team. We always encourage people to say what they think – what they would like, what they want to achieve...we do try to include people as part of the team

S: 3 I think you want to be in control of the team, don't you? As the service user? As the person that it's all about? You want to be able to direct the team, don't you?...You want to be part of it...

SU: 5 The decision process.

I: 1 Do you want to direct it, or do you just want to influence it?

S: 3 Yeah, influence.

SU: 6 Influence, I think, is probably the better word.

S: 1 Because you still want all the experience of the other people on the team rather than just making your own decision' (S&SUs-BCD)

The lifelong nature of neurological conditions means that both the delivery of treatment and the staff within the team are of extreme importance to the experience service users and their CFMs have of the NHS and ultimately how they are equipped to manage their long-term condition in the community.

'Well I think that if they could relax with whoever the therapist or doctor was. If they felt they were in a relaxed environment' (S5-F-I)

'I think if you're involved in setting goals and targets for your treatment, if you actually help select that, then that's going to make you feel more included and also, probably, find it easier to carry through. Because it's so easy sitting in the doctor's office saying, "Oh yeah, I'll do that and I'll do that" but then you've got to get on with it when you go home and it's a different atmosphere and... So I think if you're involved with it, that's going to make it easier.' (S5-F-I)

4.3 IDENTIFYING INCLUSIVE APPROACHES TO PRACTICE AND ITS IMPACT

Whilst specific medical and therapeutic treatments were always valued for the fact that they were there, the application of these was not always appropriate for the needs of service users and CFMs. Being excluded from discussions about treatment, or not having your voice heard or acted upon even though you were present during discussions (i.e. you were not included) were repeatedly cited as key reasons for inappropriate outcomes in relation to the nature of their treatment. The following were suggested by service users and CFMs as reasons where inappropriateness was not generally articulated:

- it is hard work to make your voice heard - you are not always listened to and what you say is not always taken into account
- you lack influence
- you are still sometimes just a number
- long-term conditions make you vulnerable to losing your value as a citizen and person in your own right and the ways services are provided can have the tendency to exacerbate this feeling
- you generally have to fit in to the system rather than be part of shaping the system
- there are structural barriers to accessing services - it can be a struggle to access mainstream services (e.g. health screening) when you are part of another system
- transitions between services are particularly problematic but it is not a good time for you to be stating your case

This extract below exemplifies the tone of many interviews, where service users and CFMs would not describe themselves as dissatisfied but their experiences with services left them feeling distanced from the focus of their own treatment.

'I have no complaints about the treatment. Do I feel included? I don't feel that we discuss what I am going to do next. I don't feel that we have a plan but then again maybe it just unfolds and it's to see how much progress you make...I like to know what's happening. I'm told what's happening on a minute by minute basis but I haven't really been told what the expectations are and where I might end up and those sorts of things. I suppose because I like to

have control I would like to have more understanding of why we are doing this now, what we might do next week or next month and what I can hope for. So it's not that I mind, it's not that I think anything has gone wrong, I mean I'm not a professional, what do I know? [said with irony] But I don't feel as if I'm empowered to understand fully.' (SU50-M-I)

This service user starts with articulating that they have no complaints about the treatment, but they describe a situation where there is room for making the implementation of the service more effective. This suggests that we should not muddle user satisfaction with effective practice.

Practitioners articulated a tension between both national and local priorities for service delivery and the manner in which they believed to be most appropriate for what they termed 'client-centred' service delivery. This went some way to explaining why what they considered to be important was not always possible within the imposed delivery structures. Some practitioners talked about feelings of being powerless and even feeling 'belittled' by management structures and processes. This helped them consider what it must feel like for service users and CFMs. One member of staff said

'it's a fact that I don't often think about inclusion until I'm excluded.' (S8-F-FG)

Whilst many people struggled to articulate a clear view of inclusive practice, drawing on notions of inclusion identified in section 1 above, they suggested that when inclusion was at the forefront of their engagement with the NHS their 'treatment' was most likely to be optimised and most effective from their perspective.

4.3.1 BEING INCLUDED

More inclusive treatment had a direct impact on how service users and CFMs felt about themselves in terms of their emotional wellbeing, their confidence, their place in society, how they were valued and what they themselves valued. It enabled them to be more proactive for themselves in terms of their long-term progress.

'When we're all working as a team to ... get on the right pathway...and everybody's pathway can flutter in different directions...if we all work as a team and pull our ideas together, we'll all feel...[better]' (SU38-F-FG)

More inclusive approaches had an effect on the longer term impact of treatment.

P: 'If you work as a team.... I come here quite regularly for physio at the moment and I get, you know, regular sort of input. Which helps me to kind of continue that at home. ... It makes you want to then carry on....And to try and do the best that you can at home.

I: What is it that makes you want to carry on and do the best you can at home?

P: It's just the recognition that other people want you to be the best for you that you can be. In terms of physical wellbeing, in terms of emotional wellbeing, and in terms of feeling secure and feeling valued. And you just think, "Well they're spending their time and investing their effort in you, as a person, so therefore you owe it to them, kind of thing, to carry on.".. if I didn't ...come [here] and I didn't have the regular physio appointments, there would be no encouragement ... I would just think "Oh well, I'll not bother." And then I'll get stiffer and my muscles'll get weaker and I'll find it more difficult to mobilise. And it's kind of a downward spiral. And it's hard to break out of the cycle.' (SU3-F-FG)

'I think you get a good impression as well and you carry that on into the rest of your life. You know, you go out there and you go to work. And you think... And you've had positive experiences, and you can relate that to what you're doing.' (SU23-F-I)

4.3.2 BEING EXCLUDED

The impact of not being included could mean that treatment was inappropriate or appropriate but not embedded in everyday lives of service users, and so became ineffective.

'the physio wasn't bothered that I couldn't pedal it, I was there, she had done her time, I've done my twenty minutes even if I just sat still and it was on to the next bit of equipment and there was no awareness of that didn't suit me and where I was in my life' (SU32-F-P)

'I think the one thing that's been difficult is that [physio] often wants you to do a certain exercise at home and he will explain it and we both [service user and CFM] listen to him and when we get home we haven't the faintest idea how to do it! Now whether it will be more inclusive to write down what was wanted I don't know but it's done orally and so we almost always have to go back the next treatment and say "look can you say it again" you know "is this what you meant?"...I don't think [name] is quite aware of how hard it is to do that [understand and remember]. But we do say that we haven't done that because we didn't understand it and he takes that but he doesn't actually vary his procedure the next time.' (SU25-M-I)

'the OTs were full of sort 'oh you shouldn't do that' and 'you must use this and lots of ways and adaptations and techniques' which I abandoned as soon as I got home. Well, not as soon as, but sooner or later they all went by the wayside, you know, my transfer board and my pick up stick and all of these things I just don't use, so you know I didn't feel very included in the process of rehabilitation, I didn't feel very informed, I didn't feel that there was a plan, I didn't feel very empowered by it, I sort of endured it and went through it and said, yes, no, and struggled for what I wanted... I don't think that prepared me for the reality of life and problem-solving and you know the difficulties that I've faced and overcome in my daily life' (SU50-M-I)

Many CFMs were able to give specific examples of the importance of being included as part of recognising the medical needs of those they cared for. This mother/wife of a family where Huntington's disease is well known within the family explained how they felt that, because they were not listened to, her son had years of incorrect treatment.

'My little boy has been to hell and back with different diagnoses. Injections after injections. And blood-taking and operations and procedures he's had done on him. For 9 years he was treated [for something he hadn't

got]...instead of doing what I'd said in the first place – which my own husband who has got Huntington's kept saying... "He's like me." He used to say, "He's like me." These people, the medical profession, don't like being told. ...and they [the medical profession] were so against it because it was very rare for juveniles to get it. He was just pushed aside and just treated for the symptoms. Chest infections and digestive problems. He was put on medication and then they decided that some other, but he didn't need it because his pancreas was working alright...And they used to send me to different consultants to have, like, scans done on his bowels and things like that... Until I met a Professor at the [hospital]. She is absolutely wonderful. She listened and she said, "I think you're right." I nearly fell off my chair... And it was just a case of going and confirming it for the appointment...And I got confirmation. That's how he is diagnosed with that now. But he's been to hell and back. He's terrified of doctors. He's 13 and he still sits on my knee when he goes into Consultant's rooms.' (C22- F-FG) (for fuller description see appendix 13)

The amount of time taken up by activities that do not lead to improving the health of people with LTNCs was clearly articulated by service users/carers family members. One particular focus for discussion was repeated visits to professionals, often over many years, which do not affect the lives of the people attending. There appeared to be three main reasons for this type of practice:

- i) Appointments carried out for administrative purposes but were highlighted as ineffective by service users, CFMs and professionals involved.

'I did say to him at one point... is there any point to this because nothing much was gained from my point of view except going to say to him "not much change" or "there has been a bit of change" and that was about it. You know, ten minutes at the most ...and he said 'Well, don't come, there's nothing more I can do for you really.' And that was quite good for me to know. It was blunt but quite true and I stopped going which was quite good for me.' (SU19-M-I)

- ii) Appointments where the meeting resulted in ineffective activity due to the fact that the basic premise of the meeting did not meet the needs of the service user.

Decisions that are made at appointments by practitioners about intervention, affects the lives of both service users and CFMs. Where the relevant parties are not involved or consulted, this leads to wasted time for all parties. This carer is reflecting on an experience where he was not involved in the decision-making at an appointment and was kept abreast of progress. The course of action taken by the practitioner did not take the wider long-term condition and home context into account. CFMs frequently expend additional energy and time trying to ensure 'the best' experience for the person they are supporting. Inappropriate decisions not only have an impact on family members but mean that practitioners need to conduct additional appointments in order to ensure that the 'right' intervention is being provided and deal with disenchanted relatives.

'I get intensely annoyed if something is happening and particularly if it relates to [wife] and if I don't know it's happeningor I know something is happening but I don't know quite what it is, and I'm not being told. That makes me a little bit annoyed because it can take the treatment or the resolution to that particular problem down a particular avenue which might not fit with the wider view of [wife]'s condition or her wellbeing. That means I've got to pick up the pieces when things if things start to go wrong or try and manage them back into the way we live. It's a difficult thing to describe but people start making arrangements for you without consultations ...It [has an] impact on the life we lead together. I mean I like to try and arrange things you know [to] sort of have my own little bit of life. I'm not resentful ...disappointed, but not resentful, when things get changed if I can't follow that particular life that I would like. But when somebody does it without thought, shall we say, I get annoyed and sort of point out carefully point, you know sort of make the point that you know, if you had consulted in the first place it would have made things a lot easier because people do things thoughtlessly I think sometimes.'

(C18-M-I)

One service user explained how she received help at home, the focus of which was to support her in learning how to organise her home. This had, over a long period of time, proved too difficult for her to achieve. Her own perceptions on this now were that she would benefit more from someone coming and sorting out her house, a home help/cleaner-type person rather than a professional CPN. This would then give her time, space and energy to concentrate on developing things she could achieve, rather than spending time on something she feels she can now never do. It would also be more cost-effective as expensive professional time could be used to focus on achievable aims. She had not discussed this with the professionals she saw because she felt that if she said she did not want this help they would withdraw the service and she did not want to be without anyone coming to see her.

- iii) Appointments where insufficient preparation was carried out to enable the service user to be understood.

Seeing a different person every time they attended the clinic left service users and CFMs with difficulties interacting with clinicians and building a trusting relationship. This is particularly pertinent for 'long-term' conditions where there is both regular and frequent engagement with professionals over months and years. Service users and CFMs then find they have to adapt to new practitioners and re-tell their story on a regular basis. Whilst there is a recognition that people need to learn their craft, and service users have a role in supporting the understanding and experience of the new generation of practitioners, the lack of underlying continuity can lead to frustration and a lack of confidence in the service.

The data highlighted that repeated changes in staff, particularly medical staff on rotation, can create anxiety. This anxiety is heightened where people with neurological and complex conditions have difficulties in adapting to changes in planned or 'expected events'. They felt they lacked a secure thread of continuity to support them through inevitable changes. The impact of a lack of continuity leads to:

- Repetition of story
- Increased anxiety due to the unexpected and new people with unknown understanding about you as a person and your condition
- investing in a new clinical relationship that takes time and emotional energy

- lack of trust within a new relationship that leads to limited sharing of the issues that are of concern
- implied concern that something important may not be picked up within the complexity of the condition

Examples were offered of ways of engagement that would not leave service users/ CFMs feeling that their treatment was not in safe hands.

'It's a bit like that with consultants coming and going – registrars and sidekicks and people. You see a different person every time. It needn't necessarily matter, but they're really on the ball and attentive, but they've got to look everything up. They say, "I'll just cal up this X-ray and see what's happened here." And it would be nice to see the same sort of person, but you've got to face it – these people are going up their experiential and promotional ladder, so they've got to get the experience. And, in a way, you don't mind, from that point of view, because you're helping them to get the experience, even if you've got to kind of be a bit patient with them sometimes.' (SU4-F-MFG)

'As long as you don't mind telling your story again... Sorry, I'm just... Because that's obviously a lot of the problems – you're having to tell your story of your condition, continually, to different consultants, doctors or whatever. I don't find it frustrating, but I would imagine some people would.' (SU37-M-MFG)

'If you've got a head injury and you see different people all the time, it can be quite confusing. Yeah, quite confusing.' (C8-M-MFG)

Where continuity of communication worked well, this was valued.

'Physios are, like, part-time, 2 or 3 days a week and stuff like that, you might find that I might just go to a physio 4 months ago, right you are, and this time it's a different person. But that doesn't deter from the fact that they've done their homework, sort of thing. They know my son's case, sort of thing. So

when they do see him, don't go, like, through the history which is the past case. So they're like on the ball.' (C-M-MFG)

iv) Appointments for equipment which was subsequently provided but not used

This service user explained how, because his needs were not considered in relation to his wheelchair, he ended up being issued an expensive power chair that he never uses.

'the process of getting a wheelchair was a bureaucratic process of jumping through hoops and trying to understand my choices within a very rigid framework, it wasn't processed for understanding what was good for me, what the drawback and benefits of different chairs would be, what possibilities there were. I didn't feel included in that at all and so I think I've had to struggle and find my own way... I've had to solve it myself [bought his own chair privately]. This [NHS] power chair, which is a lot of resource, is just basically sitting in my front room. I said to the wheelchair service look I'll give you back the power chair which presumably cost £6-7,000 at least and give me a voucher or buy me powered wheels "oh we can't do that". So it's a bureaucracy which I don't understand which doesn't seem very efficient and hasn't met my needs...my current chair weighs about 12/15 kilos, I can't lift it, therefore if I want to drive I need a device to store the chair which would probably be another £3,000+ to fit on the car with a hoist, and be a real hassle, or I can get a titanium chair which weighs 5 kilos which I will be able to lift and will empower me to drive and I would not need the rest. But you know those sorts of choices haven't been spelt out, we haven't thought it through...so that's a lack of inclusion in decision-making and information-sharing in understanding what the possibilities are which has left me, you know, trial and error, you know, fumbling my way towards a solution which is a waste of my time and money and it's certainly a waste of NHS time and money.' (SU50-M-I)

If the purpose of appointments is not articulated and discussed by those who have come together in the appointment (service users, CFMs and practitioners), continued engagement can be stressful, of little value and costly for both those who go to the

appointments and service providers. It also has an impact on credibility of services and the morale of both staff and service users.

4.4. ADDRESSING ISSUES AND ISSUES TO BE ADDRESSED

The data generated a number of complex reasons why service delivery, characterised here as ineffective, has not been addressed. When those who deliver services are welcoming, pleasant, working hard to deliver services, and offer a space that service users characterise as 'treatment', voicing the fact that service delivery is not getting to the heart of your needs is difficult. There are historically issues of deference, power and hierarchy to be addressed as well as wider cultural issues around critical debate being seen as conflict.

'I'm not very good at conflict really. I tend to avoid it if possible.'(SU25-M-I)

This diary entry from a service user who finds change difficult and has recently had to adjust to a new doctor, gives some insight into that complexity.

'The way I look at it the quicker I am in [to the clinic] the quicker I'm out. That's why I say to him I am fine but am not I hope when people read this they understand what am trying to say.' (SU18-M-D)

Communication systems between services were not always valued by practitioners. Transitions were consistently highlighted as areas where much time was spent re-capping, re-learning or re-engaging. This included transitions between practitioners and services within Trusts and transitions between Trusts.

'On my recent [emergency] trip to (acute) hospital I offered it [patient care pack] to the paramedics and they refused it. I took it to the hospital and every question they asked me I kept saying it's in my care pack and nobody would even open the care pack...Everything was in there. And when I was sent out, I was sent out at night in my pyjamas in the cold to an empty house, which

they knew. I had no food, no care, nothing and had they contacted the people in the care pack that would have all been organised.’ (SU9-F-I)

Links between professionals and professional services segregated service users back into silos of impairment and affected other areas of their health. This carer explained how the person they cared for, who had a history of cancer, was unable to attend breast screening because the new equipment was designed for those who can stand.

‘In the past, hasn’t been a major problem. They normally arrange a special clinic where they allow extra time for people in wheelchairs to come in. ‘Cos it takes a bit of extra time. So it’s not a real problem, but when we went this year, to the new ...outpatients – it’s all the new gadgetry and that, they couldn’t do it, because the machine doesn’t facilitate someone with [patient’s] disability being X-rayed. ... they were very apologetic and they said “sorry, you know, we can’t do it this time, but don’t worry, you can still do, like you know, the physical checks and if there is any problems, then we can do, like, an ultrasound, or something”. ...That’s exclusion, that. I got numbers to phone, that, you know, the National Breast Screening Authority, but I thought: I’m not going to bother, because I spend enough time on the phone, getting nowhere, so I thought... So anyway, the route was, we went to the GP and... he [did] a thorough examination. And he also explained that it wasn’t as good as [the hospital machine]... [patient] was very, very upset for quite a while after that.’ (C3-M-I)

Professionals who participated in this research cited a number of issues as affecting their ability to develop a more inclusive process with service users and carers/family members. These included:

- Organisational pressures, structures and systems such as time, accounting procedures
- Historical ways of organising service delivery, particularly delineation by profession

- Professional training and identity
- Personal issues - not comfortable with handling confrontation and challenge and the emotional cost of engagement.

'There's an edict come down from the Trust about patient information. Everything has got to be generic now – welcome packs and all that. So, of course, ours doesn't fit... [we were told] "This is no longer any good, you have to do x, y and z... You can't have this, you can't have that, you can't have names, you can't have pictures, you can't have..." Everything that our service users want, you can't have... And it just made me really, really cross. I thought we were being completely ignored and I was huffing and everything.'

(S18-F-I)

'You want to make people better but in particular with our client group they're never going to be, you're never going to cure them, well any kind of neurological condition that doesn't go away but physios still do have a tendency to want to fix things and they focus on wanting to fix things. Sometimes this can take you away a little bit from what people need to do to be able to do things day to day....So there is that risk of kind of focusing on how you might reduce stiffness or spasticity for instance but actually taking away some functions so that they're not actually able to be as mobile at home.'

(S6-F-I)

When a patient wants something different, staff are likely to see it as 'a blow' rather than a useful insight into how to work together with the patient.

'sometimes staff feel more secure when they're in a process...when that's stepped out of, it's harder for them. Because then they're not quite sure, "Well the patient is doing this now. Why?" And that is the hard thing. And it is sometimes a bit... Not having the control, isn't it? ...When a patient says, "I don't want to stay here any longer, I want to go home" and then it's, "But if you stay here you'll get..." "But I don't want to stay here." And sometimes that's hard for them to understand why this patient doesn't want to get better.

They actually do want to get better, just not in the same way [as how staff see it]. And then it's because, well, we don't really understand what that means, and it's a blow to staff.' (S18-F-I)

During a staff focus group one member of staff reflected on the impact of a clinic where she decided, based on something she had read, to spend the morning 'trying to kind of listen and affirm the feelings behind what people were saying' - listening more intently to her patients to see how that works in practice. To do this she had to put some of her professional protocols for medical treatment more into the background.

'I tried it for a morning... At the end of that morning, three patients said to me, "Thank you so much. You really listen." We didn't do anything therapeutic other than [listen]... And one, it was actually not the patient, it was the relative, just poured all this stuff out and I sat there, first feeling very defensive and kind of like, "Oh, you're taking up my time and I want to get on" and then I thought "No... I'm going to try." So I just changed my physical attitude and kind of tried to listen and when I wasn't listening, tried to look like I was listening. And she just went on and on. And then at the end she said, "You understand, you've heard me so well." And she's got a record of complaining and complaining and complaining and taking it to the top. I was amazed. I mean, I felt exhausted. I have to say I felt exhausted after the morning clinic. Really tired. And I hadn't done my usual... But it was interesting that that one clinic had three patients independently say thank you and I hadn't done anything other than listen properly... It was a whole revelation to me, really. Just trying to listen properly... but I don't know if I could keep it up because of that emotional cost.' (S4-F-FG)

Another member of staff in the group then asked her about how the outcome of such a consultation might be represented.

'...the cost is it's emotionally draining for you, but also perhaps you're not achieving what your manager or clinical lead is expecting that you will achieve in that time'. (S3-F-FG)

CHAPTER 5: A COMMUNICATIVE SPACE FOR DEVELOPING INCLUSIVE PRACTICE

The previous chapter looked at perceptions of inclusion and inclusive practice. This chapter draws on knowledge generated through the study, and through the approach to researching inclusion, to articulate a model for developing a more inclusive approach. We have called this the 'communicative space'.

Kemmis (2001) suggests that, in action research, the formation of a communicative space permits

“...people to achieve mutual understanding and consensus about what to do, in the knowledge that the legitimacy of any conclusions and decisions reached by participants will be proportional to the degree of authentic engagement of those concerned.” (Kemmis, 2001, p. 100)

The concept of authentic engagement is akin to McTaggart's concept of authentic involvement, where “authentic participation” is used to signify

“ownership, that is responsible agency in the production of knowledge and improvement in practice.... Mere involvement implies none of this and creates the risk of cooption and exploitation in the realisation of the plans of others” (p. 28)

The concept of the Communicative Space goes beyond a space where talking and listening take place and towards a space where this develops into in-depth, critical discussion that can be cultivated to develop shared understandings. The process of developing understandings through collaborative endeavour actively builds knowledge for, and in, practice and allows choices about the shape of practices to be made.

The concept of 'communicative space' has its roots in the work of Habermas (1998) who identified the ideal place for people to come together was in a space of

“...mutual recognition, reciprocal perspective taking, a shared willingness to consider one’s own conditions through the eyes of the stranger, and to learn from one another.” (Habermas, 1998, p.159).

This study therefore used the concept of a communicative space for authentic involvement. This space was developed through the engagement of a range of researchers, research methods and a recursive design (as discussed in Chapter 3). It aimed to enable participants to articulate and develop their own understandings of inclusive practice by firstly making explicit their own interpretations and then hearing and engaging with the interpretations of others. The notion of the communicative space grew from data drawn from the range of participants in the study. Recognising that each party needed to both find a way to articulate more clearly their own perception whilst recognising more clearly the understandings of others was key to building an agreed and practical way forward. The design and process of the study mirrored the way in which inclusion was described as being facilitated in practice i.e. through multi-party discussion where people felt comfortable to both say what was working and articulate where and why things were not

Working towards and establishing a communicative space is not easy. It is a process which requires effort and commitment from all parties. It requires give and take. It is difficult to let go of some of our long held, cherished beliefs about ‘good’ and ‘appropriate’ services to begin to build a sound basis for feasible, effective services. Participants in the study articulated some key attributes and principles necessary for developing a communicative space in relation to building more inclusive and hence effective services. These included:

- valuing individuals
- mutual respect
- trust and safety
- confidence
- recognising our shared humanness and engendering honesty in interactions
- developmental listening, hearing and responding

- agency¹⁴
- facilitated

From the perspective of the participants in the study, the qualities of an effective communicative space are:

- communicating in a way that recognises, respects and seeks to understand each other's perceptions, needs and requirements
- putting yourself in someone else's shoes
- learning from each other
- interacting in a non judgemental positive manner
- feeling free to disagree with someone and contribute to learning and understanding
- listening to others and being listened and responded to
- exercising the right as a service user/ family member to be heard.
- a positive and committed engagement by all relevant parties. This involves not just a commitment to dialogue but also a commitment to action.
- allocation of focused time

These are considered fundamental for constructing space in health care practice where the voices of service users, carers and family members and staff can be brought together. The purpose of this space is to develop mutual understanding and knowledge building in order for action to be taken to further inclusive practice in health and social care for individuals with LTC and their CFMs.

5.1 HONEST ARTICULATION

The problematic nature of articulating your feelings and understandings for service users and CFMs, particularly if they appear to be different from those of the health

¹⁴ A subjective awareness you are initiating, executing, and controlling your own choices and action actions in the world.^L

service professionals with whom you are engaged, cannot be underestimated. Bastian (2003) highlights some of the historical and cultural difficulties that surround articulating your case when visiting health professionals.

“I do remember learning clearly that part of being “good” at the doctor’s was to say whatever he or she wanted to hear. At the doctor’s, it wasn’t lying—it was making a good impression, and that was what mattered.” (Bastian, 2003, p. 1277)

As a child of the 1960s, in a family of “lower socioeconomic status” and “non-English speaking background”, the most important thing was to:

“...nod and say “Yes, doctor” no matter how mystified you were—and no matter how far-fetched the advice was”. (Bastian, 2003, p. 1277)

There is significant evidence from our data to suggest that this notion of not making a bad impression, of making sure you agree with the doctor, is still prevalent. Below is an example, offered by a CFM, of his wife’s interactions with a practitioner.

'Because I believe that [my wife] is a little bit “ooh, I can’t upset these people; I more or less depend entirely upon these people. If I get on the wrong side of these people, they can make my life even worse”. So [my wife] will agree, nod, “yes” and go along with things because of... the word I’m looking for, it’s fear isn’t it?’ (C3 & SU13-M-F-I)

This volunteer articulates the importance for service users/CFMs articulating their needs.

'we have people who are quite silent and still don’t feel that they have any rights ...If you’re not getting access to what you want, you need to be a nuisance.' (V4-F-I)

There were significant barriers to articulating their perceptions, understandings, wants and needs which stem, for example, from notions of self as a person, self as a

person with LTC, confidence, pride and trust. This service user recognised the need to be more up front about their feelings but found that difficult as it seemed like 'asking for help':

'if I didn't open up, swallow me pride and open up and ask for help...tell them exactly what's going on... I wouldn't have gotten the help that I needed and the help that I wanted.' (SU14-M-Q)

Asking questions, and asking for help, requires individuals to be able and confident to take the initiative and the responsibility to do this. Service users and CFMs valued a culture where this was possible and recognised its worth. Staff were aware of the need to improve communication.

They recognised it as a right.

'Service users of that service have got a right to tell us what they want'
(S12-F-I)

They recognised it on the human level.

'I like to know about them – not necessarily about their condition. I find out about that first. I like to get to know them. The person that comes out. So if they're angry I can come in and say, "Haway, mate. Just... Tell you what, have 10 minutes. Just have 5-10 minutes. We'll chill and then you can see if you can let me know what's wrong. Because you're very upset about something." Quite often it's just something like he's been sat in that position for 2 hours, 3 hours and his bum's sore.' (S7-M-I)

They recognised it as a way of making services more effective.

'they forget what the whole point of the hospital is. And why they're here, and who they're here for. And I think everybody does. I think I do sometimes as well – you get busy, you know. I think a lot of time would probably be saved if there was a bit more listening happened.' (S5-F-I)

This service user demonstrates the impact of an honest articulation, the outcome being the termination of an ineffective service which was a good outcome from his perspective, and likely have been so from the perspective of the hospital he was visiting.

'I did say to him at one point after going a few times, you know, is there any point to this, because nothing much was gained from my point of view except going to say to him... "not much change" or "there has been a bit of change" and that was about it. You know, ten minutes at the most so it seemed to be, and so he said 'Well, don't come, there's nothing more I can do for you really.' And that was quite good for me to know. It was blunt but quite true and I stopped going which was quite good for me.' (SU19-M-I)

5.2 LISTENING, HEARING AND RESPONDING: AGENCY

There was a tendency amongst most participants to initially conceptualise the communication process as information delivery rather than as an exchange and development of shared understandings. This forms the environment and the subsequent behaviours that take place within the communicative space. It is predicated on the values, beliefs and assumptions that are held about the situation about to be entered. If the intention of a professional is to give someone information about their condition, then this will form their view of how the session will be conducted. If the intention is to open up a space for communication and discussion where sharing this information will be part of the communication, this offers opportunities for a more inclusive approach.

The recursive nature of the research process in this study, by encouraging the revisiting of articulation, allowed people to delve more deeply into the nature of communication that enabled inclusive practice to occur. For staff, this meant recognising the historical pattern of health professionals as 'information givers' and for service users and CFMs, as receivers. The process of communicating is, however, more complex than that. The ability to effectively listen to others, and be

listened to, was seen as one of the most important aspects of interaction within the communicative space. The importance of responses that confirm the listener has heard is highlighted by this CFM.

'it's their ability to listen and understand ... and respond ...appropriately that sort of makes you feel whether you're being included or whether they're excluding you by their own remit ' (C18-M-I)

Active listening and understanding creates an active response from the listener based on understanding rather than an attempt to 'fix things' from a practitioner perspective. Listening, learning and honesty within the people with experience / practitioner relationship was valued but the rareness of that type of encounter was highlighted by the response of this CFM when it actually happened.

'I met one woman – Professor A at X [regional teaching hospital]. She is absolutely wonderful. She listened and she said, "I think you're right." I nearly fell off my chair. And I'm, "You think I'm right?" And she said, "Yeah." She said, "I think you're right." (C22-F-FG)

In a focus group of CFMs of people with Huntington's Disease, there was considerable discussion about the impact of not being listened to. Not being listened to caused real anger and frustration. Some CFMs who, because Huntington's is common in their families, had considerable experience and expertise in recognising the disease, and considerable experience in not having their insights and knowledge recognised, the impact of which is described in Chapter 4.

The criticism was not the lack of professional knowledge per se (although a perceived lack of information about Huntington's in the general training of doctors was considered a gap that needed to be filled). Participants recognised that health professionals from other disciplines are unlikely to have experience in all disease areas, especially the rarer ones such as Huntington's.

'My doctor admitted that he had never come into contact with HD [Huntingtons Disease]. So he was learning through [husband]'. (C20-F-FG)

Their concern was that professionals tended not to listen and respond to their observations as people with experience of the disease. To be listened to whilst realising that what you have said will not have an effect on the outcome of the communication, is as frustrating as not having the opportunity to have your say.

Participants in the study were all asked to think about times when they had felt included. Most found this difficult to do, but found it easy to offer the antonym. This member of staff described her role as family carer. She identified the importance that being involved in discussion and decision-making had on her own feelings of inclusion or exclusion.

