Northumbria Research Link

Northumbria Research Link

Investigating service user and staff assumptions about neurological rehabilitation practice, their influence on inclusion and examining conditions for change

H M Atkin

PhD

October 2017

Investigating service user and staff assumptions about neurological rehabilitation practice, their influence on inclusion and examining conditions for change

Helen Maureen Atkin

A thesis submitted in partial fulfilment of the requirements of the University of Northumbria University for the degree of Doctor of Philosophy

Research undertaken in the Faculty of Health and Life Science

October 2017

Abstract

Assumptions are our taken for granted interpretation of the world. They are identified as important in reasoning, sense making, behaviour and action. Anecdotal evidence from users of neurological rehabilitation services suggest that assumptions influence how they are perceived and related to, impacting on their experiences of inclusion. This study investigates the assumptions held by service users and staff about neurological rehabilitation, examines their influence on inclusion and explores the conditions influencing change in assumptions.

This doctoral study drew largely on data generated as part of a funded research project, which investigated perceptions of inclusion and inclusive practice in neurological rehabilitation. Both the funded research project and this study adopted a participatory action research approach, using photography, mapping, diaries, interviews and focus groups to generate data. Additional data was generated for this doctoral study through a workshop and reflective questionnaire which focussed specifically on assumptions. Data analysis and sense making used framework analysis and a thematic approach. Research participants and critical friends contributed to validation of findings.

The findings identified that assumptions do form the basis for interactions and practices that influence whether neurological rehabilitation is inclusive and/or effective. Addressing assumptions requires that specific attention and scrutiny are given to situations where taken for granted thought has been disrupted, therefore, creating opportunities for critical dialogue and new understanding to be developed. Importantly, when service users and staff work collaboratively to ask the question "how do we do this together" assumptions of role, knowledge and expertise can be challenged and inclusion facilitated.

The study recognises that addressing assumptions in practice requires a change in the way of working in neurological rehabilitation. A re-framing of practice is called for and a critical relational ontology proposed to replace the currently advocated person centred approach, with the acknowledgement that this is likely to radically challenge current principles and practices in neurological rehabilitation

Table of Contents

List of Figures

List of Tables

List of Appendices

Definition of terms

Terms viewed as having a specific definition relevant to this study are articulated as follows:

Critical friends

Critical friends include those people who engaged with me in this study by asking critical questions and enabling me to see through a different lens. Some critical friends were involved in specific processes of the study for example making sense of the data. Critical friends volunteered to journey with me, they included a study participant, a co-researcher and supervisors. At times, due to their engagement with my thinking and critical questioning approach, friends and family also came under the banner of being critical friends.

Inclusion

Inclusion is a complex notion; it is based on the positive valuing and celebration of difference and recognises the diversity of need including race, gender and disability (Swain, French and Cameron, 2003). These notions move beyond the concept of integration which reflects a "fitting in" to systems, norms and behaviours set up by non disabled people (Oliver, 1996, p.92).

Neurological long-term condition

Long-term neurological conditions form a diverse set of conditions which are the result of an injury or disease of the nervous system (Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, 2008). For the purposes of this study, they included 1) sudden onset conditions for example acquired brain injury, stroke and spinal cord injury; 2) acquired progressive conditions for example multiple sclerosis.

Neurological rehabilitation

Neurological rehabilitation is a process that aims to facilitate a person's health and well being alongside their integration back into the community and participation in society following a neurological impairment.

Practitioners

Practitioners are those staff who have face to face clinical contact with service users. It includes people who have received specific training for their role, many of whom are regulated by the Health and Care Professions Council (HCPC). They include for example, doctors, nurses, physiotherapists, occupational therapists, counsellors and psychologists. It also includes staff employed in the role of rehabilitation assistant, who do not have a specific professional training, but have received work based training, direction and supervision from practitioners governed by for example by the HCPC. Practitioners involved with this study were all employed by Walkergate Park Regional Neurological Rehabilitation Centre at the time of undertaking the study.

Service users

The terminology to describe people who use neurological rehabilitation services is contentious, and the terms patient, consumer or service user are often used interchangeably in practice settings. Service user is the term adopted by this study. Service users who specifically took part in this study are people with an acquired neurological long term condition who fulfilled the inclusion criteria and were associated with Walkergate Park Regional Neurological Rehabilitation Centre at the time the study took place.

Social model of disability

The social model of disability views society as disabling people. This includes environmental and attitudinal barriers to participation in society.

This is distinct from traditional perceptions of disability which view the individual as being disabled by their impairment of condition.

Staff

Staff encompass people who practice a profession, managers, those who have clinical roles that are non professional, for example therapy and nursing assistants and those people in administrative roles. Staff who took part in this study were all employed by Walkergate Park Regional Neurological Rehabilitation Centre at the time of undertaking the study

Acknowledgements

This thesis and the study it presents are the culmination of many years of work and there have been numerous influences upon my thinking and practice during that time. There are many people I would like to thank for their part in this journey.

Firstly, I would like to thank the service users and staff who worked with me and gave of their time, energy and experience. This study would not have happened without you.

I would also like to thank my critical friends Christine and Ruth who have grappled with my musings and interpretations of the findings of this study. Thank you for keeping my feet on the ground through the philosophical mire. To Lindsay Carter, (sadly deceased) who was an absent critical friend and yet continued to challenge and inspire me.

Special thanks go to my supervisors, Dr Tina Cook who has patiently undertaken this long journey with me, supporting and challenging me to think beyond what I thought were the limits of my understanding. Dr Dorothee Debuse, whose encouragement, practical support and German English has been invaluable. Thanks also to Dr Colin Chandler and Dr Alan Roulstone who offered advice in the early stages of this study.

Additionally, I would like to thank my colleagues past and present. Friends and family deserve special thanks for their understanding, support and encouragement. To my parents, (sadly deceased) who would have been delighted, proud and perhaps somewhat amazed at this thesis.

Finally, to Phillip; this journey would not have been possible without your love, encouragement, emotional and practical support. "Thank you" is not enough to express my gratitude for being there through the highs and lows of the past years. Thank you from the very depths of my heart.

Author's declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee / University Ethics Committee on 15th December 2008 and the NHS National Research Ethics Service on 10th April 2009.

I declare that the Word Count of this Thesis is 72,555 words

Name: Helen Maureen Atkin

Signature:

Date: 28.10.2017

Chapter 1: Introduction

1.1   Inspiration for this study

Imagine

Take a moment and place yourself in the position of this service user* who is recounting their experience following the delivery of a training session to health care staff:

> *"I was presenting at a training session for staff on service user involvement, I was using my own voice which people sometimes find difficult to understand. I was having difficulty making myself understood, staff started calling out from across the room, words and phrases that were their "best guess" at what I was saying. They were trying to be helpful; filling in what for them were 'missing blanks', their intention was to do good, but they were creating a story that wasn't mine. They were basing their interpretation on their own experience, making assumptions about what I was trying to say rather than waiting for me to get my words out or asking me if they didn't understand. They had colourful imaginations; it became like Chinese whispers and bore no resemblance to what I was communicating, I was feeling excluded from my own presentation. I put up my slide 'if you make assumptions about me or what I am trying to say, you will make an **ass** out of **u** and **me**'. The room quietened with the realisation of what they were doing, I waited, let it sink in, then spoke again."* [1]

I was also there, delivering the training in collaboration with this service user in my role as an Occupational Therapist and Service User Involvement Lead

---

* See Definition of terms on pages vi - viii
[1] This reflection has been co-created between the service user and myself and is used with permission

in neurological rehabilitation. This workshop and our subsequent discussions brought home to me the powerful nature of assumptions on staff thinking and behaviour, which, in turn, had a profound effect on someone else. It was disturbing to see the ease with which such misrepresentation, misunderstanding and labelling took place, and how readily that led to feelings of discrimination and being treated unfavourably. It was also disconcerting to see how staff in particular could be so well intentioned, and yet so quickly silence the service user's authentic voice. Whilst that was meant to be supportive, it rapidly became an oppressive act. This was not the only scenario that influenced my motivation to undertake this study, which investigates how assumptions influence experiences of inclusion, but it was highly influential in highlighting the harm that can so rapidly result from the apparently innocuous assumption of being helpful.