'I was thinking of a time recently when I felt excluded – because when decisions were made over my head, without any discussion. And technically you might get a sort of vague thing saying, "Oh, this has happened and therefore we've included you." But actually not been able to influence it. Not being able to give voice.' (S4-F-FG)

The need to give voice is clearly important to her feeling included in the interactions that concern her family member. What she highlights, however, is that feeling included in the communication was more than being told, more than being listened to. To feel included she has to have offered her voice and had some influence in and on the process.

Staff members wanted to reposition themselves as 'listeners' but as they engaged in the communicative space of the research process they began to articulate the complexities of that listening process.

P: 2 I tend to listen then anyway – as in we do the goal negotiation and there are lots of their goal negotiations that come in from all the different therapists, or therapies, including social and leisure - they've [service user] then been asked if they want to attend the group . But yes, we don't take it to the next step of... And I think they're aware, as well, of what the links are with their goals, but we haven't taken it to the next step of, kind of, what are your

expectations or, you know, what do you want to get out of the group? So it's kind of we've done half of it, if you like, but it hasn't gone to the next half.

(S3-F-FG)

The backdrop to this kind of active listening and open communication is, for service users and CFMs, the need to feel welcome, not just in clinics but in the space in general. Being welcomed is not partial, it needs to be universal. The role of staff such as ambulance people, porters and reception staff is essential in creating the right space and environment for a more communicative space to flourish.

'Well I think the reception that they get when they come in is very important. You do need a friendly sort of face there. Because I think it can be quite intimidating, people coming here for the first time. It's... People are apprehensive or nervous coming for an appointment or what have you for the first time. And I think that's very important. Knowing directions – where they're going. If people need wheelchairs we go and get them. If people don't like the lift we take them up and down. So just trying to make them feel as comfortable as possible and they're in a nice place. People are here to... to help them.' (SU30-F-I)

5.3 RECOGNISING THE INDIVIDUAL: MUTUAL RESPECT

Recognising the individual and respecting their views are key values and principles for developing, entering, acting within and reviewing the communicative space. These values, whilst championed in national policies (DoH 2005; 2009) and local NHS mission statements (see appendix 7), are not always found in practice. This gap between policy and practice was recognised by service users, CFMs and staff.

'I think the whole culture ... is to very much treat people with respect and dignity, and I don't think it always happens.' (S16-F-I)

'if the mutual respect was there and it was correct, everything else would fall into place.' (SU-BCD)

The service user above had articulated a notion of mutual respect. The basis for effective communication was not that one party should respect the communication of another, but that all parties should have respect for the perceptions of the others.

Habermas (1998:159) raises the importance of the need, in a communicative space, to be willing to see your own situation through the eyes of a stranger. He alluded to this as 'reciprocal perspective taking'. This study revealed the importance of being able to put yourself in someone else's shoes as a pre-requisite to developing shared understandings for effective long-term services. As this service users says, 'It's back to the adage: "wear my shoes."' (SU5-M-I)

This staff member, in articulating her own thoughts, recognised the importance of reciprocity and mutuality.

P: 2 'it's with the shared, sort of, problems or ideas or successes or joint interests. Where it's definitely got to be a two-way reciprocal thing, really. That as much as you support and listen to them, they support and listen to you, you know. So it's a mutual... It might be at different times and, you know, no-one is keeping a tally. But it feels open enough that that's the way it is. There's no... No score.' (S3-F-FG)

These two staff members articulated another aspect of their practice that engenders mutuality in another way. They highlighted the importance of making a bond with patients and they discussed the use of humour through shared laughter [which includes laughing at yourself].

P: 4 [humour]... 'Yes, sometimes you can use that with patients, can't you? It's easy to get it wrong, but when you get it right, sharing laughter, you feel like you've got a bond with that patient or... I think, don't you?

P: 3 I think it can make feel somebody feel very comfortable as well. You know, as long as you're laughing with them. Or, like, even laughing at yourself.' (S3 & S4-F-FG)

Part of the exchange that takes place within the communicative space relates to feeling safe within the space. This provides a freedom to ask questions that are important without fear of judgement.

‘She didn’t judge him, she didn’t judge me, she valued me, she valued him...And I felt safe that she was there... she was completely professional can I say, she wasn’t nicey nice or sympathetic, she was professional and I really trusted her’ (C27-F-I)

Creating an interactive space that is entered into with non-judgemental attitudes is not then about ‘being nice’, but a deeper expression than that. It is one of valuing the individual and recognising the person within their context and environment. It involves levels of understanding that come from frankly shared perspectives in a trusted space. The space has to be entered into with confidence and trust that honesty and transparency in communication can be safely fostered.

This member of staff articulated, from her own experience, the role of uncertainty in making people feel uncomfortable and unable to participate.

P: 2 ‘I think when you’re in an environment where you’re comfortable, you relax a lot more and you just feel much more certain about what may or may not happen. I think it’s that unpredictability that makes you unsure. And uncertain. And I think it impacts on the way that you behave a lot as well....If I can speak from personal experience, I would behave very differently... Sort of take my role at work – in a meeting where I’m comfortable and where I know everybody and I know what the agenda is and I understand, to an extent, what people think and feel and how they might behave. But put me into a meeting where that’s not the case, then I don’t necessarily feel included or involved or as comfortable to speak up and have my say. (S3-F-FG)

5.4 MULTIPLE PERSPECTIVES

The combination of perceiving, knowing, critiquing and learning from multiple perspectives enables participants to articulate notions of theory or practice that they may not have been able to see if their own perceptions had not been critiqued by the ideas of others. When the general picture enjoyed by practitioners is punctured by thinking from another perspective, the communicative space provides opportunities for clarification of the already known (explicit knowledge) and what is nearly known (implicit or tacit knowledge). This is the precursor to the creation of something entirely new (transformational knowledge). Destabilising and disrupting ways of thinking can offer ways into creativity and erudition affording a space for participatory learning.

5.5 TIME: IMMEDIATE AND LONGITUDINAL

Developing a communicative space necessitates that time is given to the needs of that space when service users and CFMs engage with services, but also that it is maintained over time so that understandings can be revisited, revised and developed in the light of further consideration of what has been discussed, changes in understandings or changes in circumstances. There are practical issues.

‘Because some of our people coming in might not be able to express themselves. They talk slowly or maybe some of them... We’ve got one gentleman who can hardly talk – some people use the little key pads that they type in little... You know, little things like that. So I think they need to feel that people have got time. We don’t sort of rush them. And try to understand’

S30-F-I

An element of the study that enabled the participants to understand issues relating to inclusion was the recursive nature of the approach. The longitudinal rather than one-off approach, allowed for repetitions of information and the revisiting of thoughts and ideas (a recursive process) to add breadth and depth to the data. Participants engaged in exploration sense making in relation to inclusion and were offered opportunities to revisit that topic in the light of what they, and other participants, had articulated.

5.6 FACILITATION

The role of the facilitator was to open the floor to discussion in a stimulating way, to get ideas into the open and help members of the group listen to each other, debate, reflect and make meaning from debate. Hunter et al (1993) characterise facilitation as an artful dance, with the role of the facilitator offering:

“...an opportunity to dance with life on the edge of a sword – to be present and aware – to be with and for people in a way that cuts through to what enhances and fulfils life.”

(Hunter et al, 1993:1, cited in Hogan, 2002:51)

Cameron (2001) points out that the role of a facilitator differs from that of chairperson at a meeting. Typically a chaired meeting focuses on reviewing progress and agreeing action by working through a strict agenda. Facilitation in the context of the work presented here has the primary intention of enabling people to interact both with their own thoughts and ideas and those of others. It is about helping people “get their wading boots on” and to do “the mucking” (Caro-Bruce, 2000:106). The facilitation role is not to find or establish a final truth, but to keep conversations going. It is to enable participants to recognise their own current understandings and those of others. The facilitator helps provide a lens for seeing and supports what Mellor (2001) termed ‘the knowledge trick’ i.e. helping take the process forward to analysis and meaning making. It is different from advocacy

‘Advocacy helps you to say what it is that you want to say more effectively. The other end of the conversation is listening and I think we’ve seen in several of these clips [scenarios on the DVD shown at the BCD] people not hearing what is being said to them and that’s again a skill. It can be taught and but it isn’t systematically. I felt sorry in a way for both the nurse who’s sitting there getting this sort of complex jumble of issues and stuff and she seems lost, you know, not to know how to start explore it. In the same way with the doctor with the girl who was having trouble getting to the clinic, but then didn’t do her any good, I mean, there’s two issues going on there, but she, she failed to detect them because she wasn’t listening accurately

enough. So I would argue that both ends of the communication process need to work.' (C-BCD)

5.7 IMPACT OF A COMMUNICATIVE SPACE

Where people found they could trust the communicative space and offer their honest and open questions, they felt more positive about the outcomes. They had more confidence in the relationship with the practitioner facilitating a discussion based around issues important to the individual.

'I think I've been incredibly fortunate to be surrounded by people who have let me ask those questions and let me ask awkward questions without me being deemed as a difficult service user or a difficult patient.' (SU32-F-P)

'And it's a totally different feeling here, isn't it? You can go in all cheerful. And relaxed. You feel you can ask things. And it is. It's lovely.' (SU9-F-MFG)

This member of staff feels that the impact not listening has on service users and CFMs is a lack of understanding between staff and service users. This leads to staff being considered as making the judgements about what is best for people and determining the progress that should be made. The impact of this is:

'I think people feel... Disheartened. Not properly listened to. That they're failing because they don't seem to be quite doing what the staff are expecting them to do. Or what the systems are expecting them to do... A sort of bit of a disengagement.' (S10-F-I)

Her comments reflect the focus of discussion amongst service users, CFMs and voluntary sector representatives on this issue. That engaged listening, that employs respect, understanding and honest representation, is at the heart of more effective service delivery.

This staff member, recognising the policy initiatives, the local imperatives and her own concerns that she did not spend sufficient time engaging with patients and CFMs and their experiences, determined to try out more of a listening approach during one of her clinics¹⁵. During one clinic she provided the opportunity for a CFM to have an open and honest discussion about how she was.

‘Well the outcome of one consultation was all the time was taken by the carer. But I rationalised that to myself that the carer is looking after the bod. And if she’s looked after, she’ll look after him better. If she’s feeling better then she’ll be feeling better about where she is. And then it came out that she was near to running away or killing herself, you know, with all she was dealing with. So I rationalised not paying attention to the patient but paying attention to the carer, you know. And running over time. But it’s hard to do that, isn’t it? It’s hard because there’s not... What can I write in the patient’s notes?’
(S4-F-FG)

The cry of ‘What can I write in the patient’s notes?’ was heartfelt. She identified that listening required energy, was time consuming and yet was effective in meeting the real needs, particularly of family members. For service users and CFMs it feels more effective. As a consequence of her listening experiment she was surprised to find that

‘at the end of that morning, three patients said to me, “Thank you so much. You really listen.” And we didn’t do anything therapeutic other than [listen]. It was interesting that that one clinic had three patients independently say thank you, you know. And I hadn’t done anything other than listen properly.’
(SU4-F-FG)

Reflecting on her experiment in respect of listening to a CFM during what is essentially a patient clinic, she was concerned, however, that spending time talking rather than doing does not easily fit with the way her work is monitored and evaluated. The paperwork she was required to keep did not enable her to record her

¹⁵ NB: This was something she had done independently and was not part of this study, although her reflections on her experience are particularly informative for this study.

interaction with a CFM and there was little room for flexibility. One service user made a heart felt cry about becoming 'system-shaped, rather than the system flexing to how you are, and adapting and flexing a little bit to accommodate what you might feel are your needs' (SU-32-I-theme verification) and it seems staff might have a similar call.

5.8 GENERATING A COMMUNICATIVE SPACE: THE ROLE OF POLICY IN PRACTICE

The staff member above highlighted the difficulties she experienced in rationalising the time she spent listening. Her perception of the experience was also that it was very time consuming. It seems to be a general perception amongst staff, that to include time for in-depth communication would mean that appointments would be longer. Certainly the literature does not necessarily support this assumption. Cape (2002) and Steward (1995) both reported that when patients are given the opportunity to ask questions in their own way actual consultation time did not increase. They also reported that patients felt they had actually spent more time with their doctors.

These discussions have illuminated important issues about how the way in which the NHS monitors and evaluates practice need to be tailored to include different processes for practice development in respect of LTC. Staff worried that taking out time to shape a communicative space with services users eclipsed opportunities to do other parts of their role.

P: 4 'If you've got a kind of agenda of "I need to check out these physical things with the patient, or I need to... I think I need to check their health things and that there's nothing going haywire that I need to do something about. ..." There's a particular issue over, yeah, whose agenda? Whose agenda, I suppose.' (S4-F-FG)

This member of staff also felt caught between agendas

P: 2 'Well they will be quality performance indicators, but also certain things we will have to achieve each time. Whether it's an outcome measure or whether it's this or whether it's that or whether it's the other. So that puts us under pressure to... There are two agendas going. There's... I suppose patient-orientated and we, I suppose, give free rein and... But then the cost is it's emotionally draining for you, but also perhaps you're not achieving what your manager or clinical lead is expecting that you will achieve in that time.'

(S3-F-FG)

What has been highlighted is the key role a communicative space plays in developing inclusive practice, but the difficulties in practice in establishing such a space. Whilst policy is towards greater communication the complexity of developing this demands facilitation and training.

CHAPTER 6: DISCUSSION

Drawing on a social model of disability which explains disablement as the result of behaviours, or barriers, that prevent people with impairments taking part in wider society, this research brought together a range of perspectives to discover more clearly how inclusive practice is conceptualised. It looked at how feelings of inclusion have an effect on ways in which people with neurological impairments and their carers/family members participate in treatment, are engaged with the NHS community and use knowledge from treatment in their daily lives.

This study

- identified some key characteristics for inclusive practices and principles for developing more inclusive services
- provides an indication of the potential impact of inclusive services on effectively embedding treatment in the lives of service users and their carers/family members
- identified enablers and barriers to inclusive practice
- identified approaches to treatment practices within services for those with LTCs that would contribute to making them more inclusive, effective, efficient and hence reduce costs for all stakeholders.

6.1 CURRENT PERCEPTIONS OF SERVICE DELIVERY

- There is a general satisfaction with the delivery of medical and health services that were specific to long-term neurological conditions (LTNCs).
- The existence of a Centre that specialises in LTNCs is crucial to people's physical and mental health and social and emotional well-being.
- There is considerable dissatisfaction in relation to a number of technical services linked to LTNCs (e.g. wheelchair clinics, transport services).
- Services accessed through other providers were the most problematic (e.g. ophthalmology, urinary clinics, breast screening). In non-neurological services accessed by service users with neurological impairment, physical barriers to

access alongside a lack of understanding of the impact of the LTNC in relation to the clinical issue ,caused dissatisfaction and distress.

- Transition periods raise high levels of anxiety and are perceived as areas of uncertainty where ‘fighting for your corner’ is necessary rather than being inclusive.
- Long-term community support, both at home and within residential settings, is delivered in a friendly and practical manner but is not sufficiently tailored to meet the nuances, needs and lifestyles of service users and their CFMs.
- Boredom is endemic in long-term rehabilitation.
- Services are not designed to be inclusive.
- Some practitioners are more inclusive than others .

The core research team worked together to design a research process that enabled spaces for people to firstly articulate and understand their own perceptions, then offered opportunities to hear and examine the perceptions of others. The range of methods offered for this were specifically designed to support participants in being comfortable in their articulations but also to prick their general perceptions of ‘the way things are’. Using this approach service delivery was considered by participants with a more critical eye and opened up an articulation of both effective practice and barriers to effective services.

This critically reflective approach did not change the overall perception of services as generally worthwhile and well-received, but offered greater insights into areas that needed attention to improve service outcomes. Key practice areas that received immediate critical opprobrium and suggestions for improvements were:

1. travel

- i) public transport - negotiations with public transport in respect of accessible services would improve access to services and the disposition of service users/CFMs on arrival at clinics.
- ii) road systems - discussions with councils in respect of road and pavement systems for wheelchairs, buggies etc. would enable easier

journeys to appointments and improve the disposition of service users/CFMs on arrival at clinics.

iii) ambulance/patient transport systems - improved use of communication systems could reduce waiting times and hence reduce the frustration and feelings of lack of respect for their time and effort that ensues when people are left waiting.

2. appointments

i) delayed appointment times - managerial imperatives to improve time keeping are vital to avoid frustration and disappointment. Such experiences repeated over time can lead to lack of respect of services by service users and CFMS and a reluctance to engage.

ii) remembering appointments - improved use of communication systems to support service users, particularly those with memory impairments, in keeping their appointments. This could reduce service users' feelings of having let services down and staff perceptions of them as not committed to attending.

3. environment

i) access and navigational difficulties (even where buildings have been specifically designed for purpose) consulting with service users and continuing that consultation throughout the design and implementation phase of building could provide more inclusive environments and less ongoing 'snagging' issues. This saves service users and staff from expending energies in addressing access issues that they believed had been clearly articulated.

ii) parking - provide sufficient space for adapted vehicles at all NHS facilities.

4. atmosphere

i) the reception is vital to feeling comfortable in an institutional setting - where it was good, it was very good, but it was person dependent. Training is needed for all staff, but particularly transport and reception staff, in recognising the importance of their attitude and actions in enhancing opportunities for people with LTNCs to engage with services.

5. transition procedures

- i) more attention needs to be given to careful planning supported by multi-disciplinary involvement which includes all parties who have strong and meaningful relationships with the service user,.
- ii) the way service users are transferred needs to be addressed.

6. general hospital services

- i) services that deliver non-neurological support and are based in other types of hospital/out-patient service provision appear to be insufficiently aware of the needs of patients with LTNC. This takes the form of access issues but also the importance given to care-plans and other forms of communication particularly drawing on and valuing the knowledge of service users and CFMs.

Addressing these physical, environmental and practical issues are part of developing inclusive practice, but not sufficient in themselves. They are perhaps the easiest to articulate and are indicators of an underlying approach for thinking 'about' the person when delivering services but they are not inclusion. Careful attention to the practical elements of service delivery is an indicator of a more inclusive approach but inclusive practice is more than a set of physical/practical design solutions. The thinking behind the design, the philosophical underpinnings and the way the environment is used, is key to inclusive practice. It is what lies behind the public face. The translation of physical access into inclusive practice has a powerful effect on the comfort, self-esteem, confidence and commitment of services users and their CFMs and their ability to make the best use of their engagements with services.

6.2 KEY CHARACTERISTIC OF INCLUSIVE PRACTICE

Inclusion is different for everybody. Whilst there may be a plurality of motivations and ideological commitments there is, however, an underlying 'inclusive paradigm' which gives it some elastic ties and enables us to identify some of its key characteristics. Key characteristic of inclusive practice include:

- **Active and ongoing communication** - talking and listening, by all

- **Shared decision-making** - which includes taking the lead
- Having **real choices** – not just choices from a set menu devised by others
- Having **control** over your own choices in a given situation
- **Influence and agency** - having your input acted upon
- **Recognition** of your needs and rights - for yourself and by others
- Having **responsibilities**, taking responsibilities and being given responsibilities - not delegated or removed
- **Recognition of the person** is at the heart of the process (functionally, emotionally, cognitively, contextually and culturally and spiritually)
- **Respect** for the person
- **Positive** attitudes towards aspirations
- Environmental designs that enable physical **access**
- It is forged through **co-labouring** in a **communicative space** - it cannot be delivered 'to' people

Inclusion goes beyond notions of integration, where integration is seen to mean fitting in to what is available, it is deeper and more complex than that. Inclusion is the outcome of forging together shared understandings of an appropriate service. It involves recognising and respecting contributions from all parties and where contributions are valued, considered, and used as a means of shaping and developing that service. It involves thinking 'with' the person and shaping practice based on co-labouring. It is a way of thinking that caters for diversity of needs, experiences and lifestyles and where service users can have control of their own choices.

'sometimes there are so many aspects of what happens through disability that your identity gets affected and, you know your body gets affected, so things just start to take on another ... so many different realms of it. But if you can get peoples' attitude to think well I'm still me in the middle of all of this and I would still like to be given the choice to be involved and included then ... then that helps. So attitude I think is the first thing, awareness is probably the next thing' (SU32-F-P)

Being included is not having the opportunity to choose from a menu of predetermined options but is being part of shaping and developing that menu. It is not about being in control of everything but choosing where you need to have control and about not feeling out of control in relation to the key aspects of your life. Inclusion is not something that can be 'done to' people, it is a shared process where people work together to find their own place and way of being in the situation in which they find themselves. 'Inclusion is created by people and it's felt by people'. (SU40-M-I)

As one service user suggested at the beginning of this research,

"Inclusion is important as it has 'us' in the middle of it: **Inclusion.**" Service user researcher.

Inclusion became the logo for this project.

6.2.1 DIFFICULTIES IN ARTICULATING INCLUSIVE PRACTICE AND ITS IMPACT

Articulating inclusion was difficult. It was considered as something that was desirable but was often conflated and confused with positive social engagement or physical access. People found they could articulate exclusion but not inclusion. Inclusion seems to be the point where you do not have to think about whether you are included or excluded, it is where you just are there, without effort. Difficulties in articulation were found:

For professionals/practitioners/staff

- a. recognising what inclusion might look like
- b. recognising the mutual benefits such an approach might bring
- c. recognising the impact of their own notions of professional or institutional practices considered inclusive on the ability of service users to articulate theirs
- d. recognising the notion of responsibility for all parties, especially when service users had cognitive impairment or behavioural changes

For service users and CFMs

- a. what inclusion might look like
- b. the mutual benefits such an approach might bring
- c. the impact of their own expectations of engagements with health services on the outcomes of those engagements
- d. the importance of their own knowledge in engaging with services
- e. the notion of responsibility for all parties, especially when service users had cognitive impairment or behavioural changes.

Participants were not necessarily unaware of these issues but they were neither easy to consider nor easy to articulate. They were part of their tacit knowledge (see page 97). To bring that knowledge to the fore involved some very personal critical thinking and, for some, recognising that long-held understandings and beliefs about how services were delivered were perhaps not as effective as they had believed. Thinking in this way, if not carefully supported, can destabilise notions of practice, leaving participants feeling de-skilled and without a way forward. The design of the study, through developing the series of probing, in-depth discussions with participants, enabled us to garner some of the more esoteric, but fundamental elements of inclusive practice that have an effect on the impact of services.

6.2.2 COMMUNICATIVE SPACE: A MECHANISM FOR FORGING INCLUSIVE PRACTICE

At the heart of inclusion was what we have termed the communicative space. This space both enables articulation of what inclusive practice might look and be like for each individual and supports knowledge building for understanding how practice might be shaped more appropriately around the lives of service users and CFMs. The communicative space, shaped by trust and confidence, mutual respect, open and honest conversations, is where differing perceptions are brought together and critical reflection takes place with the intention of forging action.

This study focused on the interface between differing perceptions, and the struggle to find what is inside what Stephen Buetow (2009) called the negative space. Here, negative is conceptualised as used in film-photography, i.e. the space bounded by the pictured, not as unconstructive. It is a way of conceptualising important spaces that cannot be seen, but that are framed by those that have more tangible substance. He suggests that in medicine the negative space signifies ‘what is not seen, not heard, not felt, or otherwise not done or experienced’.

“Negative space frames and provides context for what is present, for example, during clinician-patient interactions. The context of these interactions is incomplete without alertness to the negative space, because, in the practice of medicine clinicians can easily fail to notice - and be responsive to - what is absent in perceiving what is at hand” Buetow (2009, p. 80).

This study extends the notion of a ‘negative space’ where clinicians fail to notice what is present but not articulated, to a space where all participants struggle to notice and articulate key aspects for understanding that would make services effective for them. The communicative space offers opportunities for all participants, which may include staff, service users and CFMs, to delve into their own thoughts, to construct their own opinions based on both the articulation of their own ideas and those offered by others. It offers a space for all participants to see what they know, to have that knowing contested, to see things differently and to understand differently, to see new opportunities and ways of developing both their own ways of engaging and being involved with the health service and the ways of others. It also creates a space to mark semi-permeable boundaries; things people can and cannot contemplate in their long-term engagement with services at certain times, but that can be flexed in the light of new knowledge and understanding. Communicative space makes a place for tacit knowledge to become explicit, shared and developed. This provides opportunities for practice based on a shared conceptualising of more inclusive and effective services.

This study created such a space for inquiry. Without this space we could not begin to delve below the practical, tangible perceptions of inclusion to find out what the underpinning elements of inclusion can/will/might look like and the impact of

inclusion on the lives of people with long-term neurological conditions. This conversation between two staff members exemplifies how the facilitated communicative space within the study, through enabling articulation, revealed and developed their understanding of inclusion. They began talking about something that was inclusive, a night out with friends, but friends who have children and they do not. They began to recognise that they did not always feel included in this and as they continued their discussion, a small prompt from the researcher led to a realisation of their behaviours and its applicability to practice.

'S:8 'I suppose, like with my friends, a lot of them have had kids and when they go on a night out, sometimes the conversation goes to children. In a way, I can relate because I've got nieces and nephews of a similar age but then I feel excluded when I make comments, you know, like it's kind of dismissed. I've had that a couple of times where... So I'm included in the social event, but then when the conversation turns to something that I haven't got as much of an experience with, or if I try to include myself and it's kind of, you know, like brushed off. Like, "Oh well, what would you know...you haven't [got children]

S:3 It's funny, that exact same situation, I would say I deliberately include myself by saying I sit and smile. But I exclude myself as in I don't give an opinion in that situation anymore for that exact reason. As in I don't have direct, first-hand experience of having children. Therefore, my opinion isn't valid or grounded on experience. So...

S:4 So do you exclude yourself or do you feel excluded by the...?

S:3 Well I probably feel excluded by past experience and allow that to influence how I behave the next time. I mean .. I smile and ask questions and listen, but I don't offer opinions about, you know, maybe how things are developing or what might be happening because... Or how you might manage a situation or... Often I wouldn't have an idea anyway. But the odd times I do spark an idea I don't express it. Which isn't really an issue except that you said it links really with how you can...

S:4 Exclude yourself. Or assume that you will be excluded.

S:3that you are excluded because of past experiences, really.

S:4 You protect against it happening.

I: Do you think your friends notice that?

S:3 I don't know. Some do and some don't...Some people are very receptive and some aren't. So if it was one-to-one with the more receptive person, I wouldn't be, you know, feeling like that. But if it's the more group scenario or... And it depends on how well you know people.

I: I think you've raised a very interesting issue there ... because it makes me think, so what if somebody comes, you know, a service user comes, and they feel a bit excluded ... but they're politely looking okay about it, how would you ever know?

S:3 But that's where we all have to take responsibility for... I know I'm behaving in that way, like so either I could address that directly with my friends or I could... You know, at what point does your own personal responsibility come in if you wish to participate in something?

S:4 I mean you're confident enough to say – to make a joke .. But it's quite hard to be confident, isn't it? In that situation. And to take charge of it.

S:8 I think it can become quite upsetting...certainly after it happened to me, I was quite reluctant to speak out but then... because it was actually my best friend who was carrying the conversation and stuff, I just carried on the way I was and obviously it upset me – the way it went on... but I can see what you're saying about, you know, relating to a patient and in a group or... Mm-hmm, yeah. (S3,4,8-F-FG)

For these staff members their discussion was sufficient to make them question their own practice in relation to how they developed a more inclusive approach to that practice that recognised more subtle forms of the power/knowledge relationship.

This aspect of the study mirrors and exemplars an approach for practice, the communicative space. Without this space, service users, CFMs and staff, all of whom have perceptions of 'treatment', 'care' and successful outcomes, may not recognise each other's perceptions. If notions of effective practice remain travelling on parallel lines all parties can become dissatisfied but not able to recognise the root of that dissatisfaction. Carefully teasing these out within the communicative space facilitates understandings through an inclusive approach. Without this space, in long-term practice the interface between services for those with LTNCs and those who use them can remain ineffective. Communicative spaces hold possibilities for

- recognising what is inclusive
- recognising what is unproductive
- shaping treatments to suit lifestyle preferences as well as physical cognitive and emotional abilities
- support for CFMs enabling them to better support service users and themselves
- people contributing to the work of neuro-rehabilitation service provision beyond their own treatment
- giving positive critical voice to all parties
- focusing on solutions

6.3 IMPACT OF INCLUSIVE PRACTICE

Inclusive practice affects

- how people feel about themselves: self-esteem, motivation and confidence
- how treatment is embedded into the everyday lives of service users and CFMs
- the ability to shape appropriate understandings of individual contexts for treatment

- the efficacy of treatment
- treatment costs
- notions of practice as a delivery model to notions of practice as a shared endeavour

6.3.1 *SELF-ESTEEM, SELF-CONFIDENCE AND MOTIVATION*

Being included means people

- feel better about themselves and their daily lives both within and beyond the NHS community
- feel more able to take control over treatment and shaping that treatment so it is an acceptable and positive part of their daily lives
- gain confidence in addressing issues that affect treatment and daily life and making choices in respect of that
- are motivated to be more active and take responsibility for aspects of their treatment and care and within their daily lives in general
- are motivated to want to find their place in wider society (for some that includes wanting to help and support others, for others it means living their own lives confidently)
- are less frustrated and angry because they have more control over their situation, and therefore find more energy for other aspects of their lives
- feel more positive
- are happier

Staff members generally strived to be more inclusive, although this was a difficult concept to recognise and articulate. Those who developed a more nuanced approach to inclusion considered that it:

- improved the impact of treatment
- gave them confidence and a morale boost as a practitioner
- improved their relationship with service users and CFMs

- enabled them to develop their own practice through finding new ways of conceptualising services
- enabled them to recognise the importance of addressing difficult situations as a means of improving long-term practice
- was a form of learning

6.3.2 *EFFICACY OF TREATMENT*

Inclusion tends to be perceived as something that is done to make people feel more welcome; done for social/emotional reasons. The impact of this conceptualisation of inclusion is generally articulated as affecting feelings, motivations and general well-being, but rarely articulates a direct influence on the efficacy of treatment. This study demonstrated that inclusive practice, practice that gets beyond politeness, rhetoric, fear, deference and historical perceptions of services that are delivered to rather than developed collectively, has the potential for a direct impact on outcomes for people and the NHS. It can:

- improve people's opportunities to embed their treatment in their daily lives
- improve people's confidence in articulating symptoms, needs and wants appropriately
- improve people's ability to understand opportunities, possibilities, aspirations and limitations in context and in a timely manner
- improve the chances of gaining appropriate equipment for daily living

It was clear from this study that ineffectual treatment was commonly endured rather than addressed. This was likely to be a long-term situation; for some it had lasted not months, but years. It had long-term impact on their physical, and indeed mental, health, for both service users and their CFMs.

6.3.3 *FINANCIAL COST*

If inclusion, or indeed exclusion, has a direct effect on the efficacy of treatment it therefore has direct cost implications. The financial costs to service users and CFMs of ineffectual treatment include:

- Transport costs (where using own transport) of attending appointments with no outcomes
- Private expenses of buying their own equipment when they have been unable to reach a comfortable outcome with NHS services. This appeared widespread in the case of wheelchair service provision, but could also be heard in other arenas such as home-based equipment services (hoists etc).
- Time off work for attending clinics etc

Inclusive practice can reduce the continuation of ineffectual treatment. This study revealed situations where service users and their CFMs repeatedly

- go to appointments with no outcomes
- go to appointments but are then not able to use the outcomes of those appointments in their daily lives
- receive services at home, on a long-term basis, that are either unnecessary or do not meet their needs or abilities
- are provided with equipment that they do not use
- do not feel able to offer important information in respect of their impairment and/or do not feel able to offer important information in respect of their own lifestyle, preferences or contexts.
- are offered information that they cannot act upon
- offer information that is not acted upon

The financial costs to NHS services ineffectual treatment include:

- Long-term provision of clinics and appointments that are not making a difference to the lives of service users and CFMs
- The repeated provision of expensive equipment that does not meet the needs of service users

- The provision of more expensive services due to inappropriate service delivery elsewhere - for instance ambulance services due to difficulties with other forms of mobility
- The use of expensive specialised staff in more generic service provision where service users are excluded from those generic services either for environmental or emotional reasons.

Appendix 8 offers examples of basic costs of transportation and consultation. This study did not attempt an actual economic costing but this indicative costing suggests that the cost of carrying out actions that are not effective in practice may be significant.

6.4 ENABLERS AND BARRIERS TO INCLUSIVE PRACTICE

6.4.1 *RECOGNISING THE PERSON, IN CONTEXT*

At the heart of inclusive practice was the ability of the practitioner to recognise the person and the daily experience of that person, the way in which they lived their lives, their aspirations, their personalities and preferences and their immediate support (or lack of it).

Service users and CFMs offered many examples of the importance of being recognised as themselves, as a person able to take their own decisions and contribute in their own right. Some examples were drawn from life with friends. This person talked about working with a friend to help paint a room.

‘it was almost like an expectation that you will do because you're here and there's a paintbrush and it didn't it didn't matter where I started, and where I finished might not be the whole room, but that the part that I could play in it was important and it was an expectation as well as being included. So that was good, and it was just part and parcel of a stay with a friend' (SU32-P-HA)

Some from the community

'when I started going to the local one [leisure centre] one thing – I'm always up front with people. I'm always up front – I say I've had a head injury. There's no point trying to hide it, I find....the staff on reception – and sometimes I could be there chatting for 5, 10 minutes just about anything and everything. And I walk around and I go swimming and I go in the sauna. And it's just like....I'm treated just like anybody else. I'm not, "Oh, there's Z, he's the one with the head injury." It's just, "Hello Z." And they don't treat me any different to anybody else, I feel. So when I go there, I feel comfortable. I feel as though I can relax. I'm not looking over my shoulder thinking, "Oh what do they think about me now? Are they talking about me?" Like, sometimes, you feel like it's what they're going to do. But they don't.' (SU16-M-FG)

Some examples of choices made may have previously been considered negative, for instance where consultations were terminated, or reduced, because of the shared understanding that attendance was a real struggle for the service user and CFMs and that attendance had become a formality rather than a practical, functional, supportive engagement. Mutual recognition of the need to end, as well as the need to continue with services, could be a positive outcome from shared understandings. For others a similar scenario where it would seem that practical application of medical knowledge had reached its limits, ongoing conversations were important for other reasons (see 9 for detail).

6.4.2 *RECOGNISING THAT DEVELOPMENT WAS NECESSARY*

Satisfaction should not be confused with efficient and effective service provision.

a) *Perceptions of satisfaction:* Almost universally, people who used the specialised services of neuro-rehabilitation found a great deal of merit in service provision¹⁶. Whilst people could always point to scarce resources and wish for more of everything, resource issues did not dominate. They considered that professionals have a high standard of medical knowledge and were generally friendly and

¹⁶ There are a number of distinct services where this would not be the case

approachable. It was clear from the study however that friendliness, whilst appreciated by service users and CFMs as a way of making them feel comfortable, was a double edged sword. It could be motivational or it could also prevent service users from engaging in what they perceived as critical conversations with practitioners. Many service users, in their discussions during the study, perceived that their practitioner was working against a background of pressure and time constraints, and did not want to add to that pressure. They commented that people were always busy, that they had lots of other patients and important meetings to attend, so they were careful about how much time they took themselves. This was considered an acceptable accommodation by service users, it was not said as a complaint about their practitioner.

Parts of the service most talked about as inclusive were in voluntary service provision in and around the neuro-rehabilitation centre and in the community, and also in their own fora such as the Service Users Forum, rather than in the health input itself.

b) Service user and CFM perception of self as a patient/carer: For some service users and CFMs the articulation of their real needs is frightening, not because of the person they are talking with, but because they find it difficult to accept for themselves. The process incorporates having to articulate to themselves what their needs might be, and for many, the fear of the changing nature of those needs in the future. Coming to terms with disease/acquired injury is a long and complex process during which time emotional, psychological, physical and home contexts may change radically for both service users and CFMs. This makes it even more important that deference, fear of articulating their real needs, and fear of developing a collaborative critique about the efficacy of treatment in context is addressed.

c) Service users/CFMs perception of role: People see it as their role to fit in. Despite the imbalance between their own lives and the medical approach, they can amend their own lives to accommodate new ways of living with their medical/rehabilitation interventions, as much as they can, and for as long as they can. Given that their lives are often intertwined with whole family cultures, their lifestyle in context may mean they are not be capable of accommodating such changes. They then fail to embed treatment into their daily lives without 'confessing' this. They may not address the issue due to a range of factors including the fear of

being labelled disruptive. CFMs who cannot embed treatment process into their daily lives can feel responsible and then feel unable to address this with professionals due to their feelings of guilt.

d) *Staff perception of self as inclusive:* Given that participation in this study was voluntary, staff in this study were likely to be biased towards considering themselves inclusive practitioners. Those with no interest or who considered it irrelevant were unlikely to volunteer to participate. Within this positively biased sample there was evidence that challenges were recognised.

'I mean it's one of those other challenges isn't it, to make sure that what you're doing is relevant and meaningful to the person to whom you're delivering a service.' (S6-F-I)

Staff often felt overwhelmed by all the other duties, many of which, including administration, would take priority over time for communication with service users, largely due to accountability procedures. Service 'delivery' was at the core of practice and reconceptualising that model was not readily seen as important or even desirable. This is especially true when the impact of inclusion is conceptualised as being 'nicer', rather than being more effective.

Power relations and an inability to recognise the person within the condition hindered the development of a communicative space.

'I mean if you have a patient who's aggressive or uncooperative or fights or whatever, or is violent or whatever, it's a barrier and you can't build up a good relationship and it doesn't it just doesn't work whereas if you have a patient who you can build up a good relationship, is cooperative, you get on with, it all it does make the job a lot easier.'(S17-F-I)

For other staff it was more finely nuanced, and based more on a lack of opportunity to delve into their own practice through the prism of the notion of inclusion. Recognising that your perceptions, however well intentioned, are not always the perception of the service user whose life is at the centre of the engagement process, demands a level of insight. The acquisition of this is not readily evident within

organisations. It would seem from this study that all stakeholders need support in recognising the need for a communicative space as a way of developing inclusive practice.

6.4.3 IMBALANCE BETWEEN CULTURES WITHIN SERVICES AND THE LIFESTYLE/CULTURAL CONTEXTS OF SERVICE USERS

The supposition that service users had time, space, frameworks and abilities for carrying out, particularly physical activity, but also organisational or behavioural tasks, could be at odds with the lives of service users and CFMs. This service user, who spends time both living on their own and with their partner, demonstrates clearly how context has an impact on the ability to carry out the recommendations of the physiotherapist in practice. This service user had previously spoken how clearly the need to carry out frequent and regular physiotherapy had been articulated to them and the importance they placed on achieving an improvement in their physical ability.

'I was told every day you don't do is a day longer [that you remain unable to walk]. That jolted me.' (SU50-M-I)

Yet whether the exercises were achieved or not was closely related to lifestyle and personal frameworks for living.

' [when living alone] it feels more of rush in the morning, I don't have a routine. So that's how rehab's slipped by, slips you know, and so you know oh I've got to brush my teeth and go to the loo and have a shower and dressed and ready, the taxi is coming at 9, oh well I won't do my exercise today, not that I constantly think in those terms but those are the times I don't do the exercises and somehow I've only ever managed to do exercises in the morning. I should do them when I go to bed at night but I've never got into that routine.... [when living with partner] we have a routine. We go to work, you know I have work to go to at 9, sometimes a bit earlier than that, and so, you know, we get up at 7, [partner] has a shower, I do my exercises then we get up and have breakfast together because I have done my exercises the night before, then we get up

and do breakfast together and ...and I get dressed and then I'm ready and we leave.' (SU50-M-I)

Service users face:

- surrendering their own preferences, routines, habits and ways of being, to those determined by notions of treatment delivered by services
- risking being labelled as not accepting or adhering to treatment because they have not been able to see a way of incorporating treatments, be they physical, cognitive, psychological, etc, into their own contexts, the social, cultural and emotional spaces that frame their lives.

Such behaviour is also affected by assumptions of what Papadimitriou (2008) terms the 'preferred' and 'good' patient. Her interviews with staff working with spinal cord injured patients revealed that staff had expectations that these patients would be 'difficult to work with' and that 'patients who are motivated' are easier to work with than those 'who just get depressed and bored'. Motivated patients appeared to be those who were able to

"keep a light and presumably non-depressed attitude; are on time for therapy are open and co-operative to suggestions, corrections and innovations from staff; are not rude to staff; are not violent when they disagree or dislike an aspect of therapy; are friendly and courteous and gracefully and stoically accept pain, discomfort and adversity." (p. 369)

Service users and family members were keenly aware of such assumptions.

P: 'It can make you wary. But it can make you think, "How could this have been done differently? And what could have been done differently about it?"'
(SU32-F-verification interview)

The 'difficult' patient is one who is often moody and unpredictable, forgets appointments, does not appear interested and seems to keep changing their mind about what they want. Fear of not knowing what is happening to them can make

people upset, irritable or angry, it can mean they fail to mention their symptoms as they do not even wish to acknowledge they have them, fatigue causes people to lose motivational ability, to become passive and appear uninterested and may mean they forget appointments. Many of the long-term conditions represented in this study have some or all of these symptoms and behaviours as a consequence of the condition. Carers and family members may have lived with this behaviour for many years and are equally dispirited, particularly if they feel that their lives are not been respected and recognised. In these instances, behaviours that the general population, and the health service, see as being a 'bad patient' can result in a certain distance being maintained by practitioners. Paradoxically then, the people most in need of support can be the ones who are less well favoured by practitioners and so can receive the least. (See 9).

Difficulties with getting simple adaptations to homes, particularly if these fell outside the usual adaptations such as ramps, grab rails, hoists, etc. could be a major frustration and turned service users into 'difficult patients'. This service user had asked for a replacement door entry system to enable her to speak to visitors via intercom and open the door remotely from within her house. For this she had to be assessed, which resulted of a full assessment of her physical capabilities in her own home.

'When I challenged him about that at the time, [why she needed a full assessment] and said that everything else as far as I was concerned was fine, and that if it wasn't I knew where to go to and when to go to people – or I felt that I did and would hope that I did – and that as far as I was concerned my request was purely and simply for a door entry system, not to be a performing seal on and off my shower seat, [they had asked her to show them how she used the shower] he wasn't happy... When he went, after we'd had the chat that we had – when I told him I wasn't happy – I felt... I felt I needed to let the other therapist know what had happened because I wasn't happy about it. I wasn't comfortable in what had happened. She then passed it on to her line manager and I got... I've got it somewhere – I got the most incredible letter from her. Obviously, and quite rightly, defending the member of staff. That, you know, putting me in my place. That really he was here to ensure that all

my needs were met... And so I am aware that I can be seen as just a boatload of bother, really.’ (SU 32 -F verification interview)

6.4.4 PROFESSIONAL, ORGANISATIONAL AND SYSTEMS IMPERATIVES

This study highlighted tensions between what many practitioners considered to be good practice in relation to developing a communicative space with service users and CFMs and what they believed to be practically possible. Barriers to taking this forward included notions of professional role and organisational accountability frameworks.

Professional: The way in which the practice of professionals is monitored is predominantly based on observables and measurable outcomes. It can be argued that the UK position remains similar to that in the US, where, as Papadimitriou (2008) suggests, the ‘third-person’ view remains the dominant perspective in rehabilitation culture

“a view that concentrates on what can be stated ‘objectively’, that is visible from the outside, thus tending to miss what phenomenologically informed sociology sees as important features of people’s actual life-worlds and meaning structures.” (Papadimitriou, 2008, p.366)

Time for developing and maintaining a communicative space is not readily accounted for. Staff members who attempted to create a communicative space became concerned because of accountability processes (see p. 100).

Papadimitriou (2008) found that many physiotherapists in America perceived ‘talk is a waste of time and money’. “Treating the medical diagnosis rather than the ‘illness experience’ seems to be what Physiotherapists are comfortable with” (p. 369). Nonetheless, patients bring talk to clinical encounters, whether those encounters are in a hospital environment or community appointments. Staff working in neuro-rehabilitation considered talk to be important, but as a precursor to rehabilitation treatment, rather than as a centre part of the rehabilitation in practice. Talking about

real life issues that patients brought to therapy was not considered real work, although it was considered important. Mattingly, in Papadimitriou (2008), found that occupational therapists did not want to engage in talk primarily because they are concerned about crossing professional boundaries and acting as psychologists or social workers. This study had similar findings, 'talk' tended to be homogenised under the heading of 'making people feel comfortable' and extended discussions about notions of practice were avoided.

Organisational: Accountability measures that do not incorporate opportunities for developing vital communicative spaces between stakeholders make it difficult for individuals to swim against the tide. Successful strategies need to take into account the needs, fears, and motivations of staff. Despite working within policy frameworks that take what Davies et al term an 'activist view' to managing cultures as a way of improving health care,

“assumptions about measurability, aggregation, and transferability of knowledge are deeply ingrained in medical care”. (Davies et al, p 114)

The way organisations are held accountable creates tensions between reporting measurables and engaging in fundamental underpinnings for practice that are not readily translated into fixed targets. The outcome of this is that many policy objectives are difficult to contextualise. This research has illuminated a gap between personal aspirations, overt statements about cultures and practices in respect of inclusion both in national and local Trust policies/mission statements (see appendix 5), and the ways in which services are managed and delivered.

Despite the policy focus on the recognition of the person (for example *Putting People First: a shared vision and commitment to the transformation of adult social care* (2007) and *Our health, our care, our say: a new direction for community services DH* (2006)) the organisational culture of health services tends to remain embedded in professional power. Whilst there is considerable debate about the notion of organisational cultures (Davies et al 2000) and the emergent nature of such cultures, there is substantial agreement among those who conceive of culture as an organisational variable that

“organisational culture emerges from that which is shared between colleagues in an organisation, including shared beliefs, attitudes, values, and norms of behaviour. Thus, organisational culture is reflected by a common way of making sense of the organisation that allows people to see situations and events in similar and distinctive ways.” (Davies et al 2000, p112)

Davies et al go on to say that it is “the way things are done around here”, as well as “the way things are understood, judged, and valued” that has importance in organisational culture. It is often the invisible, intangible beliefs that shape organisational culture and hence individual behaviour. There is much literature on where culture and convention interact but this not the focus of this report. It needs, however, to be recognised as the background against which all participants are working. Cultural change cannot easily be wrought from the top down by simple exhortation but without systems that enable change and the facilitation of changes in practice, alternative approaches remain difficult to embed.

6.5 IMPACT OF DESIGN

The design of this study mirrored the nature of engagements between practitioners and service users and CFMs. It was not a one-off engagement, it was longitudinal. At the heart of the research process was the intention to develop a communicative space, starting with the way in which the core research team worked together and then with participants in the research. Bringing together a range of perceptions to develop a form of deliberative discussion and critique was brought to the fore. The aim was to build a space to co-construct what we might know about inclusion and its impact.

6.5.1 QUALITY OF THE DATA

The design of a study necessarily has an impact on what can be understood from the research. Some studies are designed to collect data, this study was designed to generate data in respect of the known, the nearly known and what is yet to be

known. Participation in the study, whether as a researcher or as a participant, was intended as a learning process where knowledge could be forged together. The further people travelled with the study, the greater the opportunities for developing understandings of and for inclusive practice that had the potential to affect our own behaviours.

In the early stages of the development of the study, the lay researchers were not confident in articulating their ideas and questions. Working together over time however, allowed confidence to build. This had a direct impact on the quality of the design of the study as it opened it up to critical scrutiny from a number of angles and perspectives. Each person came with their own lens which allowed new ways of seeing what challenged our own ideas and shaped our methods accordingly.

The experience of the core research team mirrored the experience of participants in that there were service users, a CFM, staff and voluntary sector representatives. This acted as a bridge between researcher and participants and was intended to support a more rapid construction of a communicative space. In the initial round of the research process, wherever possible, the experience of the researcher was matched to the prospective participants. Appendix 10 illuminates this in action. Appendix 11 offers an example of the impact of not being able to achieve this when an academic researcher, because of resource issues, had to interview a participant living in a care home. The lack of shared experience was keenly felt. With no recourse to facilitation in this one to one interview situation neither she nor the researcher managed to overcome this issue. The service user chose not to engage further in the project so opportunities for developing a more productive communicative space were lost.

As the study progressed the communicative spaces became more robust and knowledge more fiercely contested. This was especially so at the BCD where data generation and data analysis were melded. Existing themes emanating from the data were offered to all who attended to confirm, contest and develop, so blurring the boundaries between core researchers and participants. The method that perhaps had the most impact on the BCD was the DVD. When participants were presented with their own data, filmed so that they were able to actually see their own data, they

were able to actively discuss it amongst themselves during the day, and refine, re-shape, clarify, add to and confirm the meanings that were being suggested from that data. This did more than provide triangulation for the data, it generated new ways of seeing into it.

The depth and complexity of the data generated throughout the study was an outcome of the recursive, participatory design. As participants became more involved they wished to support understandings more fully and the core research team were delighted to receive suggested reading and further clarifications from service users and CFMs outside of the planned data collection process.

Particularly notable at the BCD was the input of staff. In the early stages of the study staff had been difficult to recruit. One reason for this was the call on their time, but another suggested reason was that for staff this could feel like a perilous engagement. Would they be subjected to criticism and have to defend their practice? This reflected the kind of concerns some staff had in respect of engaging in shared decision-making in practice. For some not having control made them apprehensive. For those who generally have the control this is a difficult path to tread. As the study progressed however, management supported participation and more staff were recruited. Interest developed in the project and by the time the BCD was advertised there was sufficient interest for staff who had not taken part in the earlier stages to ask if they could attend too. Unfortunately the design of the project precluded that happening, but it acts as an indicator of how, when fears are reduced, a communicative space can have a motivational force.

The organisation of the study, whilst considered particularly successful in terms of hearing the voices of service users and CFMs beyond those who are already actively engaging in groups and fora, missed the voices of those who have more severe cognitive impairments and hence were deemed unable to consent to participate.

6.5.2 ADMINISTERING THE RESEARCH IN PRACTICE

Whilst the impact of involving lay researchers and developing a participatory research design has been the quality of the data and rigour of the research process, this has been at a cost. The necessary attention to detail means that the timescales for collaborative processes are far in excess of expectations (even when you have worked in this manner before and think you have been more realistic about this). This puts considerable strain on the academic researchers who are facilitating the process.

Working with lay researchers put considerable strain on the systems within which we were working. Established for other purposes, as alluded to in Chapter 3 of this report, they often acted as barriers to, rather than facilitators of the research process. We hope, having tested some of those systems, and worked towards shaping some to be more responsive and inclusive towards the needs of diverse research populations, we have opened the way a little more for those who might come next, but there is still work to do.

The timescale of the project, in this case almost two years to gain funding and then three years to undertake the project, puts considerable strain on the staying power of lay researchers. The motivation of the researchers in this study was exceptional, but even so, their own lives intervened on many occasions, and whilst all members of the core team have retained an interest, the numbers actively involved in the final stages was considerably reduced. In addition, the death of Lindsay Carter in the middle of the project left the whole team reeling and time was needed to find our way once more. Lindsay had been an inspiration to the team. Her considered insights and strong held views were not always comfortable listening and instigated some heated debates. The outcome of those debates always left the team clearer about their way forward and the reasons for taking one route rather than another. Her contribution to the collaborative space was sorely missed, as what would have been her innovative contribution to disseminating the findings from this project.

6.5.3 *DISSEMINATING THE LEARNING*

As the project unfolded learning came from multiple perspectives. There was learning about the notion of inclusion and its impact, but there was also learning about the research process and its impact on what could be known. At first the core research team was reluctant to engage in disseminating our findings, but, starting with small, local presentations a number of researchers gained in confidence. From feeling they would have little to say, they realised they actually had an enormous amount of new knowledge that they were eager to convey to listeners. Particular examples of this were the presentation at the INVOLVE Conference in Birmingham (2010) which consisted of leading a workshop on participatory approaches and the writing of an article for the INVOLVE newsletter. This dispelled their concern that because they were not trained researchers others would not want to listen to them. The voice of participants who have experience of what is researched is particularly powerful and has led to many involved and constructive conversations beyond formal disseminations. A list of formal disseminations can be found in Appendix 20.

We are beginning to work with the Evidence-based Practice Group of the North East Neurosciences Network (NENN). The NENN, a commissioning led network working collaboratively across agencies, professional groups, user and carer groups and the voluntary and independent sector, has identified a need to gather the perceptions of individuals with neurological conditions about their 'outcomes' following a pathway of commissioned care. They have approached researchers from this study to enable them to draw on its findings and also to work with them to inform the development of a 'Clinical Quality Indicator for Service Experience' within Neurosciences. What is envisaged is an indicator that captures both service user experience of services (outcomes) and the quality of collaboration between service users and the organisation (process) to inform Commissioners.

CHAPTER 7: NATIONAL SERVICE FRAMEWORK FOR LONG TERM CONDITIONS

This research was undertaken against the backdrop of the 11 quality requirements (QR) in the National Service Framework (NSF). These were not overtly discussed with participants but data generated from the research has important implications for policy and practice.

QUALITY REQUIREMENT 1: A PERSON CENTRED SERVICE

Putting people at the centre of their own life planning forefronts the need for a holistic, inclusive interdisciplinary approach to care planning, review and service delivery involving a range of agencies. How this happens, how people are included and in a way that means they have choice and control, or choice about control, were key elements of this study.

The study revealed that having information delivered is not sufficient for a model of practice that enables people to feel in control of their own lives. Consultation and discussion remain rooted in the articulation of preferences from a predetermined set of options. Engagements with services users that truly shape ways of living with neurological impairments, planning the shape of your own treatment within that life, were almost entirely absent from the data. Inter-disciplinary and multi-disciplinary approaches to planning remain professionally organised and led, with service users and CFMs being informed but often feeling out of control and without agency within the process. Most prevalent was a range of ad hoc approaches where services were delivered from a range of sources, with the best intentions of practitioners but often to the detriment rather than enhancement of the wellbeing of service users and their families.

Current practice remains to try and shape people's lives to fit current service provision in line with an ideal framework held by those who are distanced from the actual context of that person. This way of service delivery is termed, within this

report, as integration. This study suggests that for more effective use of service we have to move beyond notions of integration, where service users and CFMs are invited to join in to something that already has a shape, to being part of shaping the framework for their engagements with services and the way in which services will shape their future lives. The cost to all parties of not doing this has been revealed as significant.

The research approach demonstrated a model for a more communicative space based on facilitated communication. In this space all parties are supported to work together to build deeper understandings to form the building blocks for treatment and care. In the space the focus is the shared understanding of the context which, in long-term conditions with long-term treatment plans, may include medical, social, emotional and lifestyle factors. Barriers to developing the communicative space include

- politeness;
- deference;
- historical understandings of a delivery method of health care;
- general perceptions of ways of working located in both service user/CFM and practitioner rhetoric about what health care engagements should look like;
- professional imperatives;
- perceptions of a hierarchy of knowledge;
- power relationships.

These barriers are not peculiar to developing a communicative space within the practice of neuro-rehabilitation but exist broadly when shaping this model for development in other arenas. They are discussed widely within the literature on action research that informed this study. The role of the researchers in this study was shaped by notions of facilitation as a means of developing a space for democratic and critically constructed understandings. To create a communicative space in practice it would follow that facilitation has a role to play. The implementation of a care coordinator, case manager or community matron, as outlined in this NSF, was notable by its absence from the accounts of participants.

This study suggests, however, that the role needs to go beyond co-ordination to developing that communication. A facilitator who can form a communicative space with service users, CFMs and practitioners is important for helping articulate all voices. Having a named point of contact is not the same as active facilitation.

A facilitator is not the same as an advocate. There is distinction between someone whose role is to develop a communicate space and someone who actively seeks to hear and support the voice of the individual who may not be able to articulate their own want and needs, and forefront this. Advocates are service user-centred, which is particularly necessary where there are disputes about provision, including disputes within families and where there are issues of mental capacity.

The lack of a facilitator and associated advocate was felt keenly at times of transition, especially if the outcome and nature of that transition was contested. Examples where angry, hurtful, unresolved disputes about the outcome of transitions now shape the lives of people and dominate discussions were shocking and had a major impact on all aspects of a range of lives.

The lack of a systematic approach for advocacy and facilitation was seen as barrier to the development of more effective services.

QR1 recommends that people with more complex needs “will need a care coordinator” (p. 20). The absence of a person who could support people through the labyrinth of service engagements (medical and social) in a way that brings their needs to the fore was highlighted as an important gap in service provision. Most people felt that they had had to find their own way through, had had to be their own ambassadors and in many cases had had to fight their own battles.

The difficulties they experienced in getting their needs met sometimes led to them giving up and retreating into unfulfilled lives where depression and other mental health issues were likely, or, in the case of equipment battles, their homes becoming storage places for equipment that they were never likely to use.

QR1 clearly states that “Not everyone with a long-term neurological condition will want to participate actively in their own care” (p. 21). This was reflected in findings from this study. What was key however was that the person themselves made the decision not to be an active participant and that this was not a one-off, nor an overarching decision. There were some aspects of treatment and care they would want to be totally involved in, and in control of, other parts of their treatment and care they would wish to leave to others to decide. Articulating where control might lie needed to be part of on-going collaborative discussions as both the lifestyles and medical needs of service users change over time.

Change was a huge part of all the lives of the service users and CFMs who participated in the study. There may have been an acute change at the onset of the neurological impairment (e.g. acquired brain injury) or a gradual change as an illness progressed. What was universal however was that this changed people’s lives and perceptions of themselves within their own life-spaces. This led to a complex set of new and changing understandings. Constant change meant re-framing decisions. Being characterised as a person that keeps changing their mind was unhelpful, and many participants articulated how difficult it was to ‘change their minds’. They felt it hindered their relationship with professionals and had the potential to lead to less effective care (see Papadimitriou’s (2008) notion of ‘good patient’ p. 122)

QR1 refers to the need for care plans to take account of identified non-neurological health issues. For many of the participants in this study, getting their non-neurological health needs met was a source of frustration. Reasons for this included

- service user/CFM perception of the importance of the health need being met was not recognised and reciprocated by professionals,
 - the generally difficulties of accessing services in terms of referral,
 - physical access difficulties where neurological impairments acted as absolute barriers to the type of health services taken for granted in the general population.
- (see Appendix 12). This also has relevance to QR11.

Recommendations:

- The notion of integration is replaced with the notion of inclusion.
- Being 'part of the planning' starts with having a choice to be 'part of shaping the framework for dialogue and planning'.
- The care-coordinator (facilitator) role is more firmly established, that it starts from referral and functions across all services, including non-neurological health care services.
- The notion of a facilitated 'communicative space' for co-labouring is embedded in longitudinal service delivery
- That an education programme on addressing personal perceptions of the 'patient' and 'good' patient is needed for both professionals and service users/CFMs

QUALITY REQUIREMENTS 2 - 5: EARLY RECOGNITION, PROMPT DIAGNOSIS AND TREATMENT AND SPECIALIST REHABILITATION

The focus of these QRs is that people suspected of having a neurological condition and those who are in the early stages of diagnosis are to have prompt access to specialist neurological expertise for accurate diagnosis, treatment and rehabilitation as close to home as possible.

The diagnosis of certain conditions is complex, and hence not always straightforward. Honest and open communications about what is known and what is not known, if part of a trusted and collaborative approach, have been articulated by participants in the study who have experienced this as a positive way forward. The study revealed a gap between this type of approach and a practice which tends to belie the experience of the person and their knowledge of their own bodies.

In cases, where people have experiential knowledge of the disease (for instance within families where Huntington's disease is prevalent), their in-depth experience and expertise can hone their observations and knowledge. Where this is over-ruled, rather than engaged with, by professionals with less experience of the disease than service users and CFMs, leads to frustration and can have an impact on disease management. It is a barrier to early recognition and prompt diagnosis and in some

cases had resulted in months or years of inappropriate tests and treatments (see Appendix 13 for more detail).

Service users and CFMs in the early stages of diagnosis or in the acute phase of treatment were harder to reach to recruit into this study.

There was more evidence about transition areas. Transition has been highlighted in the literature (see Chapter 2 above) as an area of tension, especially where people are going from hospital inpatient to community residences. The tensions are predominantly linked with questions around who decides which patients benefit from ongoing neuro-rehabilitation (as opposed to care homes) and who decides what rehabilitation might look like. The narratives of service users described unfulfilled lives in places where they lacked stimulation. The excerpt from the diary of a person in community residence (14) illuminates a life that has become something to be gone through rather than a positive experience. Appendix 15 gives detail from a diary kept by a man living at home but, whilst enjoying being with his family, his own hopes for his life remained severely limited. [This also has relevance to QR11].

Transition has the potential to create enormous rifts and tensions between and across services, between services and families and within families (16). This highlights the need for communicative space and for a facilitator who has a long-term overview of the changing needs of service users and their CFMs.

In addition, the actual transition process has been recognised as having the potential to be traumatic. As the NSF suggests, this process needs careful planning and communication between services, but also with service users and CFMs. Where service users and CFMs have discussed their experiences of transition the processes within specialist teams would appear to be communicated in more depth. Where the transition is to external services the management of a process that supports both the service user, especially those with communication and cognitive impairment, can be traumatic, with the availability of transport services and beds taking precedence of the adjustment needs of the people involved. This also has relevance for QR11.