Over many years of practice, I had intuitively tried to facilitate a way of working in neurological rehabilitation that brought staff and service users' perspectives together, to review practice, develop ideas and generate solutions. I observed that there were occasions when assumptions and points of view shifted and changed as greater understanding of each other's perspectives developed. Whilst changes in assumptions did not always happen, their dialogue led to an increased awareness of the views of other people. For staff, this awareness led to a greater appreciation of the lived experiences of service users. For service users, it seemed to generate an understanding of the organisational and operational systems and protocols that staff had to deal with on a daily basis, thereby providing an insight into some of the constraints they faced in practice. These observations, developed over several years, became an increasingly important influence on my practice and I was curious to know more about the importance of assumptions and their role in developing changes in personal thinking and practice.

1.1.1 Research inspired by service users and staff

The opportunity to undertake research in this area was created in 2008 when the existing Regional Neurological Rehabilitation Centre in Newcastle upon Tyne service was moving from an old building at Hunters Moor to a purpose-built facility at Walkergate Park. In line with legislative guidelines which required service users to be involved in service development and the planning of new services (DH, 2008a), prior to the move, I initiated and facilitated a Listening Event, engaging with service users and carers to understand what was good about their experiences at the existing facility in order to build on this for the future. The intention was to generate a service user and carer driven "philosophy of working" for Walkergate Park. As part of the event service users and carers were asked what research questions were important to them to explore in the future. People who were at the event, identified that there was something important about how they were included in treatment and the impact this had on their everyday lives.

A small research group was established of people who were interested in developing this question. It included service users, carers, voluntary sector partners, staff, which included myself, and an academic from Northumbria University. The group met for a period of two years and during that time we worked together to develop a research proposal that reflected the ideas generated at the Listening Event. This research proposal received funding from the National Institute for Health Research (NIHR) Long Term Neurological Conditions Policy Research Programme. The aim of the research was to explore how people were included in their treatment and the impact inclusion had on the outcomes of treatment. It took a participatory action research approach and used mixed methods to generate data. The members of this research group were supported and trained to become the researchers on the project.

The researchers held different assumptions about disability, charity and the role of carers, and what I found fascinating was how these assumptions influenced experiences and perceptions of inclusion. Some people viewed it

as something one does for someone else, in other words inclusion by invitation; others perceived it as a right that is not dependent on the benevolence of others. Importantly, I recognised that these conversations provided a space for the researchers' assumptions to be articulated, challenged and considered. It was these conversations with the researchers that began to crystallise my ideas about this study, and drew me towards investigating assumptions and the influence they have on experiences of inclusion. This funded project was completed in May 2010, the Executive summary can be found in Appendix 1 and the full report can be found at http://awam.org.uk/ltnc/download_files/final%20reports/Oct_11/Final_Report _Inclusive_Living.pdf.

1.2   Aims and objectives

The intention of this study is, therefore, to illuminate the assumptions held by service users and staff in neurological rehabilitation and investigate how these assumptions influence experiences of inclusion. It will additionally explore the conditions that influence changes in these assumptions. This study therefore asks the question:

> *'What are the assumptions held by staff and service users that influence experiences of inclusion in neurological rehabilitation practice and what are the conditions that lead to a change in those assumptions?'*

The aims and objectives are:

Aim: To investigate and unpack assumptions held by service users and staff about neurological rehabilitation practice and examine their influence on inclusion.

Objectives:

- Identify the nature of assumptions held by service users and staff

- Illuminate assumptions participants hold about practice
- Identify the influence those assumptions have on experiences of inclusion
- Explore the conditions that lead to changes in assumptions: What enables these changes to happen?
- Identify the implications for practice of the study's findings

This study uses a participatory paradigm which posits that "participation on the part of those whose lives or work is the subject of the study fundamentally affects all aspects of the research" (International Collaboration for Participatory Health Research (ICPHR), 2013, p.5) and provides the guiding principles for this study. In accordance with this, service users and staff worked together to design the study, generate data and comment on the early findings. Symbolic interactionism in line with Blumer (1969) provides the underpinning theoretical framework. Its emphasis on the interpretation and the construction of meaning through interaction guided the development and the implementation of the methodology.