QR 3 has a focus on emergency and acute management. Whilst not a focus of this study, it provided examples of transitions to acute services when people have neurological impairments, whether or not this was a neurological emergency. A key concern of service users was the transfer of information. Notes and care-plans, even when patient-held and so carried with that patient to the point of treatment, could be over-looked and at worst actively ignored. If care-plans are forged through a communicative space, to have them ignored at critical junctures in that care leaves service users and CFMs contemplating the value of such plans and the value of their own contribution to the plans (see appendix 18). When this system was used, it worked well and was appreciated by service users.

Recommendations:

- 'Being part of the planning' is replaced with 'being part of shaping the framework for dialogue and planning'.
- The knowledge and understanding of service users and CFMs is given due weight. This remains a training issue for professionals.
- A facilitated communicative space for co-labouring is embedded in longitudinal service delivery as a means of shaping treatment that can be embedded in the lives service users.
- The care-coordinator role is re-articulated as a facilitation role.
- The importance of patient held care plans as a means of articulating the way in which all treatment shapes lives needs to be raised for those in all health services and systematic implementation adopted across health services.

QUALITY REQUIREMENTS 5, 7 AND 8: COMMUNITY REHABILITATION, SUPPORT AND INDEPENDENT LIVING

QRs 5, 7 and 8 focus on enabling and supporting people with long-term neurological conditions to lead a full and independent life in the community. Data generated during this study re-iterated that living at home, being included amongst family, friends and the community, is the main aim of people with long-term neurological impairments. It has highlighted the key elements that support an inclusive approach

but demonstrated how difficult this is to achieve in a way that enables inclusive living.

Barriers include:

- difficulties in accessing appropriate services that meet the needs of the home-based situation.
- difficulties in acquiring equipment and alterations to support living at home in a way that gives them maximum autonomy.
- difficulties in engaging in community-based activities not connected to neuro-rehabilitation services.
- transportation and communication issues.

Living at home could be a continuous struggle to develop maximum autonomy and independence, and, for many CFMs, in terms of coping with the extra demands on their time alongside maintaining their own lives. Services to support their needs could be delivered in a way that left them feeling that they had not been seen as person in their own right. A topic that dominated both services user and CFM conversations through this study was the gap between high quality medical knowledge and the manner in which this was translated into addressing the needs of daily living in the community.

QR 5 states that

“Rehabilitation is most effective when helping people live as independently as possible and improving their quality of life when health and social care bodies collaborate with each other, with people and their families and other agencies.” (p. 36)

This study puts this at the centre of community practice, it is vital for enabling people to engage in their own lives, in their own communities and in line with their own lifestyle choices. What this study highlights however is that communication needs to get beyond sharing information, beneath the various pre-conceptions, suppositions and expectations people have, to reveal the actual lives, possibilities and expectations held by all parties. Developing a communicative space can reveal

places for feasible, functional application of the expertise of all parties rather than being based on that of professionals only. If lines of communication run in parallel, if services are delivered rather than forged, the knowledge and skills people have acquired into their own condition can be marginalised as secondary to neurological rehabilitation practices. This study has demonstrated how central they are to effective service for long-term conditions. Where one set of expertise dominates in partnerships knowledge can only be partial; practice will be based on incomplete understandings of the situation. This leads to inefficiency, extra costs and frustration for all.

The reality for many people is that living at home is a struggle. What they endure was a long way from the 'full life' which is the aspirations of QR5, where their struggles and the impact on families are also articulated clearly (NSF QR 5 p35).

This study highlighted the importance of engaging with the wider community as part of rehabilitation and living a full life. For many barriers to engagement, both physical and social, led to continued severe limitations to life beyond their own home and family. This has implications for mental and physical health. Service users who engaged in regular/frequent activities beyond the home reported that places like leisure centres, libraries, churches and golf-clubs, recognised their needs more readily and became places where they felt included and hence enjoyed going.

'I always feel very included in the golf club because I've been a member for quite a number of years and I know a lot of people and I feel very relaxed and easy going in there, so certainly I feel included, err, very much so there, 'cos apart from there, I don't really go [anywhere else]...' (SU33-M-I)

Yet the last comment made by SU33 suggests the limitations of this.

Some places, by their very design, enabled people to gain access and feel included but many places 'corralled' service users in ways that marginalised them from the general population and even from their family and friends. (See 19). Physical access and transport difficulties still dominate many people's lives despite the

concentration on addressing these issues under more recent legislation such as the Disability Discrimination Act 2005.

Condeluci (1997) states that services are relatively unsuccessful at returning individuals to generic communities and that if the ultimate goal of rehabilitation efforts is for individuals to experience meaningful realities within their communities “all functions of daily living activities are pointless unless there exists a viable setting in which people can use their renewed skills” (p. 483).

Whilst isolation and exclusion becomes a factor, to a greater or lesser extent, for many service users and CFMs, using the demographic information gathered for this study in conjunction with the data we are able to suggest that the following can tend to be particularly isolated:

- People with more complex needs, particularly those with psychological needs which include behavioural challenges
- Family members who are taking responsibility for enormous caring roles
- Service users who live on their own (see appendix 16)
- People with cognitive impairments that affect their orientation and memory
- People in care homes that do not have a focus on neuro-rehabilitation

QR7 identifies the importance of appropriate equipment and adaptations to their accommodation support greater independence and choice about where and how people live. It explains how the provision of appropriate equipment enables independence, reduces frustration and is highly cost effective.

This study confirmed that equipment to support people’s mobility (rather than mobility aides) are a key area in people’s lives, but suggests that it is an area that is in particularly need of further development. Those who use adaptations and equipment almost universally found both the acquisition process and the process of ensuring that they were fit for purpose frustrating, complex and ultimately ineffective. The complaint was not about lack of resources, but a failure to use those resources appropriately. This was particularly so in the case of mobility provision whereby wheelchairs designed for one purpose were foisted on people for another purpose.

We were left to conclude that a trawl of people's garages would reveal a decade's worth of unused equipment.

Wheelchair users, and those who used other equipment such as hoists etc., described how these aides were not home friendly. Many were institutionally painted, very large and cumbersome, resulting in them either not being used, or becoming a nuisance for the whole family. Design for home use is different from design for use in large institutional spaces and left people feeling that their lives were governed by institutional rather than home lifestyles.

We are unable to comment on equipment such as environmental controls and communication devices, standing frames and the like as very few of the participants in this study alluded to them.

QR8 requires that "Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home" and that "The availability of a wide range of care and support options allows people with long-term neurological conditions to make choices and select the services that suit them and will meet their changing needs' (p.47). Service users in this study wished to live at home and participate in their local community. The evidence from the study suggests, however, that support for living at home is not always focused on what is needed by service users and their CFMS within that situation. Institutional forms of service delivery are generally inappropriate in the less rigidly organised nature of households. Equipment that functions effectively in the larger spaces afforded by institutional environments is inappropriate for home. As we have noted previously, the design of services and equipment needs to be developed in conjunction with service users and shaped by their contexts for living. It would appear that both hospital-based and community-based services, while appreciated by participants, have been characterised by a lack of real engagement with service users and CFMS in their home context. The work carried out by experienced and expensive professionals therefore has had vastly reduced impact. The reasons service users and CFMS have give for this lack of impact is firstly that they have articulated their perspective, but have not had this valued, and secondly that they value the engagement with professionals so highly

that they do not wish to be seen to criticise the judgment of professionals by articulating that the service is ineffective for them.

Recommendations

- That the notion of a 'communicative space' for co-labouring is embedded in longitudinal service delivery.
- Develop the role of a facilitator as a pre-requisite for on-going engagement with service users. The need for a facilitator, who maintains a communicative space between service users/CFMS and services, was articulated particularly by service users who lived independently and without the support of family members.
- That work to continue raising the profile and importance of service user and CFM held knowledge is central rather than secondary to enabling people with long-term conditions to live as independently as possible and to improving the quality of their lives.
- Design for home use is an important part of being able to be included in your home situation. This aspect of neuro-rehabilitation needs more attention to support independent living.

QUALITY REQUIREMENT 6: VOCATIONAL REHABILITATION

The study did not have a focus on this area. A number of participants discussed this issue, however, and for those for whom the lack of access to employment was a key issue the passion of their feelings of exclusion and the negative impact of this on their lives was very clear.

QUALITY REQUIREMENT 9: PALLIATIVE CARE

This is not something this study is able to comment upon.

QUALITY REQUIREMENT 10: SUPPORTING FAMILY AND CARERS

QR10 states that family members and friends who care for and support people with long-term neurological conditions are often vital to the progress, wellbeing and quality of life of the person. It is important that health and social care services enable them

“to exercise choice, support them effectively and protect their health and independence” and “recognise their needs both in their role as carers and in their own right.” (p. 55)

The difficulties in recruiting CFMs to the study reflects how much harder they are to locate. Whilst for patients there is a register, there is no such equivalent for CFMs. Some CFMs come to group meetings either within hospital provision or those supported by the voluntary sector such as the Huntingdon’s or MS Societies. Those who go to groups are likely to feel less isolated than those who are not linked to others. The groups tend to be disease specific, leaving some people without the option of a support group at all. There are also issues about how voluntary sector groups link into NHS provision. Some would consider themselves embedded, others are entirely on the periphery.

There is a tension between recognising the needs of CFMs and finding the space within consultations designed for services users. Frameworks for monitoring effective service delivery and confidentiality can impede practitioners when they wish to include CFMs as their focus is pushed towards the service user. There is a lack of clarity in relation to whose responsibility it is to support CFMs and how this can be achieved, although this is a clear policy requirement. It would appear from this study that whilst there is a statutory carer’s assessment, recognising the experience of CFMs remains one of isolation.

Recognising that you have become a carer as well as a family member is not clear cut and this may have an impact on whether people feel able to join carers’ groups. Data in this report is therefore likely to be biased towards those who have more

support as they were predominantly recruited through existing groups. What is evident from this study is, however,

1. The continued isolation of carers
2. The difficulties they have in getting their needs met
3. The difficulties they have in communication with professionals
4. The difficulties professionals have in finding a place within the accountability structures under which they work, to have validated time with CFMs
5. Whose responsibility is it to engage with CFMs

CFMs find they take on the role of both carer and advocate for the service user. This puts them in the position of feeling like a 'worky ticket'¹⁷ as CFMs continue to feel that their views are not given sufficient weight. They experience a dominance of professional views in consultations and case reviews, especially if they are articulating observations in relation to the service user's health.

Most CFMs have willingly taken on the role of supporting the service user, but can find their own needs, in their own right, become submerged. CFMs find it hard to articulate their own needs and finding appropriate support remains secondary to supporting their family member.

Recommendations

- Develop the role of a facilitator who maintains a communicative space between service users/CFMs and services.
- Raising the profile and importance knowledge held by CFMs is necessary. This is a training issue.
- Implement the Carers Assessment more actively and within a supported communicative space.
- Incorporate the recognition of, and support for, the needs of CFMs into service monitoring and evaluation.

¹⁷ Worky-ticket: local word for someone who is a trouble maker.

QUALITY REQUIREMENT 11: CARING FOR PEOPLE WITH NEUROLOGICAL CONDITIONS IN HOSPITAL OR OTHER HEALTH AND SOCIAL CARE SETTINGS

Service users who were participants in this study were drawn from the database of Walkergate Park Neuro-rehabilitation and Neuro-Psychiatry Centre but all had experiences of other health care services and facilities. As part of the study they were asked to describe experiences of inclusion beyond Walkergate Park. These could be descriptions of feeling included in the community, at home, at a specific place or in health and social care provision. It has been noted that most people found it more difficult to provide examples of being included than excluded, perhaps because when people are included this does not create the kind of emotional turmoil engendered by exclusion. When people were talking about their experiences outwith specialist neurological services there was evidence that information transfer remains difficult between services. Even where there are planned admissions, service users found themselves at the mercy of the system rather than feeling in control. Data gathered from service users living in community residential settings would suggest that these people, and their CFMs, have intense feelings of exclusion that lead to both frustration and boredom. Being excluded has a significant impact on their health and wellbeing.

CHAPTER 8: THE LEARNING

The people who use and work in specialised services find a great deal of merit in them. Working at their best, specialist neurorehabilitation / neuro psychiatry services have a profound impact on improving the quality of people's lives. Professionals were praised for their high standard of medical knowledge and whilst people could always point to scarce resources this did not dominate discussions.

We learnt however, that service satisfaction should not be confused with efficient and effective services. For a host of reasons, even the most articulate, communicative and confident service users accommodated or endured a range of treatment and treatment process that were incompatible with daily living. For those less able to communicate their needs, due perhaps to communication/cognitive impairments, or because they are isolated for whatever reason, because they are afraid to be seen as a moaner or a 'worky ticket' or because they like and appreciate their therapist too much to want to upset them (see DVD Scene Responsibility) or just because it is not in their nature to speak out, this can have a significant impact on the quality of their lives. This translates into significant costs for the NHS as the impact of engagement with the service is then lost in delivery. When communication is effective, services can be more inclusive, and hence effective.

The term 'delivery' is widely used, but it became evident as the project developed that the term itself was a signifier of an approach that can limit effectiveness. 'Delivery' suggests something going from one person to another, as in the delivery of a letter. This study shows quite clearly that effective communication is more complex than that, and that effective communication is at the heart of inclusion and inclusive practice.

Effective communication allows voices to be heard, perceptions to be explored and honest descriptions of practice to be aired. It necessitates that all voices are valued and, although at times they may have different weight attached to their articulation, the balance of the communication is agreed, not dictated. It involves accommodating the unpredictable nature of emotions, contradictions, changing

thoughts and extreme shifts in perspective that can be part of living with a neurological condition. This is not an easy task. Staff have articulated how tiring it is for them, but they were able to recognise its beneficial impact on service users and CFMs. Some staff questioned whether this type of communication is too complex for service users and CFMs yet the data has demonstrated service users and CFMs are recognising the human behaviours in staff and making accommodation for them. We must ask ourselves how much more tiring it is for people who live their daily lives accommodating for various situations that impede their abilities to realise their life choices.

Without a communicative space for developing inclusive practice it is likely that services will not be effective for the very people they were designed for. Treatments, processes and procedures alien to the lifestyles, preferences, abilities, characters of those that use the services, are likely to perpetuate. The reasons for this will remain hidden.

From this study we have learnt how hard it is to articulate inclusion and inclusive practice, but that the impact of inclusion has a profound effect on the lives of services users and CFMs and the efficacy of NHS services. Inclusion is not a thing, it is a process, a set of attitudes and communications. Just because it is hard to grasp, hard to pin down, impossible to frame, it does not mean that it does not have an impact. It also does not mean that there are not some underlying principles for inclusion that can be articulated to support more effective services. These principles, key characteristics for inclusive practice (see pp 106-7 above), are central to the notion of inclusion, both within the NHS and the wider community. They are demanding of all participants and cannot be imposed. They need to be forged together. Inclusion involves changing culturally accepted norms of place and power in engagements and this cannot be delivered, it has to be part of a shared endeavour: it involves co-labouring and it involves new ways of thinking.

I: 'Is there anything you will do differently regarding staff or student training?

P: It would be good to give the students a camera wouldn't it and just let them take a few images themselves and think about what that [being inclusive] would involve.

I: Why is this important?

P: Just to make you think and to see it from someone else's point of view and to see the practicalities of it so it's not just about the training and having the ethos of it being for everyone but actually working it out in practice and putting in the effort in to make sure that inclusion works.' (S2-F-P)

The research process, by its design, modelled a form of communication that used a facilitated, recursive approach to shape a space for getting beyond delivered accounts that run in parallel. The communicative space offered an arena for articulating personal thoughts and beliefs as well as bringing together different perspectives. It created opportunities that gently prodded people into critiquing both their own articulation and those of others. The key features of a communicative space, valuing individuals, mutual respect, trust and safety, confidence, honest interactions, developmental listening, hearing, responding and agency, connect with the principles for inclusion. Both need time and facilitation.

Time for developing a communicative space with people with long-term conditions is possible, and necessary, as people are likely to be service users over time. This makes a recursive approach applicable in a way that would not be possible in other areas of the health service where engagements might be short-term and time limited. It also makes it more necessary, as long-term exclusion has a major impact on people's lives and long-term delivery of services that are not meeting the needs of service users has a long-term impact on the NHS and associated community services. Practitioners need facilitation in the art of developing a communicative space, and users and CFMs need facilitation to recognise the need for that communicative space.

The need for facilitation was first articulated in the early days of the study by a service user. As the study progressed the need for facilitators became a refrain but they were often assigned different roles. For some service users a facilitator would be a person who had a long-term commitment to their situation, who could navigate them through the maze of service provision and be their trusted link to help them thread their life story through different hoops presented by NHS systems. For others it would be the person that stood up for them in difficult situations. As the study

developed it became clear, however, that there were two distinct roles were called for, that of an advocate who is there for service users (a model for advocates and self-advocates available in learning disability practice) and a facilitator who opens up spaces to support more inclusive conversations across all parties. Professionals have the technical knowledge and service users and CFMs hold the knowledge about their own lives, preferences, skills and abilities in the everyday situation. These need to be brought together to support the translation of knowledge into effective practice. The mixing of these sets of knowledge is vital for effective treatment but hindered by:

- Perceptions of the professional/practitioner as the knower - by both professional/practitioners and service users and their CFMs
- Historical perceptions of 'being grateful' for services
- The difficulties of articulating a position when you are still struggling to come to terms with that position (for example service users coming to terms with their condition, family members recognising themselves as carers)
- Fear that critical discussion will be misconstrued as criticism and
 - that would hinder relationships - service user/CFMS
 - services would be cut rather than improved
- Inflexible bureaucratic systems
- Organisational cultures that prioritise actions above communication

'It seems to be, I suppose, the doctors, really. Who are brilliant and do a fantastic job but I think sometimes they're looking at a bigger picture, aren't they? They're not concentrating on the little things that, perhaps, would have made a difference to us. So it's lack of knowledge, from my point of view.' (C4-F-I)

This study revealed that many practitioners are keen to develop more inclusive ways of working but find themselves restricted by perceptions of their professional role and the reality of organisational accountability structures. Policy and practice in the NHS now forefronts the importance of communication and a more inclusive approach. There remains, however, considerable work to do to develop this in practice. Inclusion cannot be fitted in when other activities allow, it has to be central. As such

it requires an overt space for forging common understandings, a space that is afforded value within organisations as well as with service users and practitioners. We are not unaware of the immense nature of this project but without articulating it the process cannot be started. Our experience as researchers again mirrored difficulties of knocking at a door that is only just beginning to open. Recruiting staff to the project was difficult until local management actively supported engagement. Embedding the learning from the project has been more difficult. Where staff have been involved the communicative space afforded by the project there has been the potential to affect their thinking and hence future actions. Taking the learning beyond this ground level has proved more intransigent, despite the fact that the researchers consider that there are some clear messages about improving the effectiveness of practice through inclusive approaches that are transferrable. This has been a disappointment to us. Service users and CFMs, both researchers and participants, have asked us what impact this report might have “what you’re doing and how you’re doing it, will it have that impact? (SU 32 - I - theme verification). She goes on to suggest that it could be like

‘Dropping your stone in the pool. And just letting the ripples go. And you might not be aware of where the ripples go, but there will be ripples...You know, the likes of me are getting an incredible amount from it. But then what do we do. What is the next ripple? And where do we go with this? ...When you get to the end, you’ll put a full stop. But that’s just the beginning, because what you could do with it is not be content with that full stop and think, “I’ve done this, what is the next step? What is the next ripple? It’s like this light bulb thing going on in people’s lives ... be aware of that spark and to follow it up and to chase it up and to fan it. And just thinking, well, okay, the incredible amount of work that you’re doing on it, but there’s no end to it. When you’ve got to that stage and when you go to the DoH and they see that they’ve got their money’s worth, which they have... where’s their accountability to say, “Right, we’ve paid for this, this is what we’ve produced, it can’t go on a shelf – but what are we going to do about it?” How, then, do we move this forward? Give us the door to go through. How...? And is that, sort of, something that the service users, that we can get involved? That we can say, “Right...[let’s play our part]” (SU 32 - I - theme verification).

This is indeed the challenge. Whilst we have come to the end of the funded part of this study we have to keep pushing the door open a little wider through our joint endeavours. Being part of the Long Term Conditions Policy Research Programme has opened doors for this research and enabled it reach more ears to hear what has been learnt from the research process. We hope that a communicative space might be developed to take this forward because, in searching for the impact of inclusion, this study has highlighted the unacceptable cost of practices that exclude the very people they are there for. Whilst for the NHS the burden of this is financial, service users and CFMs shoulder a shocking cost in relation to their health and life choices. The challenge is therefore to conceptualise services that move from a delivery model to a model with co-creation at its centre.

'I think there's been lots of lessons learned here about making assumptions... sometimes it can be a bit, "Oh well, they used to do this [before their injury] and now, maybe, we can get them to do that." ... So maybe by the end of it we can get them going this way – which isn't right. But I think we are recognising that that attitude has been wrong. And we are trying hard to break down these assumptions, and collect information and let a person be who they were and recognise that, actually, we can't change them. Regardless of that they've had a head injury or come in with an illness, who they were is who they are and we need to try and support that as much as possible'. (S-F-BCD)

One service user called it 'the awareness thing'; the ability to recognise what is not there, but what might be possible if people worked together. If conceptualisations are challenged 'is there's something else...can we [challenge] ...? Dare we? Have we got the audacity to say, "Can we just try for that?" Just to see what else might be possible" (SU32-I-theme verification)

The study has highlighted the impact of inclusion on effective long-term service provision. The cost of not being included is felt socially, emotionally and economically by service users and their carers and family members. This has a

direct impact on neuro-rehabilitation/neuro psychiatry services and there is evidence to suggest it also an impact on other NHS services and community-based services. If what we have found in the North of England has got “sufficiently close to the underlying structure to enable others to see potential similarities with other situations” (Winter, 2000, p. 1) the national cost of not being more inclusive, of not challenging understandings and perspectives, and of not building a shared and more holistic picture for practice, is likely to be considerable.

‘for inclusion to matter, to be of use, you’ve got to have your opinion and you’ve got to take onboard the patient’s opinion for it actually to be worthwhile, otherwise it’s just a word. It hasn’t any meaning.’ (S9-F-FG).

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APPENDICES

Appendix One

Steering Group Membership

Eunice Bell (Carer/ family member and lay researcher), Eileen Birks (Northumbria University Researcher), Mick Bond (MS Society and lay researcher), Elizabeth Davis (Consultant Rehabilitation Medicine), Alison Faulkner (Independent Survivor Consultant), Laura Graham (Consultant Rehabilitation Medicine), Christine Hutchinson (Parkinsons Disease Society and lay researcher) Glenys Marriott (Chair North East Neurosciences Network), Paul Mitchell (Service User and lay researcher), Phil Moore (Service User and lay researcher), Margaret Piggott (DenDRoN), Stephen Ransom (Carer/ Family member), Sandra Stark (Consultant Therapist Neuro-rehabilitation), John Swain (Professor of Disability Studies Northumbria University), Richard Tomlin (Independent Researcher and Carer/ family member), Karen Urwin (Service Manager, Walkergate Park), Alistair White (Regional Coordinator Headway North East) and Barbara Wilson (DenDRoN).

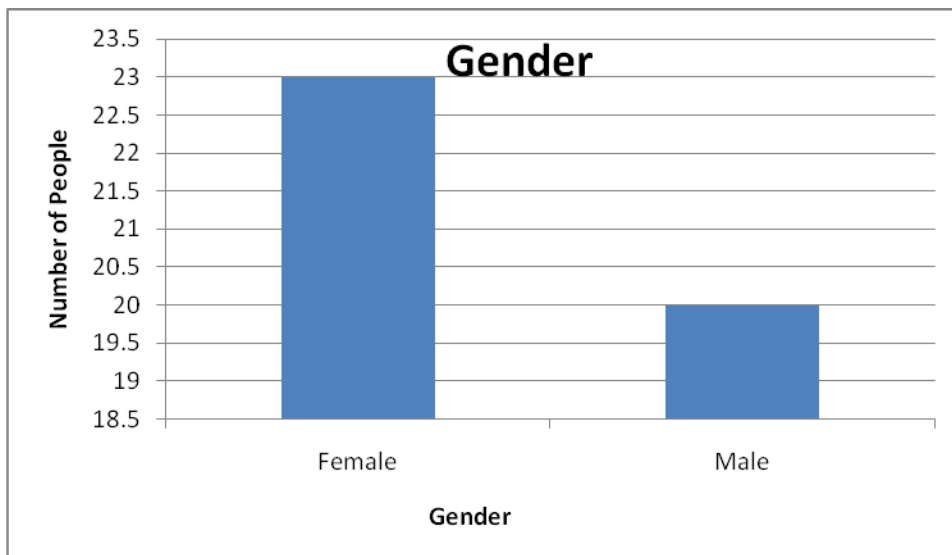
Appendix Two

Demographics

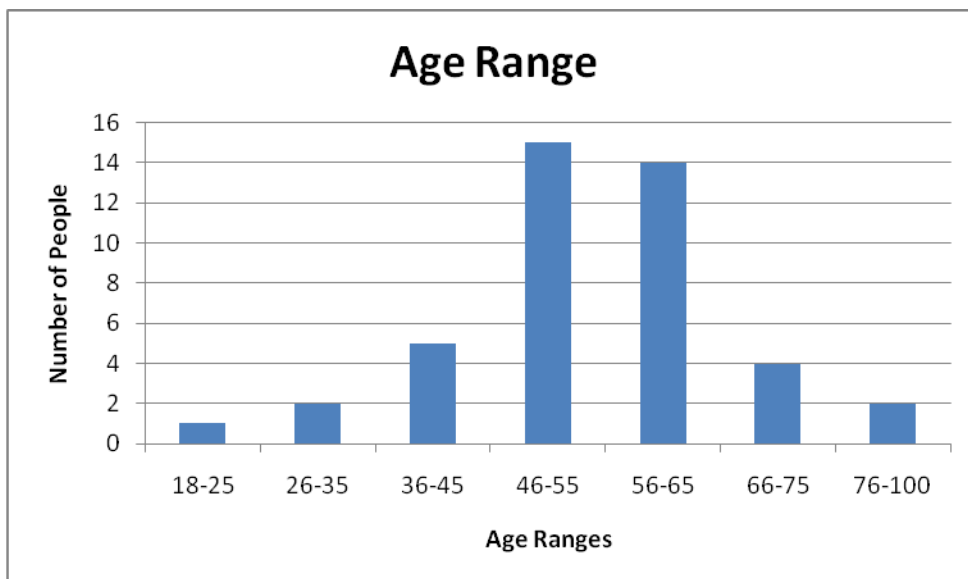
43 service users consented, provided their demographic information and took part in the study.

6 service users gave their consent and subsequently did not take part in the study. 2 people died, 1 person withdrew and we were unable to make further contact with 3 people.

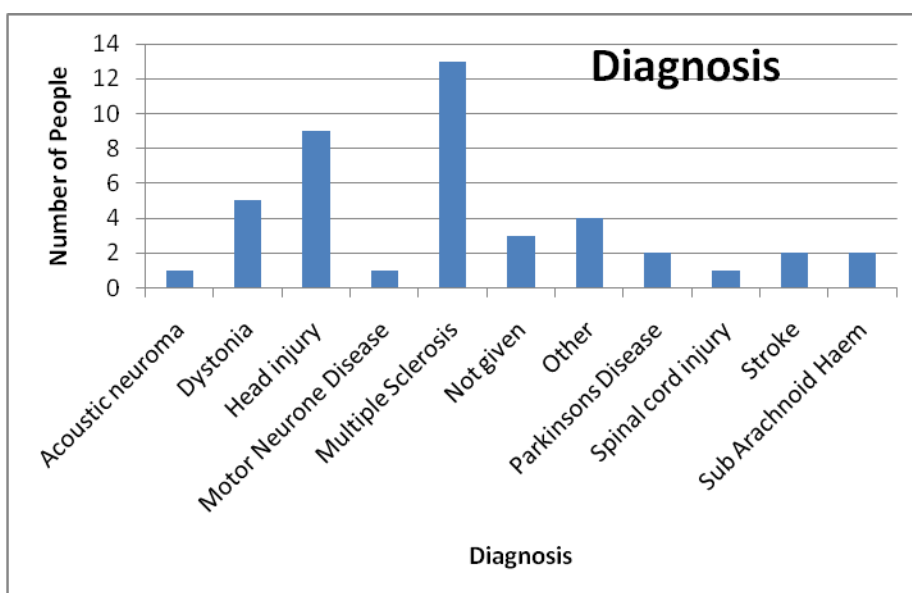
The demographic data was collected through a questionnaire that was completed by the participants themselves or someone they nominated to complete the form for them. It was a personal choice whether they provided us with this information.



Gender: Marginally more women (23) than men (20) that took part in the study.



Age Range: The majority of people were in the 46-65 age groups

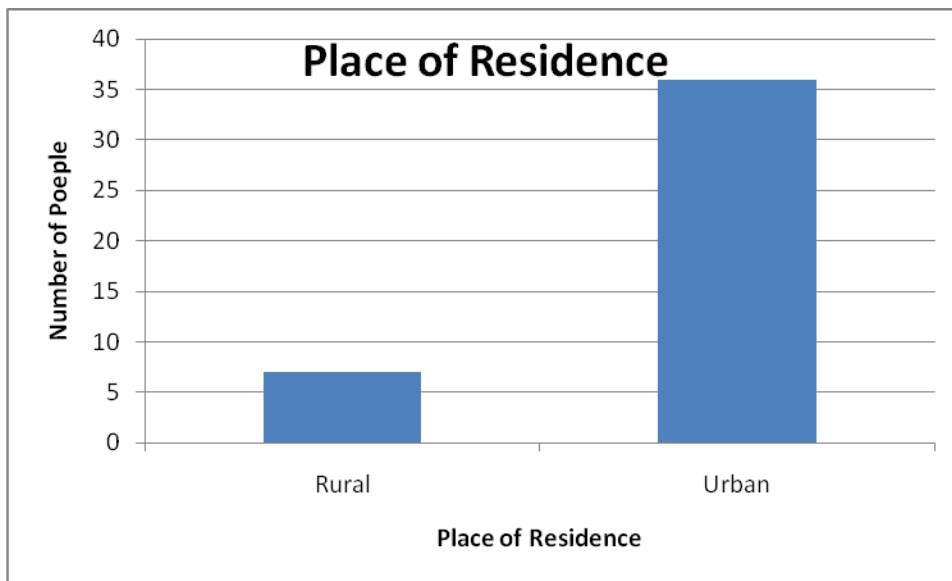


Diagnosis: The participants taking part in the study lived with a wide range of neurological conditions. However the stories and experiences of people living with Multiple Sclerosis were the most strongly represented. People with acquired head injury also had a strong voice within the study.

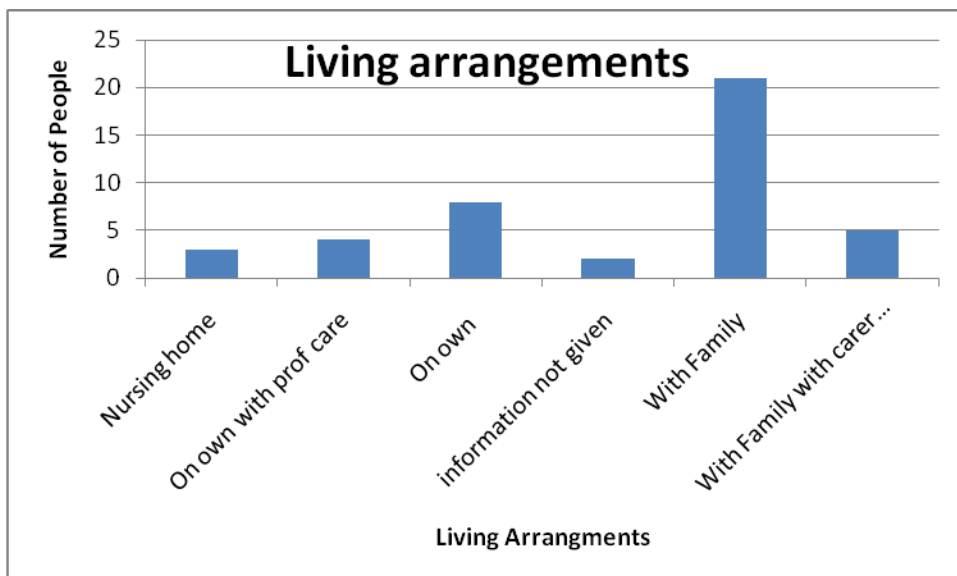
The Neurological Rehabilitation Centre involved in this research does not provide a specialist service to people living with Motor Neurone Disease (MND) and Parkinson's Disease (PD), therefore the numbers of people using the Centre will be considerably less than for those people living with Multiple Sclerosis or an acquired brain injury. Participants in the study with MND and PD will have been recruited through North East Drive Mobility and/ or the Communication and Environmental Control Services.

There is an active out patient service where people with dystonia have access to spasticity management services, particularly the provision of Botulinum Toxin. This accounts for the relatively high number of people taking part in the study who have a diagnosis of dystonia.

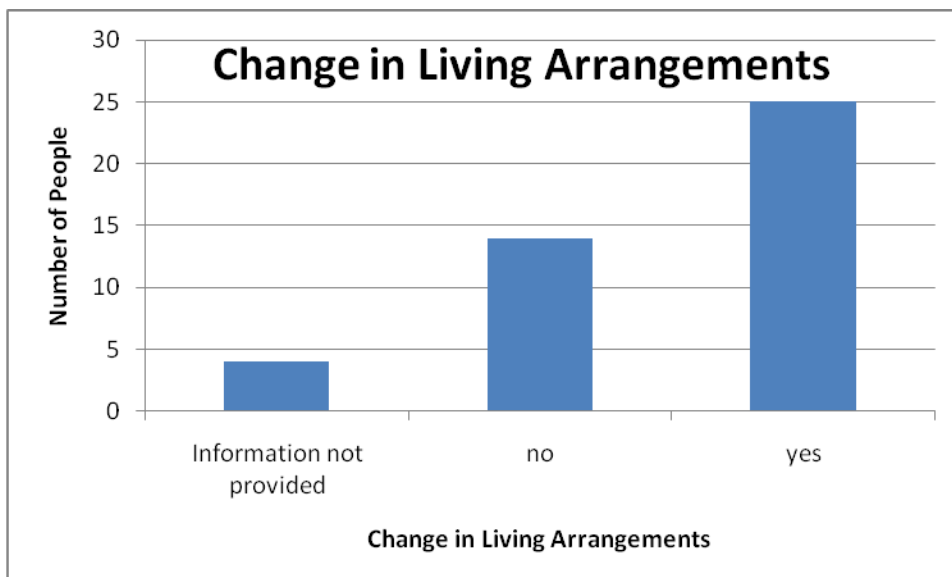
It is notable that there are no participants with Huntingdon's Disease (although CFMs are well represented).



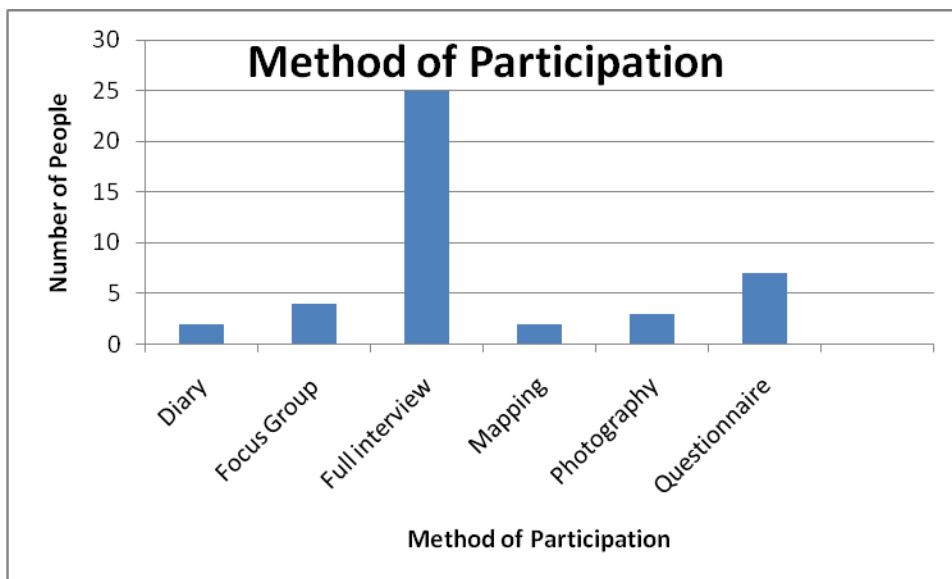
Place of Residence: The catchment area for the case study Centre was the North East of England. The majority of people taking part in the study lived in a town or city. This is surprising given the rural nature of Northumberland and County Durham.



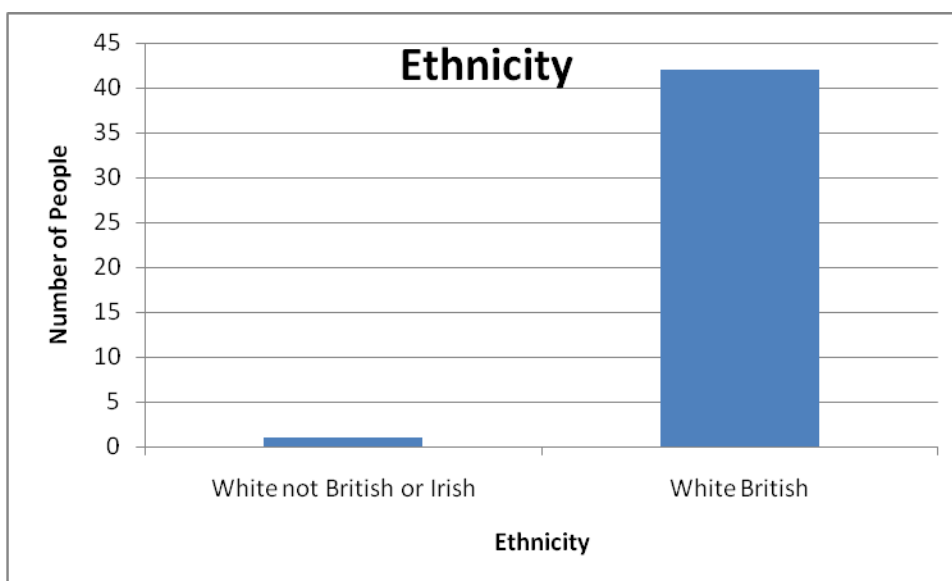
Living Arrangements: The majority of people taking part lived with their family. 9 people require some support to enable them to live either on their own or with their family. 2 people were living in a nursing home at the time of the study. Both had previously been inpatients and had been discharged to a nursing home.



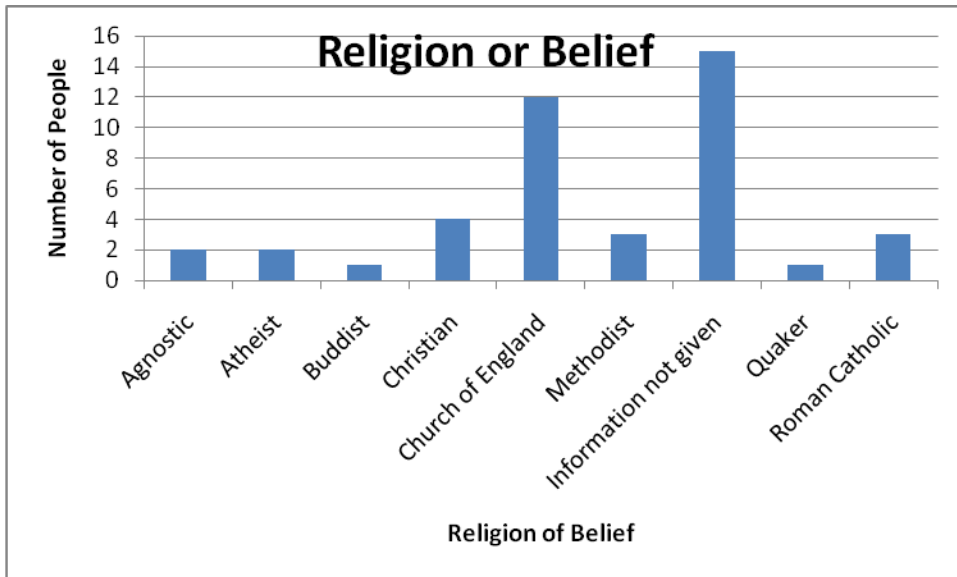
Change in Living Arrangements: Over half of the participants informed us that they had experienced a change in their living arrangements since the onset of their neurological long term condition.



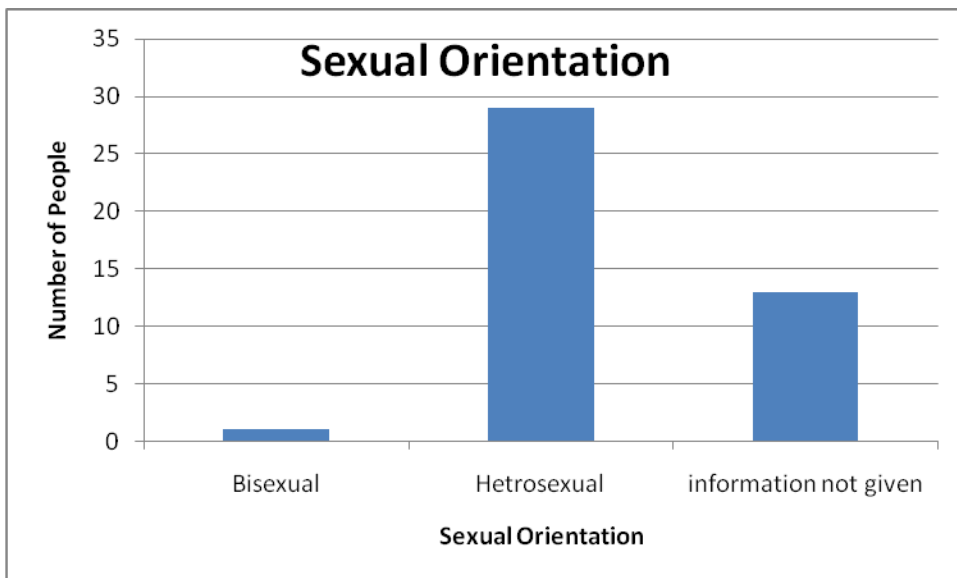
Method of Participation: The majority of people who took part chose to talk to a researcher face to face during the first stage of the project. Reasons for this choice were not explored with participants. Some of these people also went on to engage in focus groups and the Big Conversation Day.



Ethnicity: Only one person who took part was not white British. The demographics available to us from Walkergate Park Services indicated that the number of non white British using the facilities was low.



Religion of Belief: A large number of people chose not to comment on their religion or belief. The information provided indicates that the majority of people linked themselves with a Christian belief or faith.



Sexual Orientation: The majority of participants indicated that they were heterosexual.

Appendix 3

Recruitment Posters

Northumberland, Tyne and Wear 
NHS Trust

Towards Inclusive Living Research for Everyone

Inclusion?

What is inclusion? Where do you see inclusion happening in the NHS and in the community? What does it feel like to be included or excluded?

Are you a service user, carer, voluntary sector partner or member of staff involved with Walkergate Park Services?

We need you to tell us about your experiences.

Come and be a part of a research project at Walkergate Park to inform the Department of Health about the impact of inclusive practice

**Want to know more?
Contact Helen Atkin or Eileen Birks on:**

 **0191 215 6202**
 **0191 215 6083**
 helen.atkin@northumbria.ac.uk or
 e.birks@northumbria.ac.uk

**Towards Inclusive Living
Research for Everyone**

**Are you a
Carer or Family Member
who supports a person who uses
Walkergate Park Services?
Are you over 18?**


**Come and be a part of a research project at
Walkergate Park to inform the Department of Health
about the impact of inclusive practice**


Inclusion?

We need you to tell us about your experiences.

**What is inclusion? Where do you see inclusion
happening in the NHS and in the community? What
does it feel like to be included or excluded?**


Want to know more? Ask Helen on:

 **0191 215 6202**

 **0191 215 6083**

 helen.atkin@northumbria.ac.uk

Or Eileen on

 **0191 215 6202**

 e.birks@northumbria.ac.uk

Appendix 4

Recruitment Documents and Methods¹⁸

Appendix 4.1 Invitation letters

Trust headed paper

Trust logo

Date

Invitation Letter: Service users

Towards Inclusive Living

[A research study]

Dear Service User

You are invited to take part in this research study.

We are doing some research on Inclusive Living. It is a major research study funded by the Department of Health

What will this study do?

It will look at how adults with an acquired neurological impairment feel included in their experiences of Walkergate Park Services. The aim of this study is to inform and improve practice, both locally and nationally.

How did we get your name?

The Trust has sent you this letter. The researchers do not know who you are.

How could you take part?

If you are interested in taking part we will ask for your ideas about what makes you feel included or excluded and whether this affects your daily life.

There are lots of different ways in which you can take part such as:

- taking photographs of where you feel included
- talking with people (interviews and focus groups)
- writing a diary.

If you need some support to join in you can choose to bring someone with you, or if you prefer, we can provide someone for you.

Please turn over the page

¹⁸ All documents were sent out in Ariel 14 font

Who are the researchers?

They cover a wide range: some are experienced researchers; some have a neurological impairment and some care for people who have a neurological impairment.

INSERT PICTURES OF RESEARCHERS HERE


What to do if you are interested in taking part and want more information?

We have more information we can send you or we can come out and talk to you with that information.

We would also like relatives or unpaid carers to be involved in this study. If your relative/carer would like to be involved, she/he should also contact us.

If you are interested please reply by *(2 weeks from date of posting)*:

 Send your name and address to Helen Atkin by filling in the form below and putting it in the envelope provided or:

 Telephone 0191 215 6271 or


 email helen.atkin@northumbria.ac.uk

✂

Your Name:

Your Address:

 Your Telephone

 Your email

I would like an information pack Please send it out to my address

I would like you to ring me so that I can ask you some questions

Trust headed paper

Trust logo

Date

Invitation Letter: Staff

Towards Inclusive Living

[A research study]

Dear Member of Staff at Walkergate Park

You are invited to take part in this research study.

We are doing some research on Inclusive Living. It is a major research study funded by the Department of Health

What will this study do?

It will look at how adults with an acquired neurological impairment feel included in their experiences of Walkergate Park Services. The aim of this study is to inform and improve practice, both locally and nationally

How did we get your name?

The Trust has sent out this letter from its database. The researchers do not know who you are.

How could you take part?

If you are interested in taking part we will ask for your ideas about what you feel makes service users, their relatives and carers feel included or excluded and whether this affects their daily life.

There are lots of different ways in which you can take part such as being interviewed by a researcher, talking in a group, taking photographs of where you feel people are included, or writing a diary or blog. We think it will be an interesting experience for those who choose to take part.

Please turn over

What about my time?

Walkergate Park management have agreed that if you would like to take part in this study, you can do this within your working hours and there are a variety of ways in which you can engage in this project.

Who are the researchers?


They cover a wide range: some are experienced researchers; some have a neurological impairment, some care for people who have a neurological impairment and others work with the voluntary sector.

What to do if you are interested in taking part and want more information?

If you are interested please reply by *(2 weeks from date of posting)* and we will send you an information pack.

 Send your name and address to Helen Atkin by filling in the form below and putting it in the envelope provided

or:

 Telephone 0191 215 6271

or

 email helen.atkin@northumbria.ac.uk

✂

Your Name:

Your Address:

 Your Telephone

 Your email

Trust headed paper

Trust logo

Date

Invitation Letter: Voluntary Sector Partners

Towards Inclusive Living

[A research study]

Dear Walkergate Park Voluntary Sector Partner

You are invited to take part in this research study.

We are doing some research on Inclusive Living. It is a major research study funded by the Department of Health

What will this study do?

It will look at how adults with an acquired neurological impairment feel included in their experiences of Walkergate Park Services. The aim of this study is to inform and improve practice, both locally and nationally.

How did we get your name?

The North East Neurological Alliance has sent these letters out from their database. The researchers do not know your name.

How could you take part?

If you are interested in taking part we will ask for your ideas about what you feel makes service users, their relatives and carers feel included or excluded and whether this affects their daily life.

There are lots of different ways that you can take part such as being interviewed by a researcher, talking in a group, taking photographs of where you feel people are included, or writing a diary or blog. We think it will be an interesting experience for those who choose to take part.

Please turn over


Who are the researchers?

They cover a wide range: some are experienced researchers; some have a neurological impairment, some care for people who have a neurological impairment and others work with the voluntary sector.


What to do if you are interested in taking part and want more information?

If you are interested please reply by *(2 weeks from date of posting)* and we will send you an information pack.

 Send your name and address to Helen Atkin by filling in the form below and putting it in the envelope provided or:

 Telephone 0191 215 6271

or

 email helen.atkin@northumbria.ac.uk

✂

Your Name:

Your Address:

 Your Telephone

 Your email

Appendix 4.2 Information Sheets

University headed paper

Trust logo

Date

Information Sheet: Service User and Carer

Towards Inclusive Living

A research study funded by the Department of Health

Part 1

We would like to invite you to join in this research project. Before you agree to join in, you need to understand why we are doing this research and what we will be asking you to do.

Please read this information or watch it on the enclosed DVD. If you have any difficulties with this please let us know.

Do talk to other people about the project if you want to. If you need any other help to understand the information please contact us or ask at the main reception at Walkergate Park – they will contact us for you.

What is the project about?

Some service users, relatives and carers from Walkergate Park have told us that they think there might be link between the way people are included and involved in their treatment and the way they use knowledge about their treatment to develop their skills and independence in the community.

We want to find out from patients and their carers:

- How included and involved you, or your carer, feel in your treatment?
- When does this work well and what stops it from working well.
- How does this affect the way you use NHS services in you daily life.

Please turn over

Why have I been chosen?

We have invited adults with an acquired neurological impairment who have used Walkergate Park Services in the last 6 months, so your experiences are really important to this research

Do I have to take part?

Taking part in this research is entirely voluntary and it is up to you to decide. The purpose of this information sheet is to help you make that decision. If you need to talk about it further with a member of the research team before you make your decision that is fine.

The contact details for the researchers can be found at the end of this information sheet.

If you decide to take part and then change your mind, that is also fine, and you can change your mind at any time during the process of your involvement without having to say why you wish to withdraw.

If you decide not to take part, this will not affect your treatment at all.

What will happen if I agree to take part in the project?

There are lots of different ways in which you take part, for example: questionnaire, diaries, blogs, focus groups, interviews, photography and mapping. There is more information about these in this information pack and on the DVD. You can use this like a menu to decide what you would like to do.

The mix of methods means that you can choose the approach that best fits your needs in terms of personal preference and time.

If we have lots of people asking to take part, you might not get your first choice of activity. If we have too many people wanting to take part in the activity you have chosen we will let you know and discuss with you the other ways that you can be involved.

You will also be asked to fill in an information sheet which will tell us a bit about you such as your age, how long you have been service users and the type of accommodation you live in. This is to help us get a good balance in the groups and to find out if some groups of people feel more excluded than others. The information will not be linked back to you as an individual but you don't have to do it if you don't want to.

The project will end with a conference where everyone will talk about what they have found so far. We will discuss the different ideas that have been brought up during the research and how we can all work together to change practice.

If you are interested in taking part the details of how to do this are at the bottom of this sheet

Support to take part:

If you need any help to take part in the study, for example an interpreter or personal assistant to help you take part in the study, please let us know.

Travel:

We will provide you with travel expenses and work with you to help organise your transport.

How might taking part affect me?

This study will not involve any physical risks but talking about your experiences of might be upsetting or tiring. You can stop an interview or leave a group at any time and there will be someone to help you. You will not be left alone until you tell us that you are feeling better.

If you get tired easily and need regular rests please let us know.

Will taking part in the project be confidential and private?

We will follow ethical and legal practice. What you tell us will be given a number so that no one will know who was speaking. When you speak to someone on your own or in a group, it will be recorded.

Some of the information you give us will be used for educational projects as two people who are researchers on the project are doing a masters degree and one a PhD. This will also be treated confidentially.

All written information and recordings will be destroyed three years after the project has finished.

Breaking confidentiality

If you tell us something during the study that suggests that you, or someone else, are at serious risk, we would then have to break confidentiality. We would tell you that we were going to do this and we would then report it to someone who could help.

Part 2

What will happen if I don't want to carry on with the research?

You can stop being involved in the research at any time and do not have to give a reason why. This will not affect the treatment you receive.

The data you have already provided will be used in the research.

What if there is a problem?

If you are unhappy with the research, ask to speak to the researchers and we will do our best to answer your questions. If you are still unhappy, and wish to complain formally, you can do this through the NHS complaints procedure. You will need to contact:

[Karen Urwin the manager of Walkergate Park](#)

karen.urwin@ntw.nhs.uk

0191 287 5000

or

[Ali Zataar the Research & Development Manager for Northumberland Tyne & Wear NHS Trust](#)

ali.zataar@ntw.nhs.uk

0191 223 2336

What happens now?

Thank you for reading this information sheet. If you would like to take part please complete the 2 attached forms:

1. **Choice of research activity**
2. **Consent Form**

If you need some help to fill in the forms please contact us.

Once they are completed please send them back to us in the enclosed addressed envelope.

If you would like to read more about the project, see the original bid and the lay persons summary please contact Helen Atkin at helen.atkin@northumbria.ac.uk or telephone 0191 215 6271


If you would like to talk to someone other than the researchers about participating then Catherine Graham, Knowledge Centre Manager, Northumberland Tyne and Wear NHS Trust would be able to either help you or direct you appropriately. E mail catherine.graham@ntw.nhs.uk

Form 1

Towards Inclusive Living
Your choice of research activity

Your Name: _____

Your Address: _____

 Your telephone: _____

 Your email: _____

Please tell us your choice of research activity by ticking **one** box:

Talking with a researcher (interview)

Taking in a group (focus group)

Diary

Blog

Photography

Mapping

University headed paper

Trust logo

Date

Information Sheet: Walkergate Park Staff

Towards Inclusive Living

A major research study funded by the Department of Health

Part 1

We would like to invite you to join in this research project. You may well have already heard about this research, but before you agree to join in, you need to understand why we are doing the research and what we would be asking you to do.

Please read this information. Talk to other people about the project if you want to.

What is the project about?

Some service users, relatives and carers from Walkergate Park have told us that they think there might be a link between the way people are included and involved in their treatment and the way they use knowledge about their treatment to develop their skills and independence in the community.

We are asking staff, service users and carers (unpaid) who use Walkergate Park Regional Neuro Rehabilitation & Neuro Psychiatry services and voluntary sector partners about their understandings of the term 'inclusion', where it can be found, both at Walkergate Park and the general community, what enables it to happen and what might stop it from occurring. We are particularly interested in finding out how feelings of inclusion might affect the way people use NHS services in their daily lives.

If you would like to read more about the project, see the original bid and the lay person's summary please contact Helen Atkin at helen.atkin@northumbria.ac.uk or telephone 0191 215 6271

If you would rather talk to someone other than the researchers about this then Catherine Graham, Knowledge Centre Manager, Northumberland Tyne and Wear NHS Trust, would be able to either help you or direct you appropriately.

E mail catherine.graham@ntw.nhs.uk

Please turn over

Why have I been chosen?

We have invited everyone who is currently a member of staff at Walkergate Park, service users who have used Walkergate Park services in the last six months, their relatives/ carers (unpaid) and people from voluntary sector organisations who support services at Walkergate Park.

Approximately 80 -150 people will be included in the study.

Do I have to take part?

Taking part in this research is entirely voluntary and it is up to you to decide. The purpose of this information sheet is to help you make that decision. If you need to talk about it further with a member of the research team before you make your decision that is fine and contact details for the researchers can be found at the end of this document.

Whilst we would obviously like you to take part in the study not taking part in the study is absolutely your choice and there will be no repercussions in relation to your decision.

If you decide to take part and then change your mind, that is also fine, and you can change your mind at any time during the process of your involvement without having to say why you wish to withdraw.

What will happen if I agree to take part in the project?

There are lots of different ways you can take part, for example: questionnaire, diaries, blogs, focus groups, interviews, photography and mapping. There is more information about these in the information pack. The mix of methods means that you can choose the approach that best fits your needs in terms of personal preference and time. You can use the information pack like a menu to decide which way would suit you.

If we have lots of people asking to take part, you might not get your first choice of activity. If we have too many people wanting to take part in the activity you have chosen we will let you know and discuss with you the other ways that you can be involved.

The project will end with a conference where the researchers will talk about what they have found so far, and we will discuss the different ideas that have been brought up through the research and how we can all work together to change practice.

If you are interested in taking part the details of how to do this are at the bottom of this sheet

Travel:

If necessary we will provide you with travel expenses.

Support to take part:

If you need any help to take part in the study for example an interpreter or personal assistant, please let us know.

Please turn over

How might taking part affect me?

This study will not involve any physical risks but thinking about the impact of inclusion and exclusion on people's lives might be upsetting. You can stop an interview or leave a group at any time and there will be someone to talk to about your feelings if you so wish.

Will taking part in the project be confidential and private?

We will follow ethical and legal practice. When you speak to someone on your own or in a group, it will be recorded. What you tell us will be given a number so that no one will know who was speaking.

Some of the information you give us will be used for educational projects as two people who are researchers on the project are doing a masters degree and one a PhD. This will also be treated confidentially.

All written information and recordings will be destroyed three years after the project has finished.

Breaking confidentiality

If you tell us something during the study that suggests that you or someone else is at serious risk, we would then have to break confidentiality. We would tell you that we were going to do this and we would then report it to the Trust management.

Part 2

What will happen if I don't want to carry on with the research?

You can stop being involved in the research at any time and do not have to give a reason why and there will be no repercussions in relation to your decision

We will continue to use the data you have given us in the project.

What if there is a problem?

If you are unhappy with the research, ask to speak to the researchers and we will do our best to answer your questions. If you are still unhappy, and wish to complain formally, you can do this through the NHS complaints procedure. You would need to contact:

[Karen Urwin the manager of Walkergate Park](#)

Karen.urwin@ntw.nhs.uk

0191 287 5000

Or

[Dr Ali Zataar the Research & Development Manager for Northumberland Tyne & Wear NHS Trust](#)

ali.zataar@ntw.nhs.uk

0191 223 2336

What happens now?

Thank you for reading this information sheet. If you would like to take part please complete the 2 attached forms:

1. **Choice of research activity**
2. **Consent Form**
- 3.

If you need some help to fill in the forms please contact us.

Once they are completed please send them back to us in the enclosed addressed envelope.

Form 1

Towards Inclusive Living
Your choice of research activity

Your name: _____

Your work address: _____

 Your telephone: _____

 Your email: _____

Please tell us your choice of research activity by ticking **one** box:

- Talking with a researcher (interview)
- Taking in a group (focus group)
- Diary
- Blog
- Photography
- Mapping

University headed paper

Trust logo

Date

Information sheet: Walkergate Park Voluntary Sector Partners

Towards Inclusive Living

A major research study funded by the Department of Health

We would like invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it would involve if you were to choose to be a participant. To help you make your decision about participating we have set out

- i) some information about the research project and why we are doing it
- ii) the ways in which you might participate.

This research project has a number of ways that you might participate. These are described in detail after the general information. You can choose the best way for you. This information is also on DVD which is available for your use.

The purpose of the study

This research seeks to find out whether there is a link between the way people with neurological impairments are included in the NHS community and the way they use knowledge from treatment to develop their skills and independence.

Why it is being done?

Some service users and carers from Walkergate Park told us that they think there might be link between the way people are included and involved in their treatment and the way they use knowledge about their treatment to develop their skills and independence in the community.

We are asking staff, service users and carers (unpaid) who use Walkergate Park Regional Neuro Rehabilitation & Neuro Psychiatry services and voluntary sector partners about their understandings of the term 'inclusion', where it can be found, both at Walkergate Park and the general community, what enables it to happen and what might stop it from occurring and how feelings of inclusion might affect the way people use the services at Walkergate Park in their daily lives.

If you would like to read more about the project, see the original bid and the lay persons summary please contact Helen Atkin at helen.atkin@northumbria.ac.uk or telephone 0191 215 6271

If you would rather talk to someone other than the researchers then Catherine Graham, Knowledge Centre Manager,

Northumberland Tyne and Wear NHS Trust, would be able to either help you or direct you appropriately. Catherine's e mail is catherine.graham@ntw.nhs.uk

Why have I been invited to participate?

We have invited everyone who is currently a member of staff at Walkergate Park, service users who have used Walkergate Park services in the past year, their relatives/ carers (unpaid) and people from voluntary sector organisations who support services at Walkergate Park. Approximately 80 -150 people will be included in the study.

Do I have to take part?

Taking part in this research is entirely voluntary and it is up to you to decide. The purpose of this information sheet is to help you make that decision. If you need to talk about it further with a member of the research team before you make your decision that is fine and contact details for the researchers can be found at the end of this document.

Whilst we would obviously like you to take part in the study not taking part in the study is absolutely your choice and there will be no repercussions in relation to your decision.

If you decide to take part and then change your mind, that is also fine, and you can change your mind at any time during the process of your involvement without having to say why you wish to withdraw.

What will happen if I agree to take part in the project?