1.3   Context for this study

This study was based at Walkergate Park Regional Neurological Rehabilitation Centre, a National Health Services (NHS) tertiary specialist facility in Newcastle upon Tyne in the North East of England providing neurological rehabilitation for service users with the highest level of complexity. This includes services to people who are minimally conscious and those who have complex physical, cognitive and communication needs, for example following traumatic brain injury, stroke, spinal cord injury or people living with a degenerative neurological condition such as multiple sclerosis. There are few such centres across England and rehabilitation is commissioned by the NHS to provide services to populations of between 1-5 million (British Society of Rehabilitation Medicine (BSRM), 2015). The catchment area of this service is, therefore, far reaching, serving people from rural Northumberland, County Durham, and Teesside, as well as people who live in the Tyne and Wear localities. In patient, out-patient and community

based services are provided from the Centre and whilst this facility also provides services to service users with mental health needs, the service users who took part in this study primarily used the rehabilitation services.

The decision to disclose the name of this facility is a deliberate one. The National Institute for Health Research Project funded project undertaken at the same time used the same data, referred directly to the name of the Centre and is publicly available (Cook et al. 2011). As this study will refer to the funded project, cross referencing is possible and, therefore, maintaining the Centre's anonymity was not felt to be feasible. Naming the Centre also locates both myself as the researcher, the participants and provides a clear context for this study.

1.4 Context of neurological rehabilitation

1.4.1 Definition and principles of neurological rehabilitation

Neurological rehabilitation is part of a family of rehabilitation practices which has a specific focus on people who experience and live with a condition that affects their nervous system, hence the term neurological. Whilst rehabilitation across a wide range of conditions has been practiced since the end of the Second World War, it still remains poorly defined (Meyer et al. 2011). Under the United Nations Convention of the Rights of People with Disabilities Article 26, rehabilitation is viewed as a right that aims to:

> *'enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life'* (United Nations, 2007, p.19)

This definition suggests that the outcomes of rehabilitation relate to maximising ability in order to achieving personal independence, inclusion and participation in life. However, for people with a degenerative condition, for example multiple sclerosis, such independence may no longer be possible. Wade, (2009), therefore, proposed an alternative definition

reflecting the issue of wellbeing that had not previously been captured. He suggests that the process of rehabilitation aims to:

> *'optimize a person's participation in society and sense of wellbeing'* *(p165).*

Both definitions highlight the importance of the rehabilitation process to positively support a person's inclusion and participation in the community. However, the language used in these definitions seems to suggest that it is a process whereby rehabilitation is done *to* service users *by* others. These definitions do not articulate the part the service user plays in the process, they merely seem to reinforce that it is the staff member who does the enabling and optimising.

Within neurological rehabilitation specifically, the core principles for practice are commonly recognised by professionals and academics as being:

- Client centred approach (Barnes, 2003a; Cott, 2004)
- Educational: enabling the development of coping strategies for life challenges (Wade and deJong, 2000; Barnes, 2003a)
- Problem solving orientated: focussed on the persons disability (Wade and deJong, 2000)
- Goal focussed (Wade and deJong, 2000; Barnes, 2003a; Sugavanam et al. 2013)

Of particular importance to this study is the additional principle outlined by Barnes (2003a) who suggests that the process of rehabilitation is 'done by' the service user with the support of professionals rather than being 'done to' by professionals (p.iv3). This principle recognises the requirement not only for service users to be active in their rehabilitation but challenges the traditional assumptions of professionals that they provide intervention *to* people, thus directing the rehabilitation process. It is a stance that challenges the wording of the definitions of rehabilitation as outlined by Wade (2009) and the United Nations (2007).

Questions have been raised as to the use of the terms client centred or person centred, indeed they are often used synonymously. From a disability perspective, Davis (2004) argues that the term client is professionally crafted to denote choice, however, in reality little choice exists for disabled people who are assigned professionals and expected to fit into existing services. In contrast, professionals view it as an ideology, a way of relating to service users that promotes autonomy and choice (Law, Baptiste and Mills, 1995) rather than takes it away. The use of the term person centred in rehabilitation is equally questioned; there appears to be is no consensus relating to its meaning and use in rehabilitation. Leplege et al. (2007), therefore suggest that rather than using the term person centred, rehabilitation practitioners would be better placed focussing on its key features. These include for example, respect for the person, addressing the persons difficulties and acknowledge their expertise in living with their condition. Indeed it would seem that these core concepts of all 'centred practices' remain the same (Hughes Bamford and May, 2008).