There are lots of different ways you can take part: eg by being interviewed, keeping a diary, participating in blogs, focus groups, taking photographs or participating in a mapping session.

Information about all these different ways of participating is attached. You can use it like a menu to decide which way would suit you. The mix of methods means that you can choose the approach that best fits your needs in terms of personal preference and time.

If we have lots of people asking to take part, you might not get your first choice of activity. If we have too many people wanting to take part in the activity you have chosen we will let you know and discuss with you the other ways that you can be involved

What if I have to travel somewhere?

You will get travel expenses, either your car mileage or public transport costs.

What if I need help to take part in the study?

If you need any help to take part in the study e.g. interpreter you would let us know and we would try to arrange something suitable in consultation with you.

How might taking part affect me?

This study will not involve and physical risks however, talking about issues and experiences can sometimes raise questions for you, leave you confused or even upset at times. Whilst the subject matter of this research study is not of a particularly intrusive nature, this can still happen unexpectedly. If you find you are troubled by your participation in any way you can stop an interview or leave a group at any time. If you are involved in an interview the interviewer will provide immediate support and arrange for further support based on a conversation with you about what would be most appropriate. You would not be left until both parties were sure that either the issue had been addressed or there was an agreed future arrangement for addressing it.

Will taking part in the project be confidential and private?

We will follow ethical and legal practice. What you tell us will be given a number so that no one will know who was speaking. When you speak to someone on your own or in a group, it will put it on tape recorder. All written information and tapes will be destroyed three years after the project has finished.

Some of the information you give us will be used for educational projects as two people who are researchers on the project are doing a masters degree and one a PhD. This will also be treated confidentially.

All written information and recordings will be destroyed three years after the project has finished.

Breaking confidentiality

If you tell us something during the study that suggests that you, or someone else, is at serious risk, we would then have to break confidentiality. We would tell you that we are going to do this and we would then report it to someone who could help.

What will happen if I don't want to carry on?

You can stop being involved in the research at any time. We will continue to use the data you have given us in the project.

What if there is a problem?

If you are unhappy with the research, ask to speak to the researchers and we will do their best to answer your questions. If you are still unhappy, and wish to complain formally, you can do this through the NHS complaints procedure. You will need to contact:

[Karen Urwin the manager of Walkergate Park](#)

Karen.urwin@ntw.nhs.uk

0191 287 5000

Or

[Dr Ali Zataar the Research & Development Manager for Northumberland Tyne & Wear NHS Trust](#)

ali.zataar@ntw.nhs.uk

0191 223 2336

What happens now?

Thank you for reading this information sheet. If you would like to take part please complete the 2 attached forms:

1. **Choice of research activity**
2. **Consent Form**

If you need some help to fill in the forms please contact us.

Once they are completed please send them back to us in the enclosed addressed envelope.

Form 1

Towards Inclusive Living
Your choice of research activity

Your name: _____

Your work address: _____

 Your telephone: _____

 Your email: _____

Please tell us your choice of research activity by ticking **one** box:

Talking with a researcher (interview)

Taking in a group (focus group)

Diary

Blog

Photography

Mapping

Appendix 4.3 Consent Forms

University headed paper

Trust logo

Date

Consent form: Service Users:

Consent Form

Towards Inclusive Living

A Research Study

Please sign your name or make a mark in the box if you agree with the statements below.

I have read and understood the information sheet about this research and have asked questions that have helped me to understand the research.

Your signature

Witness signature

Why is the study being done?

I understand that the research is being done to look at my experiences of being included in the decisions made about my treatment at Walkergate Park and how this helps me in my daily life.

Your signature

Witness signature

What will happen when I take part?

I understand that if I agree to take part, I can choose which parts of the research I want to be involved in. I have seen the list of things that I might do. If I don't get my first choice then I will be offered something else.

Your signature

Witness signature

I understand that these research activities will be recorded and then they will be typed out.

Your signature

Witness signature

Confidentiality

I understand that my name will not be used in any information that I give. The information I give will be kept in a locked place and will be destroyed in 3 years after the research is finished.

Your signature

Witness signature

Breaking confidentiality

I understand that if I tell you something during the study that suggests that I, or someone else, is at serious risk, you would then have to break confidentiality. I understand that you would tell me if you were going to do this and you would then report it to someone who could help.

Your signature

Witness signature

What happens if I don't want to carry on?

I understand that if I take part in this research, that I can stop at any time and do not have to give a reason why.

Your signature

Witness signature

I understand that this will not affect the treatment I receive at Walkergate Park

Your signature

Witness signature

I understand that the data I have already provided will still be used in the research.

Your signature

Witness signature

I _____ (your name)

understand the information that the researcher has given me. I agree to take part in this research.

Signature _____ (your signature)

Date _____

Witness signature _____

Date _____

Signature _____ (researcher's signature)

Date _____

University headed paper

Trust logo

Date

Consent Form: Carers,

Consent Form

Towards Inclusive Living

A Research Study

Please sign your name or make a mark in the box if you agree with the statements below.

I have read and understood the information sheet about this research and have asked questions that have helped me to understand the research.

Why is the study being done?

I understand that the research is being done to look at my experiences of being included in the decisions made about the treatment at Walkergate Park for the person I care for and how this helps me in supporting him/her in daily life.

What will happen when I take part?

I understand that if I agree to take part, I can choose which parts of the research I want to be involved in. I have seen the list of things that I might do. If I don't get my first choice then I will be offered something else.

I understand that these research activities will be recorded and then that recording will be typed up.

Confidentiality

I understand that my name will not be used in any information that I give. The information I give will be kept in a locked place and will be destroyed in 3 years after the research is finished.

Breaking confidentiality

I understand that if I tell you something during the study that suggests that I, or someone else, is at serious risk, you would then have to break confidentiality. I understand that you would tell me that you are going to do this and you would then report it to someone who could help.

What happens if I don't want to carry on?

I understand that if I take part in this research, that I can stop at any time and do not have to give a reason why.

I understand that this will have no repercussions for me.

I understand that the data I have already provided will still be used in the research.

I _____ (your name)

Understand the information that the researcher has given me. I agree to take part in this research.

Signature_____ (your signature)

Date_____

Signature_____ (researchers signature)

Date_____

University headed paper

Trust logo

Date

Consent Form: Walkergate Park Staff and Representatives from the Voluntary Sector:

Consent Form

Towards Inclusive Living

A Research Study

Please sign your name or make a mark in the box if you agree with the statements below.

I have read and understood the information sheet about this research and have asked questions that have helped me to understand the research.

Why is the study being done?

I understand that the research is being done to look at my understandings of inclusion, where it can be found at Walkergate Park and in the general community, what enables it to happen, what might stop it from occurring and how people's feelings of inclusion might affect the way people use the services at Walkergate Park.

What will happen when I take part?

I understand that if I agree to take part, I can choose which parts of the research I want to be involved in. I have seen the list of things that I might do. If I don't get my first choice then I will be offered something else.

I understand that these research activities will be recorded and then they will be typed out.

Confidentiality

I understand that my name will not be used in any information that I give. The information I give will be kept in a locked place and will be destroyed in 3 years after the research is finished.

Breaking confidentiality

I understand that if I tell you something during the study that suggests unprofessional practice, then you would have to break confidentiality. You would tell me if you were going to do this and you would then report it to Trust management.

What happens if I don't want to carry on?

I understand that if I take part in this research, that I can stop at any time and do not have to give a reason why.

I understand that this would have no repercussions for me.

I understand that the data I have already provided would still be used in the research.

I _____ (your name)

understand the information that the researcher has given me. I agree to take part in this research.

Signature _____ (your signature)

Date _____

Signature _____ (researcher's signature)

Date _____

Appendix x 4.4: Information about Research Methods for Service Users and Carers/Family Members

University headed paper

Trust logo

Date

Information about methods for Service Users and Carers: interviews

Interviews

What is an interview?

An interview is a conversation between you and the researcher on the research topic.

What would happen if you choose interviews?

You would meet with a researcher who will ask you some questions about what you personally understand by the word inclusion and about your experiences of feeling included and excluded. These can be experiences that you have had whilst using Walkergate Park Services or experiences in the community.

If you are a service user, the researcher will be a service user or someone from the University.

If you are a carer or relative, the researcher will be a carer or relative or someone from the University.

Recording what you have said

The interview will be recorded so that researchers will have an accurate record of what you said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use a Litewriter or other equipment to communicate one of the researchers will read out what you have written or pointed to so that it will be recorded for the research.

If, though, you don't want to be recorded the interviewer can take notes instead. In this case the interviewer will check with you, at the end of the interview, that what she/he has written down reflects what you have said.

How long would it last?

The interview will last about 30 - 40 minutes.

You can stop the interview at any time for any reason.

If you think 30 - 40 minutes might be too long for you we can break it down into two parts and come and see you twice.

Privacy and confidentiality

As soon as we have finished the interview, what has been recorded will be given a number. That number will always be used rather than your name so that the information you have given the researcher will be confidential. It will then be typed up along with other people's interviews. The person who types it up will remove any names that have been mentioned whilst the interview was going on so when it comes back to the researchers nobody's real name will be on it.

What we will do with what you have said?

What you have said will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Where will the interview take place?

You can choose where you would like the interview to take place, for example at home, at Walkergate Park or somewhere else.

What will happen if I need some help or support?

You can choose to have someone with you if you like. That might be someone to help you get your message across or someone that helps you feel comfortable and makes sure you are OK. If you don't have anyone to help you and you would like someone, we can arrange this. We can meet with you before the interview, to find out about the help you might need.

A chance for you to see the key themes and discuss them again

When we have identified the themes we will ask you if you would talk with the researcher again, this time to look at the main themes that have come out of everyone's data, to see what you think about them. You don't have to do this if you don't want to but sometimes it helps you to say a little more when you have had time to think about things between interviews.

If you agreed to a second interview we will make the same arrangements as before in respect of how you would like to conduct the interview. It will last about 30 minutes.

Data from this second interview will be collected with all the data from everyone who has participated in the study, so it will include data from blogs, diaries, focus groups, mapping photographs and questionnaires.

Finally – a 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in interviews and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Service Users and Carers: focus groups

Focus groups

What is a focus group?

This is where a group of about 6-8 people come together in a group to discuss the research topic.

What will happen if you choose to join a focus group?

You will meet with a researcher and a group of other service users, or if you are a carer, with other carers, to discuss what might be understood by the word inclusion and experiences of feeling included and excluded. These can be experiences that people have had whilst using Walkergate Park Services or experiences in the community.

Two researchers will be there, one to act as chair or facilitator for the group and one to help out. One researcher will be a service user or former service user, the other will be from the University.

Recording what you have said

The focus group will be recorded so that researchers will have an accurate record of what has been said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use a Litewriter or other equipment to communicate, one of the researchers will read out what you have written or pointed to so that the others can hear it and so that it will be recorded for the research.

How long will it last?

The group will last about 1- 1 ½ hours

What will happen if I need some help or support?

You can choose to have someone with you if you like. That might be someone to help you get your message across or someone that helps you feel comfortable and makes sure you are OK. If you don't have anyone to help you and you would like someone, we can arrange this. We can meet with you before the focus group, to find out about the help you might need.

Privacy and confidentiality

As soon as we have finished the focus group what has been recorded will be typed up and along with what has been said in the other focus groups. The person who types it up will remove any names that have been mentioned whilst the focus group was going on and give each person's voice a number, so when it comes back to the researchers nobody's real name will be on it.

What we will do with what you have said?

What you have said will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Where would it take place?

The focus group would take place at Northumbria University at Coach Lane Campus. This is just up the road from Walkergate Park and is quite accessible.

What about travel costs?

Car mileage, public transport or taxi fees would be paid by the researchers and we can help you to organise this.

A chance for you to see the key themes and discuss them again

When we have identified the themes we will ask you if you would come to another focus group, this time to look at the main ideas that have come out of everyone's data to see what you think about them. You don't have to do this if you don't want to but sometimes it helps you to say a little more as you have had time to think about things between groups, and also it can be interesting to see what ideas other groups have had.

If you agreed to coming to a second focus group we would make the same arrangements as before in respect of how it takes place and how you get to it. It would last about 1 hour and 30 minutes.

Data from this second focus group will be collected with all the data from everyone who has participated in the study, so it will include data from blogs, diaries, focus groups, mapping and photographs and questionnaires.

Finally – a ‘Big Conversation’ Day

Before we end the research project we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in the focus groups and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Service Users and Carers: diaries

Diaries

What is a diary?

A diary is a record of your personal experience, kept by you, and is entirely about what you think and feel.

What will happen if you choose diaries?

You will be asked to keep a diary for one week about your experiences of daily life and to highlight experiences of feeling included or excluded, what made you or your relative or friend feel included or excluded, and the impact of this. This would ideally be a week when you have some contact with Walkergate Park Services.

You could keep a diary on paper, on a computer or by talking into a recorder. If you have not got your own recorder we can provide one for you and we will try and make sure that it is suitable for you to use if you need any special adaptations to it.

What will we do with what you have written or said?

The researcher will take a copy of what you have written down or recorded over the week and it will become data for this research project. Only the researchers will see what you have written. If you have recorded your diary it will be typed up and when it comes back to the researchers your real name will not be on it.

We will then look through what you have said and put it together with what everyone else has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Privacy and confidentiality

As soon as we have received what has been written or recorded it will be given a number. That number will always be used rather than your name so that the information you have given the researcher will be confidential. When other researchers in the team see it they will not know where it came from. Any names you have used in your diary will be replaced and if you have used a recorder, the person who types it up will remove any names that have been mentioned whilst the interview was going on. When it comes back to the researchers nobody's real name will be on it.

Data from the diaries will be collected with all the data from everyone who has participated in the study and put together with the data from blogs, interviews, focus groups, mapping, photographs and questionnaires.

Finally – a 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in keeping a diary and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Service Users and Carers: blogs

Blogs

TO DO THIS YOU NEED TO HAVE ACCESS TO A COMPUTER AND THE INTERNET

What is a blog?

A blog is a written conversation with other people that you do 'on line' on your computer. It is sometimes called a 'web log'.

What will happen if you choose to use the blog?

You will be given the blog address and a password and asked to use your computer to go to a special and secure web site. Here you can have a written conversation with other people about feelings of inclusion.

You would be asked to choose a different name for yourself so that you remain anonymous.

The only people who will be able to see the site are those who have signed a consent form to say that they wish to participate in the web log (blog) and the researchers.

The other people taking part could be service users, carers, staff from Walkergate Park Services or Voluntary Sector Organisations, but you would not know who exactly they were and they would not know who you were.

Other people who have chosen this way of participating in the research project will be able to see what you had written and will be able to tell you what they thought about your ideas. They may or may not agree with you. Some may criticise your ideas because they have different ideas, but this is a good way of seeing other people's perspective and having a good debate.

We will ask everyone to respect other people's views and to debate appropriately. The site will however be maintained by the researchers and any information of an unacceptable nature (racist, defamatory, nasty) or presented in an unacceptable way will be removed.

You will be asked to join in the blog for 1 month and you will be told when this is.

Important

Whilst this will be password protected do remember that this site is, like any other, still open to the possibility of determined hackers. We do not expect this to happen, but always using your false name and taking care about what you write is important to keep your identity secret.

What we will do with what you have said?

What you write on the blog will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from. This data will be put together with data from everyone who has taken part in the study. So it will include data from interviews, diaries, focus groups, mapping, photographs and questionnaires.

Finally – a ‘Big Conversation’ Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in 'blogs' and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information for service users and carers: Photography Project

Photography Project

What is the photography project?

This is when you would take photographs to show us where you see inclusive practice happening in your daily life and in the community where you live. Photography can help you be creative in recording where you see inclusion happening.

What will happen if I choose photography?

You can either use your own camera or be given a camera for a week. You will be asked to take some photographs of where you see inclusive practice happening over that time. You will be asked to take photographs only of places and not of people.

You will be asked to choose the photographs that are most important to you. Then you would meet in a group with some other service users, if you are a service user, or other carers, if you are a carer. The other people will have taken photographs too.

This is an opportunity to talk about where you have seen inclusive practice happening, what enables it to happen, what stops it from happening and what effect it has on your life.

If you don't want to attend a group one of the researchers will talk to you about it on your own if you would feel more comfortable doing this.

If you attend the group photography session there will then be a 'balloon debate'.

What is a balloon debate?

A 'balloon debate' is where the group of people who have taken photographs vote to keep only a certain number of photographs and have to say why they want to keep them. This will be used to help us identify some of the key themes from the photography work.

What happens if I don't know how to take a photograph or have difficulty holding a camera?

We have some people who would be able to help you learn how to use a camera.

We can help with advice on adapting a camera and can arrange this for you if this is needed.

If you need another person to help you take the photograph, this can either be someone you know or we can provide someone to help you.

How long will it take?

You will be asked to take photographs during 1 week. We will discuss with you which week this needs to be but ideally it will be a week when you have some contact with Walkergate Park Services.

If you choose to discuss your photographs in a group, this will take about two hours to two and a half hours.

If you choose to talk to someone on your own about your photographs, this will take about 1 hour.

Recording what you have said

The group discussion, talking to a researcher on your own and the 'balloon debate' will be recorded so that the researchers have an accurate record of what you have said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use a Litewriter or other equipment, the researcher will read out what you have said so that it will be recorded for the research

Privacy and confidentiality

The information that has been recorded will be typed up. The person who types it will remove any names that have been mentioned during the discussion, so that when it comes back to the researchers nobody's real name will be on it.

Finally – a 'Big Conversation' Day

Before the end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in photography and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Service Users and Carers: mapping

Mapping

What is mapping?

This is where you tell us where you see inclusive practice happening in both Walkergate Park and your local community.

What will happen if I choose mapping?

You will meet with 6-8 other service users in a group. Carers will meet with other carers.

We will work together as a group to create a map of:

- where you think inclusive practice is happening
- what makes your experience inclusive and why
- how being included affects you in your own daily life
- links between inclusive places and activities.

How long will it take?

This will take about one and a half hours. You will be able to take a break if this is what you need.

Recording what you have said

The mapping session will be recorded so that the researchers will have an accurate record of what you have said whilst you are mapping. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use a Litewriter or other equipment, the researcher will read out what you have said so that it will be recorded for the research.

We will also keep the map but you can have a copy of you would like to keep one too.

What will happen if I need some help or support?

You can choose to have someone with you if you like. That might be someone to help you get your message across or someone that helps you feel comfortable and makes sure you are OK. If you don't have anyone to help you and you would like someone, we can arrange this. We can meet with you before the mapping, to find out about the help you might need.

Privacy and confidentiality

The information that has been recorded will be typed up. The person who types it will remove any names that have been mentioned during the mapping, so that when it comes back to the researchers nobody's real name will be on it. Any names that are on the mapping paper will be removed.

What do we do with what you have said or drawn?

What you have said or drawn will become data for this research project.

Walkergate Park staff and people who work for the Voluntary Sector will also be asked to create some 'inclusion maps'. We will take all of the maps to the 'Big Conversation Day' where we can talk about them with other people who have been involved in the research.

Finally – the 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in the mapping and decide at a later date whether you want to come to the 'Big Conversation' day or not.

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Date

Information about methods: Service Users and Carers: Big Conversation Day

Big Conversation Day

This will be a conference held towards the end of the research project.

Everybody who has taken part in the research, service users, carers and staff and people from the voluntary sector will be invited to come.

What will happen?

The researchers will talk about what they have found so far, and we will discuss the different ideas that have been brought up through the research and how we can all work together to change practice.

This will not just be a day of researchers talking, it will be an interactive day with lots of ways of joining in and help to do so where needed.

The discussions at the conference will also be collected as data and will be treated confidentially.

When will the 'Big Conversation' happen?

This conference will only take place when we have put together all the data from the interviews, discussion groups, blogs, diaries, mapping, photography and questionnaires.

How will I know when it is happening?

If you have taken part in the research we will contact you to let you know the date, the time and where it will take place.

Remember, if you want to come to this day, whilst people would know you had taken part in the research, no-one would know what you said as by the time we get to here it will have all been put together into key ideas (themes). If something identified you in particular we would not use it.

Appendix 4.5 Questionnaire - Service users only.

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Date

Invitation letter for Service Users: questionnaire

Questionnaire letter

Dear Service User

Towards Inclusive Living

A research study funded by the Department of Health

Thank you for agreeing to take part in the questionnaire for this study.

The study will look at how adults with an acquired neurological impairment feel included in their treatment and how this makes a difference to the way they use NHS services.

Please could you fill in the enclosed questionnaire? This will help us understand what makes you feel included or excluded in your treatment or assessment at Walkergate Park

There may be some questions that are not relevant to your experiences of using the services at Walkergate Park. If so, please circle 'does not apply'. For some people a number of the questions will not apply and that is fine.

If you need some help to complete the questionnaire then please let us know and we will arrange for someone to help you.

Please send the completed questionnaire back to us in the stamped addressed envelope by *(date to be determined)*

Thank you for your time.

Yours sincerely

Paul Mitchell

Researcher

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Date

Information about methods for Service Users and Carers: questionnaire

Questionnaire

What is a questionnaire?

This is a set of questions on a form that asks for your opinions about a specific issue.

What is this questionnaire about?

We are interested in knowing about your experiences of using Walkergate Park Services and how you have been involved in the decision-making in your assessment or rehabilitation.

This questionnaire has been used in other rehabilitation centres and is for service users only.

What will happen if you choose the questionnaire?

We will send you a questionnaire through the post and ask you to fill it in. You will be asked to circle a number that is the closest to what you think about your experience.

If you have attended more than one of the services at Walkergate Park, then think about the service you would most like to tell us about, and give all your answers based on your experience in that service.

If you have only attended North East Drive Mobility, Communicate or the Environmental Control Service, there will be quite a lot of questions that don't apply to you. We are still very interested in the questions that do apply to you.

If you need some help to do this, either you can ask someone you know or we can provide someone to help you. Please let us know if you need any help.

You will also be asked to fill in an information sheet which will tell us a bit about you. Your name will not be on this but it will be given a number.

Privacy and confidentiality

Your responses will be treated confidentially.

Your questionnaire and your information sheet will be given a number so that we can keep them matched up but will not have your name on.

What we will do with what you have told us?

The information will be gathered together and we will look at the main themes that have come from all the questionnaires. We will add these to the other information we have gathered in the research project.

Finally – a ‘Big Conversation’ day

Before we end the research project we will invite everyone who has taken part in the research to come along and discuss together the key issues and see if we have any ideas for making any changes.

There is more information about this day in the pack so do take a look at it – but you don’t have to make a decision now. You can decide to fill in a questionnaire and decide at a later date whether you want to come to the ‘Big Conversation’ day or not.

University headed paper

Trust logo

Date

Information about methods for Staff: interviews

Interviews

What is an interview?

An interview is a conversation between you and a researcher on the research topic.

What will happen if you choose interviews?

You will meet with a researcher who will ask you some questions about what you personally understand by the word inclusion, about experiences of feeling included and excluded and about experiences you think service users and carers have of this.

The researchers will be from the University and will not be staff members, service users or carers

Recording what you have said

The interview will be recorded so that researchers will have an accurate record of what you have said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use specific equipment to communicate, one of the researchers will read out what you have written or pointed to so that it will be recorded for the research.

If, though, you don't want to be recorded the interviewer can take notes instead. In this case the interviewer would check with you, at the end of the interview, that what they have written down reflects what you have said.

How long would it last?

The interview would last about 30 - 45 minutes.

You can stop the interview at any time for any reason.

Privacy and confidentiality

As soon as we have finished the interview, what has been recorded will be given a number. That number will always be used rather than your name so that the information you have given the researcher will be confidential. It will then be typed up along with other people's interviews. The person who types it up will remove any names that have been mentioned

whilst the interview was going on so when it comes back to the researcher's nobody's real name will be on it.

What we will do with what you have said?

What you have said will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Where will the interview take place?

You can choose where you would like the interview to take place, for example at Walkergate Park, Northumbria University (Coach Lane Campus) or for Voluntary sector partners, within your own organisational building.

What will happen if I need some help or support?

We can ask someone to come and meet with you to talk with you about the help you might need during the interview.

A chance for you to see the key themes and discuss them again

When we have identified the themes we will ask you if you would talk with the researcher again, this time to look at the main themes that have come out of everyone's data, to see what you think about them. You don't have to do this if you don't want to but sometimes it helps you to say a little more as you have had time to think about things between interviews.

If you agreed to a second interview we would make the same arrangements as before in respect of how you would like to conduct the interview. It would last about 30 minutes.

Data from this second interview will be collected with all the data from everyone who has participated in the study, so it will include data from blogs, diaries, focus groups, mapping photographs and questionnaires.

Finally – a 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in interviews and decide at a later date whether you want to come to the 'Big Conversation' day or not.

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Trust logo

Date

Information about methods for Staff and Voluntary Sector Partners: focus groups

Focus groups

What is a focus group?

This is where a group of about 6-8 people come together in a group to discuss the research topic.

What will happen if you choose to join a focus group?

You will meet with a researcher and a group of other Walkergate Park staff or, if you are a voluntary sector partner, with other voluntary sector partners.

In the group you would discuss what you might understand by the word inclusion and experiences of feeling included and excluded.

Two researchers will be there, one to act as chair or facilitator for the group and one to help out. The researchers will be from the University and will not be staff members, service users or carers.

Recording what you have said

The focus group will be recorded so that researchers will have an accurate record of what has been said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

How long will it last?

The group will last about 1- 1 ½ hours

What happens if I need some help or support?

We can ask someone to come and meet with you to talk with you about the help you might need during the focus group.

Privacy and confidentiality

As soon as we have finished the focus group what has been recorded will be typed up along with what has been said in other focus groups. The person who types it up will remove any names that have been mentioned whilst the focus group was going on and give each person's voice a number, so when it comes back to the researchers nobody's real name will be on it.

What we will do with what you have said?

What you have told us will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Where will it take place?

The focus group would take place at Northumbria University at Coach Lane Campus. This is just up the road from Walkergate Park and is quite accessible.

A chance for you to see the key themes and discuss them again

When we have identified the themes we will ask you if you would come to another focus group, this time to look at the main ideas that have come out of everyone's (service user and carers too) data to see what you think about them. You don't have to do this if you don't want to but sometimes it helps you to say a little more as you have had time to think about things between groups, and also it can be interesting to see what ideas other groups have had.

If you agreed to coming to a second focus group we will make the same arrangements as before in respect of how it takes place and how you get to it. It would last about 1 hour and 30 minutes.

Data from this second focus group will be collected with all the data from everyone who has participated in the study, so it will include data from blogs, diaries, focus groups, mapping and photographs and questionnaires.

Finally – a 'Big Conversation' Day

Before we end the research project we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in the focus groups and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Representatives from Voluntary Sector Partners:
interviews

Interviews

What is an interview?

An interview is a conversation between you and a researcher on the research topic.

What will happen if you choose interviews?

You will meet with a researcher who will ask you some questions about what you personally understand by the word inclusion, about experiences of feeling included and excluded and about experiences you think service users and carers have of this.

The researchers will be either from the University or NHS staff researchers, they will not be service users, carers or other voluntary sector partners.

Recording what you have said

The interview will be recorded so that researchers will have an accurate record of what you said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use specific equipment to communicate, one of the researchers will read out what you have written or pointed to so that it will be recorded for the research.

If, though, you don't want to be recorded the interviewer can take notes instead. In this case the interviewer will check with you, at the end of the interview, that what they have written down reflects what you have said.

How long would it last?

The interview would last about 30 - 45 minutes.

You can stop the interview at any time for any reason.

Privacy and confidentiality

As soon as we have finished the interview, what has been recorded will be given a number. That number will always be used rather than your name so that the information you have given the researcher will be confidential. It will then be typed up along with other people's interviews. The person who types it up will remove any names that have been mentioned

whilst the interview was going on so when it comes back to the researchers nobody's real name will be on it.

What we will do with what you have said?

What you have told us will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Where will the interview take place?

You can choose where you would like the interview to take place, for example at Walkergate Park, Northumbria University (Coach Lane Campus) or for Voluntary sector partners, within your own organisational building.

What will happen if I need some help or support?

We can ask someone to come and meet with you to talk with you about the help you might need during the interview.

A chance for you to see the key themes and discuss them again

When we have identified the themes we will ask you if you would talk with the researcher again, this time to look at the main themes that have come out of everyone's data, to see what you think about them. You don't have to do this if you don't want to but sometimes it helps you to say a little more as you have had time to think about things between interviews.

If you agreed to a second interview we would make the same arrangements as before in respect of how you would like to conduct the interview. It would last about 30 minutes.

Data from this second interview will be collected with all the data from everyone who has participated in the study, so it will include data from blogs, diaries, focus groups, mapping photographs and questionnaires.

Finally – a 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in interviews and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Voluntary Sector Partners: focus groups

Focus groups

What is a focus group?

This is where a group of about 6-8 people come together in a group to discuss the research topic.

What will happen if you choose to join a focus group?

You will meet with a researcher and a group of other voluntary sector partners. In the group you will discuss what you might understand by the word inclusion and experiences of feeling included and excluded.

Two researchers will be there, one to act as chair or facilitator for the group and one to help out. The researchers will be either from the University or NHS staff researchers, they will not be service users, carers or other voluntary sector partners.

Recording what you have said

The focus group will be recorded so that researchers will have an accurate record of what has been said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

How long will it last?

The group will last about 1- 1 ½ hours

What happens if I need some help or support?

We can ask someone to come and meet with you to talk with you about the help you might need during the focus group.

Privacy and confidentiality

As soon as we have finished the focus group what has been recorded will be typed up along with what has been said in other focus groups. The person who types it up will remove any names that have been mentioned whilst the focus group was going on and give each person's voice a number. When it comes back to the researchers nobody's real name will be on it.

What we will do with what you have said

What you have told us will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Where will it take place?

The focus group will take place at Northumbria University at Coach Lane Campus. This is just up the road from Walkergate Park and is quite accessible.

A chance for you to see the key themes and discuss them again

When we have identified the themes we will ask you if you would come to another focus group, this time to look at the main ideas that have come out of everyone's (service user and carers too) data to see what you think about them. You don't have to do this if you don't want to but sometimes it helps you to say a little more as you have had time to think about things between groups, and also it can be interesting to see what ideas other groups have had.

If you agree to coming to a second focus group we will make the same arrangements as before in respect of how it takes place and how you get to it. It will last about 1 hour and 30 minutes.

Data from this second focus group will be collected with all the data from everyone who has participated in the study, so it will include data from blogs, diaries, focus groups, mapping and photographs and questionnaires.

Finally – a 'Big Conversation' Day

Before we end the research project we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in the focus groups and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Staff and Voluntary Sector Partners: diaries

Diaries

What is a diary?

A diary is a record of your personal experiences and reflections, kept by you and is entirely about what you think and feel.

What will happen if you choose diaries?

You will be asked to keep a diary for one week about your experiences of daily life and to highlight experiences of feeling included or excluded, what made you feel included or excluded, what you think made service users and carers feel included or excluded, and the impact of this.

You could keep a diary on paper, on a computer or by talking into a recorder. If you have not got your own recorder we can provide one for you and we will try and make sure that it is suitable for you to use if you need any special adaptations to it.

What we will do with what you have said

We will take a copy of what you have written down or recorded over the week and it will become data for this research project. Only the researchers will see what you have written. If you have recorded your diary it will be transcribed and typed up. We will then look through what you have said and put it together with what everyone else has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from.

Privacy and confidentiality

As soon as we have received what has been written or recorded it will be given a number. That number will always be used rather than your name so that the information you have given the researcher will be confidential and when other researchers in the team see it they will not know where it came from.

Any names you have used in your diary will be replaced and if you have used a recorder, the person who types it up will remove any names that have been mentioned whilst the interview was going on. When it comes back to the researchers nobody's real name will be on it.

Data from the diaries will be collected with all the data from everyone who has participated in the study and put together with the data from blogs, interviews, focus groups, mapping, photographs and questionnaires.

Finally – a ‘Big Conversation’ Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in keeping a diary and decide at a later date whether you want to come to the ‘Big Conversation’ day or not.

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Trust logo

Date

Information about methods for Staff and Voluntary Sector Partners: blogs

Blogs

What is a blog?

A blog is a written conversation with other people that you do 'on line' on a computer. It is sometimes called a 'web log'.

What will happen if you choose to use the blog?

You will be given the blog address and asked to use your computer to go to a special and secure web site to enter into written discussions on the research topic.

You will be asked to choose a different name for yourself so that you remain anonymous.

The only people who will be able to see the site are those who have signed a consent form to say that they wish to participate in the web log (blog), and the researchers.

The other people on the blog could be service users, carers, staff from Walkergate Park Services or Voluntary Sector Organisations, but you would not know who exactly they were and they would not know who you were.

Other people who have chosen this way of participating in the research project would be able to see what you had written and would be able to tell you what they thought about your ideas. They may or may not agree with you. Some may criticise your ideas because they have different ideas, but this is a good way of seeing other people's perspective and having a good debate.

We will ask everyone to respect other people's views and to debate appropriately. The site will however be maintained by the researchers and any information of an unacceptable nature (racist, defamatory, nasty) or presented in an unacceptable way, will be removed.

You will be asked to join in the blog for 1 month. You will be told when this is and you can contribute as much or as little as you like.

Whilst this will be password protected do remember that this site is, like any other, still open to the possibility of determined hackers. We do not expect this to happen, but always using your false name and taking care about what you write is important to keep your identity secret

What we will do with what you have said

What you have written on the blog will then become data for this research project. We will look through what everyone has said to see where there are similarities and differences, where there are some things that are really important to lots of people and where there are key issues that we can all learn from. This data will be put together with data from everyone who has taken part in the study so it will include data from interviews, diaries, focus groups, mapping, photographs and questionnaires.

Finally – a ‘Big Conversation’ Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in 'blogs' and decide at a later date whether you want to come to the 'Big Conversation' day or not.

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Date

Information about methods for Staff and Voluntary Sector Partners: photography project

Photography Project

What is a photography project?

This is when you will take photographs to show us where you see inclusive practice happening in your daily life, in the community where you live and where you think it happens for service users and carers. Photography can help you be creative in recording where you see inclusion happening.

What will happen if I choose photography?

You can either use your own camera or be given a camera for a week. You will be asked to take some photographs of where you see inclusive practice happening. You will be asked to take photographs only of places and not of people.

You will then be asked to select the photographs that are most important to you and meet in a group with some other staff and voluntary sector partners who have taken photographs. The purpose of the group is to talk about where you have seen inclusive practice happening, what enables it to happen, what stops it happening and what effect it might have on the lives of service users and carers.

If you don't want to attend a group one of the researchers will come and interview you about your photographs.

If you attend the group photography session there will then be a 'balloon debate'.

What is a 'balloon debate'?

A 'balloon debate' is where the group of people who have taken photographs vote to keep only a certain number of photographs and have to say why they want to keep them. This will help us identify some of the key themes from the photography work.

What will happen if I don't have a camera or need help to take photographs?

We have some people who would be able to help you learn how to use a camera.

We can help with advice on adapting a camera and can arrange this for you if this is needed. If you need another person to help you take the photograph, this can either be someone you know or we can provide someone to help you.

How long will it take?

You will be asked to take photographs during 1 week. We will discuss with you which week this needs to be but ideally it would be a week when you have some contact with Walkergate Park Services.

If you choose to discuss your photographs in a group, this will take about two hours.

The 'balloon debate' will take about one and a half hours

Recording what you have said

The group discussion, interviews and the 'balloon debate' will be recorded so that the researchers will have an accurate record of what you have said. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use a Litewriter or other communication equipment, the researcher will read out what you have said so that it will be recorded for the research.

Privacy and confidentiality

The information that has been recorded will be typed up. The person who types it will remove any names that have been mentioned, so that when it comes back to the researchers nobody's real name will be on it.

Finally – a 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in photography and decide at a later date whether you want to come to the 'Big Conversation' day or not.

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Date

Information about methods for Staff and Voluntary Sector Partners: mapping

Mapping

What is mapping?

This is where you tell us where you see inclusive practice happening in both Walkergate Park and your local community and you draw it on a map. The map will also show connections between places.

What will happen if I choose mapping?

You will meet with 6-8 other people in a group. Voluntary sector partners will meet with other voluntary sector partners, Walkergate Park Staff would be with other Walkergate Park Staff.

We will work together as a group to create a map of:

- where you think inclusive practice is happening
- what makes that experience inclusive for service users and carers and family members and why
- how being included affects service users and carers and family members in their daily lives.
- links between inclusive places and activities.

How long will it take?

This will take about two hours. You will be able to take a break if this is what you need.

Recording what you have said

The mapping session will be recorded so that the researchers will have an accurate record of what you have said whilst you are mapping. This can seem quite strange to begin with but you will soon forget that you are being recorded.

If you use equipment to help you communicate, the researcher will read out what you have said so that it will be recorded for the research.

Privacy and confidentiality

The information that has been recorded will be typed up. The person who types it will remove any names that have been mentioned during the mapping, so that when it comes back to the researcher nobody's real name will be on it. Any names that are on the mapping paper will be removed.

What we will do with what you have said or drawn

What you have said or drawn will then become data for this research project.

Service users and carers will also be asked to create some 'inclusion maps'. We will take all of the maps to the 'Big Conversation Day' where we can talk about them with other people who have been involved in the research.

Finally – a 'Big Conversation' Day

Before we end the research project, we will invite everyone who has participated in the research to come along and discuss together the key issues and see if we have any ideas for making changes where necessary.

There is more information about this day in this pack so do take a look at it - but you don't have to make a decision now. You can decide to take part in the mapping and decide at a later date whether you want to come to the 'Big Conversation' day or not.

University headed paper

Trust logo

Date

Information about methods for Staff and Voluntary Sector Partners: Big Conversation

Big Conversation Day

Information for Staff and Voluntary Sector Partners

There will be a conference held towards the end of this research project. Everybody who has taken part in the research, service users, carers and staff and people from the voluntary sector will be invited to come.

What will happen?

The researchers will talk about what they have found so far, and we will discuss the different ideas that have been brought up through the research and how we can all work together to change practice.

This will not just be a day of researchers talking, it will be an interactive day with lots of ways of joining in.

The discussions at the conference will also be collected as data and will be treated confidentially.

When will the 'Big Conversation' happen?

This conference will only take place when we have put together all the data from the interviews, discussion groups, blogs, diaries, mapping, photography and questionnaires.

How will I know when it is happening?

If you have taken part in the research we will contact you to let you know the date, the time and where it will take place.

Remember, if you want to come to this day, whilst people would know you had taken part in the research, no-one would know what you said as by the time we get to here it will have all been put together into key ideas and themes. If something identified you in particular we would not use it.

Appendix 5

CLIENT-CENTRED REHABILITATION QUESTIONNAIRE

Cheryl Cott

Instructions

Please **circle the one response** that is closest to what you think about your rehabilitation experience. **Staff** includes all of the nursing staff, therapists, and physicians working in your treatment of assessment program at Walkergate Park

Please **circle one response** for each question. If this question does not apply to you, please circle the last column.

It is okay to ask for assistance in answering questions as long as the answers represent your own feelings. There are no right or wrong answers.

How strongly do you agree or disagree with the following statements?

		Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
1.	The staff and I decided together what would help me.	1	2	3	4	5	Does not apply
2.	I had difficulty getting the health care information I needed.	1	2	3	4	5	Does not apply
3.	I was kept well-informed about my progress in areas that were important to me.	1	2	3	4	5	Does not apply

		Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
4.	My family/friends were given the support that they needed by the Trust staff.	1	2	3	4	5	Does not apply
5.	The staff treated me as a person instead of just another case.	1	2	3	4	5	Does not apply
6.	The staff tried to accommodate my needs when scheduling my therapy.	1	2	3	4	5	Does not apply
7.	I had to repeat the same information to the different staff.	1	2	3	4	5	Does not apply
8.	My physical pain was controlled as well as possible.	1	2	3	4	5	Does not apply
9.	The staff took my individual needs into consideration when planning my care.	1	2	3	4	5	Does not apply
10.	I was given adequate information about support services in the community.	1	2	3	4	5	Does not apply
11.	I accomplished what I expected in my rehabilitation program.	1	2	3	4	5	Does not apply
12.	My family/friends were given the information that they wanted when they needed it.	1	2	3	4	5	Does not apply
13.	I was treated with respect and dignity.	1	2	3	4	5	Does not apply
14.	My reports of pain were acknowledged by staff.	1	2	3	4	5	Does not apply
15.	My treatment needs, priorities and goals were important to the staff.	1	2	3	4	5	Does not apply

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
16. The staff and I discussed my progress together and made changes as necessary.	1	2	3	4	5	Does not apply
17. My family/friends received information to assist in providing care for me at home.	1	2	3	4	5	Does not apply
18. I knew who to contact if I had problems or questions during my rehabilitation program.	1	2	3	4	5	Does not apply
19. I had adequate time for rest and sleep.	1	2	3	4	5	Does not apply
20. I was encouraged to participate in setting my goals.	1	2	3	4	5	Does not apply
21. I received the information that I needed when I wanted it.	1	2	3	4	5	Does not apply
22. I learned what I needed to know in order to manage my condition at home.	1	2	3	4	5	Does not apply
23. My family and friends were treated with respect.	1	2	3	4	5	Does not apply
24. I know who to contact if I have problems following discharge.	1	2	3	4	5	Does not apply

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
25. Treatment choices were fully explained to me.	1	2	3	4	5	Does not apply
26. My therapy program was explained to me in a way that I could understand.	1	2	3	4	5	Does not apply
27. My family/friends were involved in my rehabilitation as much as I wanted.	1	2	3	4	5	Does not apply
28. I felt comfortable expressing my feelings to program staff.	1	2	3	4	5	Does not apply
29. I was told what to expect when I got home.	1	2	3	4	5	Does not apply
30. Staff tried to ensure my comfort.	1	2	3	4	5	Does not apply
31. My emotional needs (worries, fears, anxieties) were recognized and taken seriously by the staff.	1	2	3	4	5	Does not apply
32. My therapists, nurses and doctors worked well together.	1	2	3	4	5	Does not apply
33. There were times when I received more information than I was ready for.	1	2	3	4	5	Does not apply

Additional questions

The research team made contact with Cherly Cott who kindly furnished us with the original questionnaire free of charge and additional ideas for augmenting the questionnaire. These were used to inform the questions below. These were intended as a framework for discussion once the structured questionnaire had been completed .

1. Being included

We often talk about wanting to be included, so to help us to find out what that means and feels like for you, could you tell us a little about

- Where you feel included
- What makes you feel included
- What makes you feel excluded
- Where you feel excluded

2. Perspectives

There are a few words that we use that seem to almost mean the same – do you think there is any difference between them?

- Integrated
- Included
- Involved

Which would you rather be, integrated, included or involved? – and why?

3. Feelings

How do you feel when you are *integrated/included/involved*? (Prompt to facilitator: use the word they chose from above)

Where do you feel most *integrated/included/involved*? (Prompt to facilitator: use the word they chose from above)

What makes you feel that here?

If you could take a photograph of being *integrated/included/involved*, what would that photograph have in it/look like? (Prompt: can you describe what that might look like it to me?)

Appendix 6

Abbreviations used to indicate source of data

E.g. (SU50-M-I) would translate as: Service user 50, male, interview

SU	Service User
S	Staff
C	Carer/family member
V	Voluntary Sector Partner
M	Male
F	Female
I	Interview
P	Photography
M	Mapping
D	Diary
FG	Focus Group
MFG	Mixed Focus Group
BCD	Big Conversation Day

Where more than one person is speaking I= interviewer, P = Participant.

Appendix 7

Examples of mission statements, visions and aims

Local (North East) NHS Trusts

Example one

Our Vision is: "To improve the wellbeing of everyone we serve through delivering services that match the best in the world".

Our Values are:-

We place users and carers at the centre of everything we do,

We treat users and carers with respect and dignity,

We support and show respect towards our staff; we encourage their personal and professional development; we acknowledge their expertise and professionalism; and we value the role that they fulfil,

We always look to do things better – encouraging and acknowledging improvement and innovation,

We promote effective team and partnership working,

We are honest, show trust, have integrity and are open and transparent in our work,

We embrace diversity,

We will listen to the views of others.

Example Two

Aims

To put patients at the centre of all we do, providing the safest and highest quality health care

To be the healthcare provider for Newcastle and a national specialist centre

In partnership with Newcastle University Faculty of Medical Sciences and others to be nationally and internationally respected for our successful clinical research and development programme which leads to benefits in healthcare and for patients

To maintain financial viability and stability

To promote healthy living and lifestyles

Values

To place our patients at the heart of everything we do

To value and enhance the contribution of staff, volunteers, members, Governors and other partners and stakeholders

Zero tolerance of unsatisfactory behaviours

Consistently high personal and professional standards in all activities

To focus upon continuous improvement in the pursuit of excellence

To have pride in public service and all that we do

To continually seek best value for money

Appendix 8

An indication of costs resulting from ineffective communication processes based on narratives from the data.

1. Cost of repeated appointments to Consultant Neurologists

Narrative (service user): "My neurologist was Professor X at the [NHS venue]....I found him very good as a person. I would say one of the best, but very kind of austere in a way because he's a Professor... Often these people are quite austere cos they're top of their status position. But I found him, you know, helpful in terms of giving me information.....He said come and see him once a month.... or three months or whatever it was. And I did say to him at one point after going a few times, you know, is there any point to this because nothing much was gained from my point of view except going to say to him... not much change or there has been a bit of change and that was about it. You know, ten minutes at the most so it seemed to be, and so he said 'Well, don't come, there's nothing more I can do for you really.' And that was quite good for me to know. It was blunt but quite true and I stopped going which was quite good for me.

Now again at [another NHS venue], I'm beginning to find the same thing again. I'm going every 6 months and I've been twice up to now and once I had an aggravating experience getting there you know.... But the information's not good, because I had one neurologist there when I went the first time, another one after that because the first one had left, so I had another neurologist. So the person you're engaging with, you know, not the same person, it's a bit of an odd thing. And I had a real sense, there's no point me being in here, you know, this person is just filling in for his wage, you know, it's not really being helpful to me.

I went on a course called expert patient...about a ten week course....Well the Expert Patient thing was an attempt to kind of get people to be more in control of being a patient...so, when I went to see people at [NHS venue] I had a list of questions, cos that is one of the things they recommended cos often you forget in the heat of the moment. So I had a list of questions and the first guy I found to be very helpful. He was actually very helpful. Very sympathetic, empathetic whatever word you want to go..... He offered me concrete solutions to the problems I was setting up for him, and that was fine, great. The second one I would say was completely useless from my point of view. I don't want to say too much because I don't want to get anyone into trouble or anything like that. I just found him totally

useless....I've got to go again this month for my third one, it's every 6 months, I'm going to say, you know, is there any point in me going, as I said to Professor X, is there any point in me coming anymore, you know, cos I'm not getting anything from this it's just an irritation".¹⁹

NB: The costs to service user of repeatedly going to see consultants was therefore the consultants' time plus transport costs for the NHS and a great deal of energy, effort, stress and frustration for him. The outcome of his frank discussion will reduce all these costs but leave him without recourse to positive opportunities that could support him. This service user uses a buggy and therefore cannot use the local Metro transport system where they are banned. Costs on the Metro (which stops near both the first hospital referred to by the service user above and Walkergate Park, the later destination) for 6 appointments = £21.60.

Projected Costs

Consultant ²⁰	£130.42 ²¹
Approximate costs of a taxi pick up	£75.00 ²²
Administration (reception, appointment letters etc)	£20.00
Report writing/Inter-professional communication etc	£130.42
Subtotal Cost: (one appointment) NHS	£355.84

If service user had been for **6 appointments** that were deemed to be not effective for reasons given above, the unnecessary cost to the NHS would have been **£2190.04**

¹⁹ This scenario is acted out in the DVD

²⁰ Staff costs are based on the midpoint of the salary scale, 2011/ 2012 pay and prices and are inclusive on costs

²¹ Costs are provided for 1 hour contact time.

²² Travel costs for the above were based on a 40 mile round trip – see below –as this is a regional service some patient costs will be proportionately larger. Patients are paid 14 pence per mile when using their own vehicles. The distance travelled is worked out using AA Route Planner – Postcode to Postcode.

Approximate costs of an ambulance pick up - 40 miles	£100
Approximate costs of a taxi pick up – 40 miles	£75
Approximate cost of patient own travel - 40 miles	£5.60

2. The cost of physiotherapy treatment that does not get embedded in daily life.

Narrative (service user): “I think the one thing that’s been difficult is that [the physiotherapist] often wants you to do a certain exercise at home and he will explain it and we both [service user and CFM] listen to him and when we get home we haven’t the faintest idea how to do it! Now whether it will be more inclusive to write down what was wanted I don’t know, but it’s done orally and so we almost always have to go back the next treatment and say “look can you say it again” you know “is this what you meant?”...I don’t think [name] is quite aware of how hard it is to do that [understand and remember]. But we do say that we haven’t done that because we didn’t understand it and he takes that but he doesn’t actually vary his procedure the next time”.²³

Projected Costs

Band 7 OT/PT	£31.19
Service user and CFM own travel	£12.00
Administration	£20.00
Report writing/Inter-professional communication etc	£31.19
Subtotal Cost: (one appointment) NHS	£92.38

If service user had been for **6 appointments** that merely repeated the former for reasons given above, the unnecessary cost to the NHS would have been **£554.28**

²³ This scenario is acted out in the DVD

3. Cost of appointments where the basic premise of the meeting did not meet the needs of the service user.

i) Community Psychiatric Nurse

Narrative: One service user explained how she received help at home, the focus of which was to support her in learning how to organise her home. This had, over a long period of time, proved too difficult for her to achieve. Her own perceptions on this now were that she would benefit more from someone coming and sorting out her house, a home help/cleaner-type person rather than a professional CPN. This would then give her time, space and energy to concentrate on developing things she could achieve, rather than spending time on something she feels she will never do. It would be more cost-effective as expensive professional time could be used to focus on achievable aims. She had not discussed this with the professionals she saw because she felt that if she said she did not want this help they would withdraw the service and she did not want to be without anyone coming to see her.

Projected Costs

Band 7 Community Psychiatric Nurse*	£80.03 ²⁴
Administration	£20.00
Report writing/Inter-professional communication etc	£31.19
Subtotal Total Cost: (one appointment) NHS	£131.22

If service user had been for **6 appointments** that merely repeated the former for reasons given above, the cost to the NHS would have been **£787.22**

The cost of a personal assistant to clean and tidy house

<i>Set up cost - Administration</i>	<i>£20.00</i>
<i>One hour visit</i>	<i>£10.00</i>
<i>6 visits</i>	<i>£60</i>
Total cost to NHS	£90.00

²⁴ £31.19 + £48.84 travel

ii) Occupational Therapy

Narrative (service user): “The OTs were full of sort ‘oh you shouldn’t do that’ and ‘you must use this and lots of ways and adaptations and techniques’ which I abandoned as soon as I got home. Well, not as soon as, but sooner or later they all went by the wayside, you know, my transfer board and my pick up stick and all of these things I just don’t use, so you know I didn’t feel very included in the process of rehabilitation, I didn’t feel very informed, I didn’t feel that there was a plan, I didn’t feel very empowered by it, I sort of endured it and went through it and said, yes, no, and struggled for what I wanted... I don’t think that prepared me for the reality of life and problem-solving and you know the difficulties that I’ve faced and overcome in my daily life”.

Projected Costs

2x Band 7 OT/PT*	£62.38
Approximate costs of a taxi pick up	£75
Transfer Board	£55
Pick up Stick	£10.00
Home visit for learning to use Transfer Board in situ	£80.03 ²⁵
Administration	£20.00
Report writing/Inter-professional communication etc	£31.19
Total unnecessary cost to the NHS	£333.60

²⁵ £31.19 + £48.84 travel

iii) Wheelchair clinic

Narrative (service user): “The process of getting a wheelchair was a bureaucratic process of jumping through hoops and trying to understand my choices within a very rigid framework, it wasn’t processed for understanding what was good for me, what the drawback and benefits of different chairs would be, what possibilities there were. I didn’t feel included in that at all and so I think I’ve had to struggle and find my own way... I’ve had to solve it myself [bought his own chair privately]. This [NHS] power chair, which is a lot of resource, is just basically sitting in my front room. I said to the wheelchair service look I’ll give you back the power chair which presumably cost £6-7,000 at least and give me a voucher or buy me powered wheels “oh we can’t do that”. So it’s a bureaucracy which I don’t understand which doesn’t seem very efficient and hasn’t met my needs...my current chair weighs about 12/15 kilos, I can’t lift it, therefore if I want to drive I need a device to store the chair which would probably be another £3,000+ to fit on the car with a hoist, and be a real hassle, or I can get a titanium chair which weighs 5 kilos which I will be able to lift and will empower me to drive and I would not need the rest. But you know those sorts of choices haven’t been spelt out, we haven’t thought it through...so that’s a lack of inclusion in decision-making and information-sharing in understanding what the possibilities are which has left me, you know, trial and error, you know, fumbling my way towards a solution which is a waste of my time and money and it’s certainly a waste of NHS time and money”.

Projected Costs

Wheelchair clinic Band 7 OT/PT* assessment	£31.19
Approximate costs of a taxi pick up	£75
Administration	£20.00
Report writing/Inter-professional communication etc	£31.19
Cost: (one appointment) NHS	£157.38
Plus	
1 x Electric Wheelchair (daily use) ²⁶	£1000

²⁶ An electric wheelchair will not go on a roof box – for this to be transported patients need a large car eg VW Caddy. Usual cost is £18-20 000 with between £5-8000 in addition for adaptations

1 x manual folding wheelchair (not light-weight) for car	£450.00
1x Roof Box and Car Hoist.	£3500.00
Training for the above Wheelchair clinic Band 7 OT/PT*x 6	£187.14
Administration (x6)	£120.00
Report writing/Inter-professional communication etc x6	£187.14
Total cost of outcome (NHS)	£5444.28
<u>Projected Costs using service user preference</u>	
Wheelchair clinic Band 7 OT/PT* assessment	£31.19
Approximate costs of a taxi pick up	£75
Administration	£20.00
Report writing/Inter-professional communication etc	£31.19
Subtotal Cost: (one appointment) NHS	£157.38
Plus	
1 x Extra Lightweight folding wheelchair	£1000
Training for the above Wheelchair clinic Band 7 OT/PT*x 6	£169.80
Administration (x6)	£120.00
Report writing/Inter-professional communication etc x6	£187.14
Subtotal Total	£1477.04
Total cost of outcome (NHS)	£1634.42

Appendix 9

Impact of effective communication on costs

For this service user, who had reached the end of one aspect of her treatment, the existence of a communicative space addressed another aspect of her life as a person with a LTNC.

‘Shared knowledge – that was it. What I value about the times I see Dr. A in that for all he’s going to an absolute end, there’s nothing else that he’s going to do, pain management wise, and we talked about ___ but he’s still prepared to see me. I think, just to be there and offer support. In the past, when I’ve seen him, ... because of his knowledge of, sort of, the conditions and just physiologically and anatomically, he’s always brought something that’s raised or helped my awareness of why I’m feeling as I’m feeling and why things hurt in the way that they do. And he’s always, sort of, added to where I’m at with it. To help my understanding of it. And then brought that sense of just being able to accept things as they are. And I think it’s his knowledge, my knowledge and just meeting together in the middle and thinking, well, this is why this is happening. This is what’s happening to you. You tell me how you are, and we’ll try and make some sense of that.’ (SU32-I-theme verification)

Appendix 10

Service user to service user interview

The short excerpt from this interview between two service users illustrates the ease with which the interviewer and the service user can communicate. The common bond of similar experiences that enables that openness and frankness in communication. These people interact in a conversational way, telling each other their stories, feeling free to ask each other questions, and interrupt each other. Data generated from these types of conversations were rich and informative.

I: ...because yes I have travelled and erm more recently, yes you are allowed to go on the first 2 rows of the plane ok get yourself to the door of the aircraft and then you're told you can't take the chair, your wheelchair, what do they expect us to do?

P: Can you walk at all?

I: No.

P: No. I mean we always go to the assistance place.

P: I mean I think in the end we threatened to sleep on the well we threatened to sleep in the airport if they didn't ring ahead and check. But they almost feel like they're under no obligation.

I: Yes, I

P: I think it's probably things like travelling where I feel it's most, it's most difficult and most hitty missy.

I: Right yeah, because from my experience, okay, it was bad enough that they said well definitely no chair, I sat in the chair until I got to the door of the plane and then I was expected to walk but I couldn't. Yes I'd taken a friend with me as carer whatever so he literally lifted me over the step and onto a seat. Now dragged me down the aisle ... and it wasn't comfortable at all. Then when I got to the far end I could see my wheelchair. it hadn't been put in the hold but taken right across the other side of the airport. I said 'what's going on here' and have I got to walk to the other end I said. It's a miracle that I happened to be on the plane and they had a....

P: [interrupting] I think generally they consider you to be a nuisance actually.

I: Yeah

P: Not so much the airport but the airlines.

I: When you book a holiday you've got to insist that they know it, that I am disabled.

P: No....they don't make a lot of effort to make it user friendly ..., they always say I'll put you on first so that you haven't got to go on in front of everybody else but you always end up getting on last so that everybody else watches while you sort of, they struggle to carry you in, and it is undignified really.

I: Exactly.

P: I think that's the

I: [interrupts] That's a good word "undignified".

P: Yeah. So that's my main sort of grief

Appendix 11

Academic Researcher and Service User Participant

Overwhelmed by fact that the researcher came from university, despite her own connections (which she discussed in other sections of the interview) with academics in her own family, this participant started the interview by stating that she did not think she would have anything to tell the researcher. This appeared to be a statement about how she valued her own contributions but also, as the interview stuttered along, it appeared that she could have also presumed that the interviewer was there as part of a complaints procedure, and she did not want to complain about anything. It had been her choice to live in this home and she was keen to articulate that she was happy with that choice.

I: I just wondered if we could talk about feelings of being included.. erm... when, where you might feel included and what makes you feel included in things?

P: [Silence]

I: Well, are there any particular places you go where you feel more part of things than others?

P: Well (slight laugh) I don't know how to answer that

I: No?

P: I've never felt left out or anything.....

Trying to invoke another situation the researcher asks

I: So when you go for an appointment at the hospital, do they give you some things that they think you should be doing in your life, or make some suggestions?

P: No, no they just see how I'm walking

I: And do your appointments help you in your daily life, when you come back? [long pause] What is it about your appointments that help you?

P: Erm, well I don't know what to say to that?

I:, Well when you come back, do they give you any tips for...

P: No I don't think so [said before Interviewer had finished trying to shape a question]

A little later, the researcher tried another tack

I: If I say the words included and involved, do they mean the same thing to you?

P: Erm well, with involved, that means more doing things doesn't it?

I: Ok, so do you feel involved your care do you think?

P: No I don't do anything like that

I: And is that because you don't want to or because you think other things stop you?

P: No I don't particularly want to.

I: You don't want to

P:No

I: No

P: I don't feel the need to

I: So you are making that choice for yourself?

P: Yes

I: Yes, right, and what about the word integrated? Does that mean anything different to you?

P: Erm, well integrated is really just the same as involved isn't it?

I: Right, but some people have different ideas about the different words, and these are all words that get used about people being involved in, say, Walkergate Park, and other words, like integrated or included, and erm, so we're just trying to find out whether you might understand them in different ways.

P: Uhhu

I: Erm right well thank you. So it sounds to me then like the being involved is something that you've made the choice not to do that.

P:Uhhu

I: Good. Well I think I've got one last question. Do you think that you are doing everything that you should be doing to help improve your health?

P: Yes, I don't know what else I can do

I: Right, so....

P: I have my own physio

I: Yes, do they come and see you here?

P: Twice a week. Well actually the present one works here so she comes when her day is finished, twice a week.

I: and she does physio with you.

P: Uhu

I: Are there any exercises you have to do when she's not here - like homework?

P: no, no. I mean I do exercise myself

I: Yes and that's to keep yourself fit is it?

P: Yes I sit and do my feet and one thing and another with the legs and so on

I: yes, yes. So those are good things for your health?

P: Yes, yes

I: so you are doing things to keep you healthy?

P: Yes, yes

I: And are those things that you've decided to do or are they things that you've been...

P: Just repeats of what I do with [Physios name]

I: With the physio. ..

P: I do a walk with her you know, down the corridor and back, and some exercises when we get to the – well it's the dining room that we go to –because its after hours.

I: so exercise actually must play quite a big part in your day then if you have got to...

P: Yes [she interrupts the struggling researcher]

I: And you're happy with how that fits.... [she interrupts the struggling researcher]

P: Yes, yes

I: Well you sound like you are a very happy customer

P: Well I'm very settled here and I don't feel that really I'm giving you anything much.

Appendix 12

Difficulties accessing general health care

This family member recounts an experience of taking his wife (SU13) for routine breast screening. His wife is a wheelchair user and he acts as her advocate due to her communication impairment. The narrative below highlights the difficulties faced by service users with complex neurological long term conditions when accessing essential public health services. And 'reasonable adjustments' are not considered and discussed.

'in the past [it] hasn't been a major problem. They normally arrange a special clinic where they allow extra time you know, for people in wheelchairs to come in. 'Cos it takes a bit of extra time. So it's not a real problem, but when we went this year, to the .. outpatients – it's all the new gadgetry and that, they couldn't do it, because the matching, er, doesn't facilitate someone of SU13's disability being X-rayed...the person's got to like, twist now; the machine doesn't [do it]. So they were very apologetic and they said "sorry, you know, we can't do it this time, but don't worry, you can still do, like you know, the physical checks and if there is any problems, then we can do, like, an ultrasound, or something". But from that, I made a couple of phone calls to the MS team and they were a bit shocked, you know, 'cos I mean, that is really exclusion, isn't it?...I got numbers to phone, the National Breast Screening Authority, but I thought: I'm not going to bother, because I spend enough time on the phone, getting nowhere, ... So anyway...we went to the GP and Dr. A., ... he done the, like a thorough examination And he also explained that it wasn't as good ... and I don't know if he's going to make some enquiries, but I thought: it's not going to just be SU13 who can't be on that machine, is it?...SU13 was very, very upset for quite a while after that. Very worried, because [she] has had an instance of a cancer scare before. It was about seven year ago now, ...when they found some cancerous cellsso SU13 is always aware and she knows what the consequences of cancer can be, so obviously, not being able to have this check...It was horrendous...SU13 was... you were extremely depressed, weeks after. Worried sick....So I made a few phone calls, didn't... people were shocked, but nothing happened. The doctor was a bit shocked. But nothing's happened...and as you know, it's not just having an effect on SU13; it's having an effect on me. I mean, there's times I feel like banging me head on that wall, because of what you've just said, the response you get from some people.... You get very angry; you've got to try and handle it....SU13 gets extremely frustrated, which makes me frustrated, so it's a big, big vicious circle.' (C3-M & SU13- F-I)

Appendix 13

The cost of not being listened to

My little boy has been to hell and back with different diagnoses. Injections after injections and blood taking and operations and procedures he's had done on him. For 9 years he was treated [for something he hadn't got]...instead of doing what I'd said in the first place – which my own husband who has got Huntington's kept saying... "He's like me." He used to say, "He's like me." These people, the medical profession, don't like being told. I mean one doctor had said to me, "I always tell people, listen to the mum, she knows what she's talking to." Some doctors are like that – not all are. Some dismiss you as a neurotic mother. But after looking after [husband's] mam and then [husband] and even [husband] himself knowing that [her little boy] was like him, and they [the medical profession] were so against it because it was very rare for juvenile's to get it. He was just pushed aside and just treated for the symptoms. Chest infections and digestive problems. He was put on medication and then they decided the some other, but he didn't need it because his pancreas was working alright...And they used to send me to different consultants to have, like, scans done on his bowels and things like that...how many times I filled that family tree out was unreal. Every time I saw our consultant – "Well, we're going to do a family tree." And I'm like, "For God's sake, can you not just photocopy it and pass it around you?" It was a nightmare. You felt like you were repeating yourself, and every time you repeated it and you told them what you thought was going on, "Oh no. No, no. He can't have that. No." Until I met a Professor at the [hospital]. She is absolutely wonderful. She listened and she said, "I think you're right." I nearly fell off my chair...And it was her who got onto them. They had a meeting and they decided, right, yes, we're not going to put this child through anymore. And we're going to test for the obvious before we can do anymore tests. And it was just a case of going and confirming it for the appointment. He said, "It's not good news." I said, "I know that." I said, "I'm only here for confirmation." And I got confirmation. That's how he is diagnosed with that now. But he's been to hell and back. He's terrified of doctors. He's 13 and he still sits on my knee when he goes into Consultant's rooms. He is terrified.' (C22- F-FG)

Appendix 14

Excerpts from the diary of a man living in a Community Home

Through his diary, which he kept for a week, this man re-iterated his boredom and the impact of that on his mental health and motivation. He was recruited to the study through the in-patient services and had subsequently been discharged to the nursing home. His days revolved around his routine personal care, having a cigarette, the occasional game of cards with others and sporadic visits from his family. One of the things he was enjoying here was keeping this diary. His thanks at the end were to the researchers for including him in the study. He repeatedly thanked the researchers as it made him feel good that he was part of something.

Friday 4th December (7.30am til bedtime)

I have been to the doctors got a few things sorted out but am waiting to see psychology for help with the anxiety so not sure when this is happening but soon as possible. Had an alright day yesterday enjoyed stuff by helping myself out to do things. Best part by playing cards with people and sat down to do a puzzle which took over 2 hours to do by myself. I like to go in the bath every day to have a nice wash and clean myself up the nice way then go and have a fag then go downstairs for breakfast and get my medication. I like to go in the bath everyday to keep myself nice and clean and to feel a lot better. After waking up don't know what I will be doing today, probablys another bored dayness of doing nothing as usual. I am getting so much pain in dealing with anxiety these days cause I am getting moods, arguing with myself. doesn't feel right for me cause this only started when this happened to my head injury what I had, not right for me.

Well, been alright today but been a bit of a horrible day not being able to relax or nothing cause been that bored of doing absolutely nothing at all.

Well written today. Think I will go up for a sleep now, thanks.

Monday 7th December (8.30 til bedtime)

Another day in what I think of in paradise. I wish it could be. Well just wake up to go and have a bath to get myself cleaned up then for a cigarette and then down for medication. Soon as I have had my medication need to get my head on something to do cause I wake up the same day having nothing to do but the same things that I am used to that stick in my mind cause I get absolutely boring of the same old days. The anxiety has my mind in such a

serious problem since that happened to my head injury. Some days I just can't get on with anyone especially myself. I just don't realise what is happening or doing cause my head gets a lot of stress affecting it to see which way I can turn. I just wish everything would go away from and then wake up to be somebody else like who I used to be then I would be back to normal if it never happened to me. I feel so weak on my insides. My jaw has been giving me a lot of problems cause it keeps clicking all the time especially every day and night can't hear when I'm asleep. Need to see the doctor and get an appointment to see if I can get sent to the hospital for a check up about it cause in the end I might need an operation to get my jaw clicking fixed. Well I have had a good day writing this letter starting to get bored so I think I will lie down to rest myself.

(SU15-M-D)

Appendix 15

Excerpts from a week in the life of a man living with his wife and child

Keeping a diary was important to this participant. He wanted to readers to understand how his life had changed since his head injury. His days are routine and revolve around housekeeping tasks, preparing meals for his family and walking the dog. He feels a great sense of loss for his life prior to his head injury. At the end of the diary entry he lists all of the activities he is no longer able to take part in.

1st October 2009.

Time 1.30pm

My name is..... I life with my wifeand my [child]... 21 years ago I had a head injury that has left me with epilepsy and damage to frontal lobe and also deafness in my left ear, 9 times out of 10 I have to be prompted by my wife 3 to 4 times to do thing's. Like get wash have a shave and get clean cloth's on: me andhave been married for 17 years and we have our up's and down's like every married couple do but with.... she has to cope with me and memory loss, my sons [illness] and her [own health problems] so this is why am voluntary writing this diary so people can understand how my day to day has changed over the last 21 years. I just hope you can understand my wrighting and spelling because theve gone to pot over the years so let's hope you can understand what am trying to say as well.

10 am I had 2 lovely lady's from Northumbria university come to see me and my wife for me to volunteer to do a diary on myself so I agreed.

10.45 I started the house work. I always start with my [child] room then make my way down the stair's It take me 4 hours every Thursday to clean the -house. From top to bottom. I love a clean house,

3pm Finish house work had a cup of tea. Then I feel realy tyerd. Going to bed; got up

4.30 took the dog for a walk then came home had our tea then washed dishes and tidy up kitchen then

6.30 watch. TV until 9pm then took dog for her last walk of the night, then went for a shower. And then took my tablets they are carbamazepine 600mg heppra 1000mg and paracetamol 1000mg then I went to bed.

Fri 2nd Oct 09

Time 8.45

I woke up at 4.30 am because the dog was unsettled walked into kitchen she was telling me she had messed her bed so I started to clean her then settled her down then my shaken

started because I always shake first thing in the morning when I get out of bed. I wait 30 mins and it wear's off then I take my tablets then my b fast then I waited for [child].to wake up so I made his b fast then I got [wife] up at 6.45 and made her coffee

8am wife takes [child] to school then I tidy the kitchen and make the bed's then I waited until wife came home and did some washing in the washing machine

12 noon gave the dog no dinner because she not herself today so I just gave her water made wife her 3rd cup of coffee. Now am starting to feel really tyerd so am going to bed.the reason I go to bed is my left side starts to go numb from my leg to arm then I feel dizzie. I am not a lazie person I just can't help this when it come's over me (the time is 1pm). I didn't get up untill 3.40 feel really ruff. I takes an hour to trun myself around:

6pm I had my tea, mash pot and saus lovely. Start cleaning the kitchen wash dish's and put them away gave dog her food then watch TV until 9pm took dog for walk had shower took tablet then went to bed.

Sat 3rd Oct 09

Time 7.45

Woke up at 6am went into kitchen waited 30 mins until the shaken had stoped took 500mg keppra 600mg carbamazepine and 1000mg paracetamol then had my b'fast then took the dog for 45 min walk came home washed b'fast dishes and gave dog her b'fast then sat down and listen to classic FM until wife woke up. will finish this later(time is 8.45am).

time is 10.45 made bed's tidy ... bed room took dog for walk. [child] going swimming with his friend so I have time to wright this diary. Some day's I feel realy depress with myself for no reason at all then some day's I feel tyerd and some days I don't want to get out of bed then there are day's I just want to be left on my own. I know it may same strange to people that what I am now before my accident you never see me in the house I would go out with my mate get drunk have fun stay up until 3to 4 am in the morning then go to work at 6am now I can't keep my eyes open after 11pm and people can't understand that because I get really ratty with myself if I don't go to bed my normal time. I do feel sorry for my wife..... left on her own when I am in bed but she say's she's used to it now. I still get mad every time I think of the accident and why it happened to me. I will never forgive the firm for it because it ruind my life mentliy and socily but you hear people say forgave and forget. I can't and I wont that's me talking from the heart am wrighting this quick because I will forget what I've been writeing in a few hour time the time is 11.30am.I will wright some more later.

1.30 pm had lunch then took dog for walk. It funny 8 year's ago I never liked dogs but since we took in a rescue dog I love them this is why am going to say this I trust dog's more than people because you can tell a dog anything you like and they won't repeat it to anyone also they are loyal that's true.

3.30pm came home from walk feel nackerd and had a cup of tea then fell asleep. 5.30pm went to mass yes am a roman catholic and I believe in God and yes I do get slaged off by people saying am a god freak but it dosent bother me because at the end of the day we will meet our maker sooner or later. I am not afraid to die because I've made my peace with God

and my soul. You may think am mad but that's the way I've been all my life and if God take's you sooner he must want you for something.

7.15 picked me up from church. I said to her Farther ...ne is not well and he's takeing two weeks off to recover then we went for chink's the home. Watched TV until 9pm then took the dog out for her last walk for the night then came home had shower took my tablets then went to bed.

And so on until the last day's entry

Fri 9 Oct 09

Time: 9am

Woke up at the same has every morning took the dog for her walk had b'fast made and coffee made bed's wash dishes the women from the uni is coming to pick up the diary today and I hope she and the rest of the people can understand what am trying to say and what I mean to say (life is crap). I feel like am in a dream that wont go away. No a night maire that a night maire that doesnt stop and wakeing up and starts again over and over again.

Your's truely

.....

PS These are the thing I can't do anymore

1 drive a car

2c limb step or ladders

3 go and watch football at St James

5 drinking

6r ead a book because I can't remember what the book was about

7 watch a TV program and get into it because I lose the plot

8 can not hold topic of discussing for then 5 mins on any subject let alone remember it.

9 us a computer because the screen gives me headach

10 remmber to take my tablets because I have to be prompted by my wife or leave them out so I can remember to take them.

11 remmbering people I've known for year's and not knowing there names

12 also not knowing what my mam and dad looked like without a pic and what we did together

13 also cant remember my wedding day and who was there.

Appendix 16

Living on your own: isolation

Service users living on their own could be particularly isolated. They found themselves struggling between maintaining independence and becoming reliant upon friends and acquaintances. The difficulties of travelling beyond the home were evident, particularly for electric wheelchair/buggy users who, in Tyne and Wear, are banned from using the Metro transport system. This makes getting to hospital appointments difficult whichever hospital they are using, but particularly so in terms of getting to their local neuro-rehabilitation centre which is not in the city centre and is well-served by a Metro they cannot use. People with cognitive impairments that affect their orientation and memory also encountered transport difficulties that left them isolated in their homes, bored and frustrated.

People articulated the need for more contextually embedded services that recognised their aspirations for living. During a discussion between service users, SU38 articulated that a problem for her was that people came to her house to 'put right what has gone wrong' but she would prefer to pre-empt that stage and have help with doing it right in the first place. She would like someone she called 'an enabler'. She finds living amongst her 'chaos' frustrating but has to endure it until someone comes to sort her out. She sees the root of her difficulties as being that 'they [still] don't know how I live' and that they have 'not found the right path'.

SU:38 'I feel as though because I'm better than a lot of them [other service users] I've been pushed off and I've got a CPN nurse which, to a certain degree, is a waste of time and space because the problems I had at home are independent living...

I: So for you it would be important that somebody came and looked at you in a different way to see what you're...

SU:38 Yes. Well if somebody came and spent time with me at home, even though I am physically okay, I can't manage my home. The washing, the cleaning, the making the bed. I'm doing... I'm in that room, I'm in that room, I'm that room [referring to different rooms in her house]. If you went back to my place now, I haven't done the dishes because I didn't have the time this morning to get out. I've got to go home and it takes me all [my time to do it]... If somebody came in and helped me I would probably have it all done in 2 hours. But leave me on my own to do it...

SU:3 Do you not get any support from Social Services like that?

SU:38 Well it would cost me £27 a week for 2 hours....I haven't got that much money spare to pay somebody. And they don't do it on their own, it's called an enabler. I would do it with them. But it's still... It's still they don't know how I live. All they do is come in and help me put right what's gone wrong.' (SU38-F-FG)

Later in the focus group she goes on to say

'We've got abilities and capabilities. It's just finding the right path. I mean, I'm looking for... I don't just want to sit at home every day and think, "Well what am I going to do today?"'
SU38-F-FG

Appendix 17

Transition

Two strong themes run through the Carer's story of her partner's transfer from hospital to another institution; the 'invisibility' of X, someone who is not recognised as a person and X not being enabled to have his voice heard, either through being asked or having an advocate to represent him in the absence of his carer.

Chance events led to the Carer arriving earlier than planned and finding her partner 'ready' to be transferred.

'I think this was probably the most upsetting day for me. Because X was sitting... I'd left some clothes out for him to travel over in. Bearing in mind this was the first time he was going to be out of a hospital environment since the [date]. And he was sitting in these old green hospital pyjamas. Unshaven.... I went in and I thought, "My God." He looked like as if he didn't belong to anyone. Sitting in his chair – the bed was already stripped. Bags... Plastic bags around him. And I just said, "X have you not been shaved?" And he went, "No." So I said, "Right, come on. We'll have a quick shave." He shaved himself. I said to the male nurse, I said, "Look, X can't travel to Newcastle like this. Can you please just put him some clothes on?" "Oh, I didn't see them." I said, "Oh well, no problem." I said, "But, you know..." So we got him sorted out.

Considerable time had passed since X had been outside the hospital and he was very apprehensive, a situation aggravated by his condition. Recognising the apprehension of leaving a familiar environment the carer sought to ease his mind by following his taxi in her own car.

'We had a fantastic hospital taxi driver. He was great. And I just said, "Look, I haven't got a clue where we're going. Can you just please not go too fast?" And he said, "No problem." He carried all the bags down, put them in my car. And I remember X getting in this hospital taxi and he just looked absolutely lost. He didn't know where he was, he didn't know where he was going. So I went back over to him and I said, "X, I'm going to be following you in my car and I'll be there when you get there." And he was like, "Oh, right, right. Okay." The nurse travelled over with him. Got him there and the Ward Manager came out, and I could tell by her reaction as much to say, "This doesn't look right." Because X was literally hanging onto the door like this. He was scared. Absolutely petrified. The nurse couldn't transfer him from the car to the chair. It had to take the taxi driver and me to do it. When X sees me, I can... You know, he can calm down because I can reassure him. And I said, "X, come on. You need to just calm down, you're going to be fine." We got him in. Ward Manager just said, "Look, you know... Just stay an hour because the visiting is very strict" and by then it was like 2 in the afternoon. I said, "That's no problem." They got him a sandwich, they got him something to eat.'

This CFM went on to say how she had repeatedly articulated her disquiet about the where X was being resettled to and her disappointment, anger and frustration that, to her mind, X had

not had the opportunity to say what he really wanted, either by himself or through and advocate.

'I knew it wasn't the right place for X....We had 2 or 3 reviews at the hospital. I was asked to go, but I was never really asked what I wanted. You know, it was... They knew my position. They knew that X and I wanted to be together. That was obviously going to be the last part of this journey. I put... You know, I put my cards on the table to them all. I said, "You know, I want to care for X. I can take early retirement. I know this isn't going to be now, but I want this noted." And all the time I kept thinking..., "Why isn't somebody asking X what he wants?" But he was never asked what he wanted. Never. Or never invited to reviews or anything like that.' (C2-F-M)

Appendix 18

The use of care packs

When they work

...we've got a thing in... if SU13 goes into hospital, it's like a datasheet if you will, which hopefully they use. One doctor last year – SU13 was in hospital a few times last year – through the admission, we handed it to her – 'cos you know how busy they are – and she comes back about half an hour, an hour later and she said "that was extremely useful, thank you very much", which I thought was great. I thought, you know, we're not wasting our time here. (C3-SU13-M-F-Theme verification)

..and when they don't

i) A carer's experience

You know, she [another practitioner] saw me once coming out of a review meeting ... and she knew. She just looked at my face and she said, "We'll forget this. You sit down and talk to me." And I remember having X's file with all of his, you know, samples of all his fantastic improvement that he'd done and she said, "this is wonderful." And she took her time reading it... I said, "You know, I had that in the review and nobody wanted to look at it. Not one person wanted to look at it." I just found it very cold and very, just... Oh God, I think they thought I was a bit mad, to be honest, half the time, right? "Oh, it's her again," you know. But I've had to be X's voice. I've had to be, for the last year. (C2-F-M)

ii) A service user's experience

On my recent trip to hospital I offered it [care pack] to the paramedics and they refused it. I took it to the hospital and every question they asked me I kept saying it's in my care pack and nobody would even open the care pack. My list of drugs was in there, I had to search around in my handbag in the emergency ward to find that. Everything was in there and when I was sent out, I was sent out at night in my pyjamas in the cold to an empty house, which they knew, I had no food, no care, nothing and had they contacted the people in the care pack that would have all been organised.

I: Yes. And when you were offering this care pack to the staff in the hospital you were there because you were unwell.

P: Yes, I was an emergency.

I: Yes.

P: The whole point is because when you are an emergency you can't think very well or..... and that would have informed my GP, district nurse, everybody, where I was, what I needed, and they wouldn't even pick it up.

I: So what's the GP practice calling this document..?

P: A "Care Package".

I: Care Package. And they [the GPs] see that as part of their study into looking at patient involvement.

P: Yeah, they're doing a 2 year study into COPD.

I: Right.

P: And treatment and to make sure it does, it's inclusion, involvement and everything.

I: Right, right, that's good, and you were taking your part in that by making sure everyone

.....

P: Yes, I grabbed it beforebecause that's what they said, if you're taken into hospital give them this then they've got all the information they need and it will make it easier for everybody.....So I took it all the way there and brought it all the way back still unopened.

(SU9-F-I)

Appendix 19

Accessible and included: Accessible and excluded

i) A Shopping Centre

I like shopping, as most women do. Men as well, I don't want to, you know, generalise. But basically I generally... In terms of access I find it very easy to navigate the ...Centre because my sense of direction is not the best. And I know my way around because I go there quite frequently. ... And I can just get my way around the shops in terms of the space that, you know... And I don't find it too... I'm not bothered by or inhibited by, you know, overcrowding or people being around me. I'm not claustrophobic or anything. I don't have a fear of open spaces so I quite like the fact that I can just have a free roam of the, you know, the ... Centre and get some speed up on my chair. And just knock people out, really, if they get in my way. So, and like you say, in terms of the... It's just something that everybody does and I feel involved – even when you walk in, just, in the mall. And you see people around you just doing shopping, carrying bags – at least I hang them off the back of my chair and. I'm still participating in activity. Because I'm still shopping. And even though the shops aren't that accessible themselves. Some of the more boutique-ey type ones. You know, because you can't things off the rails. It takes you twice as long to try them on in the changing rooms. You can't swing a cat in some of them. But at least you can go, take the things home. You can ask for assistance. And usually, by and large, it's given to you. So you feel very much included and a valued customer because they obviously want your business or will do what they can to help you. I find. I haven't really had a negative experience when I've been shopping. And it just lifts your spirits, I think, when you come home with bags. You feel a lot better. (SU3 - F - F: and see DVD)

ii) A church

when the church was refurbished I helped them do it, there's bits of this floor that I actually got down with a power screwdriver, screwed the screws in so I feel very proud of the floor and to be part of it but when they got moveable chairs I was delighted because it meant that I didn't have to sit where I was put or parked and that I could choose where I wanted to sit. The other thing is that I didn't have to be stuck on the end of a line of chairs, that we could move the chairs out and I could we could make space and I then didn't either have to get out of my wheelchair if I didn't want to, to sit somewhere, I could stay where I was comfortable and I am comfortable in my wheelchair. So now they just space is made for me and that helps me to feel that I am part of what's going on and that I'm not just a tag on

or I don't stick out or I don't have to be walked around or treated like a roundabout but I can be part of of whatever gathering it is, whether it's in that particular picture is a church but I love it when I go somewhere and we can move the chairs out the way so I I can move into a space rather than making me tag on. (SU32 - F-P)

iii) A concert hall

P: it's lovely to go to ... because it's got I just love the whole thing of it ...

I: So you've got a picture [photograph she had taken] of some tickets.

P: ...Picture of some tickets, and I mean I don't expect the whole thing of concessions but when concessions come then it it just adds to it, you just think yeah they are happy for me to be there and whoever goes with me they get in for nothing and so we split the cost of the ticket and so that's lovely. Whenever I've rung up and asked for a ticket they have always, always given me a box which is lovely.

I: The Royal Box? [laughter]

P: I don't know what the equivalent of the [venue's] Royal Box is but it feels like Royalty in one sense because you're in there and the space is already there. There's no fuss or carry on, the 'oh well you know lets remove a thing' and the choice is given if you want to stay in your wheelchair, or if you want to sit in the seat. And there's no hassle about where you're going to be put and I know they've got places where the seats are removable, I think most of the seats in the [venue] are removable and that matters. I mean I wouldn't expect to be in the middle of a row in but it's nice to have the opportunity to go somewhere and again be part of... Erm so again it's not just this this box where all the wheelchair users go or all the disabled people go, I go with whoever I've got the tickets with and we're all sitting together.

I: Why is that choice important to you?

P: Well I think it just helps me to maintain the regardless of what's happened physically, I'm still me, with choice and to still be afforded choice is important I think, erm to say well yeah I would like to sit there or I would like to go there and if there are barriers in the way then ok lets work together about moving them.

iv) On the streets

...in Newcastle, give them some credit the council have actually worked quite hard to have actually inclinedkerbs. There are quite a few places where they exist but where they don't it's a real pain. Cos obviously, from my point of view, if I'm going along somewhere I've maybe travelled quite a long way let's sayhalf a mile, let's say, go on the pavement half a mile along. Now I arrive in this area and there is no kerb drop! So I'm stuck. So I have to go back all the way I've come' (SU19-F-I)

v) A large entertainments venue

P: I've only been to the [venue] twice and the first time I was going to get corralled where all the other wheelchair users go and I hated that I

I: What is it about that that you particularly hate?

P: I think because you're separated from the people you go with so you can't you can't sit with your friends but it's it's likeit reminds me the long procession at Lourdes where all the sick and the disabled are just lumped together and put in one place and then you know the the great others can look on us with pity and think oh dear me you know that could be me and and I just don't want to be put in that category really and I mean that might just be my wrong perception but sometimes that's how it feels and I think well if I've if I've gone to a venue I'm going to a venue to, you know, to be part of a club, if I had wanted to go with a local disabled club then I would have gone but I've gone with my friends and I want to sit with them and be with them. So I think the next time that I went erm, I just I just refused to be 'put'... the first time I went and the guys were trying to put me in the in the safe place where all the other wheelchair users went and I refused to go. It felt as if I was just hitting a brick wall with them because it was their job to ensure that as a disabled person, and a wheelchair user, I was safe ...where they had deigned me to be which was in this I mean there was bars and everything around it ... as far as they were concerned they were doing their job and they couldn't understand why a wheelchair user didn't want to be put in there because ... they were providing a safe place for me to be put. And it was ...I had a very, very difficult conversation with the guy who was doing the 'putting' but then I went to see one of the supervisors as I came out and asked why it had to be. And it's the same old nutmeg, it was the health and safety thing. Because they then knew where all the disabled people were should there be an event or a fire, or we internally combust, then they knew where everybody was and they could get us all out safely and so you just think how ... how do you fight against that level of ... of health and safety bureaucracy that hasn't got any flexibility about it to say well, you know, let them take their chances because you would take your chance. But it's almost as if you're disenfranchised over taking a risk or a chance anymore if you're going to a public venue, you've got to be 'put', which is a bit of a shame. (SU32 - F-P)

Appendix 20

Dissemination

Publications:

- Cook, T (2011) Authentic Voice: The Role of Methodology and Method in Transformational Research In Warren Kidd and Gerry Czerniawski (Eds) *The Student Voice Handbook* Emerald Press. ISBN- 978-1-78052-040-7
- Hutchinson, C., Bell, E., Bond, M., Carter, L., Mitchell, P., Moore, P. & White, A. (2010) Towards inclusive living: a record of a research journey. http://www.invo.org.uk/pdfs/Newsletter_finalwinter10.pdf (accessed 5.09.11)

Presentations:

- Cook, T. and Bond, M. (2011) 'Towards Inclusive Practice: How we know what we know' DeNDRON Conference. Durham, June 2011
- Atkin, H. and Hutchinson, C. (2011). 'Inclusion in neuro-rehabilitation: a workshop on what it means for practice and research.' Rehabilitation and Participation in Long term Conditions Conference: Dundee, May 2011.
- Cook T (2010) 'Facilitated Collaborative Action Research: challenging structural inequality in approaches to knowing Invited seminar presentation. 16th Congress on Poverty and Health', Berlin December 2010
- Cook, T (2010) 'Collaborative Action Research: putting theories into practice'. Invited masterclass at Wissenschaftszentrum für Sozialforschung (Social Science Research Centre) Berlin. December 2010
- Cook, T and Jones, A (2010) 'Notions of Involvement in North East Research Networks. As part of an Invited Presentation for Centre for Translational Research in Public Health Quarterly Research Meeting Newcastle upon Tyne January 2010
- Cook, T. and Atkin, H. (2010) 'Research in Practice: Embedding the Learning' National Long Term Conditions Support Team. Manchester, December, 2010
- Cook, T., Atkin, H., Hutchinson, C. and Moore, P. (2010). 'Inclusive ways of working in research: some participatory approaches. INVOLVE Conference. Birmingham, November 2010
- Cook, T. and Atkin, H. (2010) 'Audible voice - credible research: issues and methodological challenges.' BEACON workshop series, Newcastle University. Newcastle upon Tyne, April 2010
- Cook, T., Atkin, H. and Colleagues (2009). 'Towards Inclusive Living: Research for Everyone'. Northumbria University School of Health Community and Education Research Conference. Newcastle upon Tyne, July 2009
- Cook, T (2009) 'Audible voices and credible research: issues and methodological challenges' invited seminar presentation for the British Educational Research Association Special Interest Group, run jointly by Southampton, Newcastle and Aberdeen Universities, on Issues of Participation and Inclusion.
- Cook, T., Atkin, H. and Colleagues (2009). 'Towards Inclusive Living: Research for Everyone'. Research & Clinical Effectiveness Study Day Northumberland Tyne & Wear NHS Trust. Newcastle upon Tyne, April 2009
- Cook, T., Atkin, H. and Colleagues (2009). 'Towards Inclusive Living: Research for Everyone'. British Society of Rehabilitation Medicine Regional CPD day. York March 4th 2009

Poster Displays:

- Cook, T., Atkin, H. and Colleagues (2010). 'Towards Inclusive Living: Research for Everyone'. Northumberland Tyne and Wear NHS Trust Involving People Conference. Newcastle upon Tyne. November 2010
- Atkin, H. and Cook, T. (2010) 'Co-creating a research proposal'. Occupational Therapy Annual Conference. Brighton, June 2010
- Hodgson, A. and Williams, K. (2010) Doing, being and becoming as researchers. Occupational Therapy Annual Conference. Brighton, June 2010.
- Cook, T., Atkin, H. and Colleagues (2009). 'Towards Inclusive Living: Research for Everyone'. *Knowledge Translation in Public Health and Primary Care: Linking Patients, Practice and Research Conference*. Newcastle upon Tyne, April 2008
- Cook, T., Atkin, H. and Colleagues (2009). 'Towards Inclusive Living: Research for Everyone'. Multiple Sclerosis Life Conference. The Sage Gateshead. July 2009
- Atkin, H, Bond, M, Cook, T, Hutchinson, C, Piggott, M and Williams, K (2009) 'Audible voice - credible research: issues and methodological challenges for inclusive research' School of Health, Community and Education Research Conference, Northumbria University, July 2009.

Appendix 21

Example of Population Mix in the region service by Walkergate Park

The North East has a relatively small black and ethnic minority population compared to the rest of the country.

Ethnic Minorities in the North East of England

Data

Local Authority (Upper Tier)	Total White	Total Black	Total Asian	Total Mixed	Total Chinese or Other	Total Ethnic Minorities	Total
Darlington	96100	400	1400	700	600	3100	99300
Durham	489100	1500	4000	2800	3300	11600	500700
Gateshead	183600	1200	2700	1400	1500	6800	190500
Hartlepool	88900	200	1100	600	400	2300	91200
Middlesbrough	126900	1400	7400	1600	1100	11500	138400
Newcastle upon Tyne	243000	3300	14800	3500	5900	27500	270400
North Tyneside	188000	900	2800	1700	1700	7100	195100
Northumberland	303400	800	2500	1600	1400	6300	309900
Redcar & Cleveland	135600	700	1900	1000	500	4100	139500
South Tyneside	143500	600	5000	1200	600	7400	151000
Stockton-on-Tees	180900	1000	4500	1700	1200	8400	189100
Sunderland	270800	1400	4600	1800	2100	9900	280600

Notes: Source: ONS. Year: Mid 2006 Estimate Experimental. Data rounded to the nearest 100. Totals may not add up due to rounding. More information on these data and published data sets can be found at: <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=14238>