Increasingly, these principles and concepts that underpin rehabilitation practice are no longer taken for granted but are being critically examined using critical and postmodern theory (Hammell, 2006, 2011; Nichols, Gibson and Fadyl, 2015). The specific focus of this study on assumptions is in line with McPherson, Gibson and Leplege (2015), who suggest that whilst there are many different interpretations of rehabilitation, what is important is that taken for granted issues are continually questioned by practitioners and attention is paid to "what really matters and how to bring about change" (p.5).

1.4.2 National policy and neurological rehabilitation

Specific to the context of this study, the National Service Framework (NSF) for Long Term Conditions (DH, 2005a) has been the only English NHS policy driver that has been specifically developed for neurological long-term conditions in recent years. It was produced in recognition of the need to improve the lives of people who lived with such long-term conditions by:

- "giving people choice, through services planned and delivered around their individual needs;
- supporting people to live independently and play their full part in society;
- co-ordinating partnership working between health and social services and other local agencies" (DH, 2005a, p.1)

The framework presents 11 quality requirements, based on available evidence and service user experience that highlight best practice. In relation to neurological rehabilitation, they specifically identify the need for it to be person centred, based on need and goal orientated. It is suggested that goals are to aim for normality, increasing functional performance, independence and an improved quality of life. These quality requirements mirror the broad principles of neurological rehabilitation, but in so doing, it could be argued that they also echo the rhetoric of service users being the recipients of care and treatment that are determined by professionals.

Despite the NSF being widely welcomed at the time, it is argued by practitioners that its impact has been limited (House of Commons Committee of Public Accounts, 2012). It is a policy that was released just before a general election in 2010 and, disappointingly, was never fully implemented. Indeed the National Audit Office are still highlighting that promises to deliver personalised care planning to everyone with a long term neurological condition by 2015 are yet to be realised. The report indicates that only 11% of people are known to have received a written care plan (National Audit Office (NAO), 2015). Practitioners also argue that a lack of investment, clinical leadership and a lack of engagement with both service users and staff to influence the standards and commissioning of services, have all acted as constraints to moving practice forward compared to the implementation of the National Service Framework's for other disease groups (House of Commons Committee of Public Accounts, 2012).

1.4.3 Inclusion in neurological rehabilitation

Inclusion is recognised as important within health care, particularly in learning disability (DH, 2001, 2009) and mental health (DH, 2007a). However, it receives little mention in the NSF for neurological long-term conditions (DH, 2005a). Its value to staff and service users in neurological rehabilitation has also only recently been clearly articulated (Cook et al., 2011). Up until this point, attention had focussed primarily on the prevention of social exclusion through person centred planning, goal setting and working in partnership, for example (DH, 2005a). Cook et al.'s (2011) study presents inclusion as a positive concept that requires active work from all parties in order for it to be embedded in practice. The authors concluded that at the heart of inclusion is a "communicative space" (p.16) ensuring that not only is everyone's voice heard, but that through open and honest conversations between service users and staff, practice becomes more effective and efficient. This work has been important in bringing the concept of inclusion into the consciousness of service users and staff in neurological rehabilitation. However, this research did not explore the important issue of how assumptions influence people's experiences and feelings of inclusion. This clear gap in knowledge affecting both neurological rehabilitation practice and research is the focus of this study.

1.5   Professional and personal background

1.5.1 Professional journey

The label of Occupational Therapist might typically typecast me as a white woman, weaving baskets, facilitating people to dress independently and delivering bath boards and raised toilet seats to disabled people in the community. I have done all these things and each has their value, yet my professional journey has been so much more than this. I have developed and grown within my profession and yet also pushed the boundaries of its traditions, exploring new roles and identities. In line with Lloyd and Rose (2008) I do not see my professional or personal identity as something that is fixed, but rather as something that that holds the possibility for personal

growth and self discovery, including the very process of undertaking this thesis. It is particularly through the commitment of thought and experience into the written word that I have grown in awareness of how my own assumptions have influenced my thinking, action and interaction with others. This next section outlines how my professional and research practice have coalesced with my personal life experiences leading to the development of this study.

My career as a practicing clinical occupational therapist has spanned 27 years, of which 19 years were in the field of neurological rehabilitation. It is a career that has followed the development of neurological rehabilitation as a clinical speciality, from the inception of a specialist regional centre in the early 1990's, until I left clinical work in 2008. From the outset of my professional life, I was clear that being employed in a medically orientated acute hospital setting was not my preferred option. Such an emphasis on rapid discharge appeared to allow little room for working with people holistically in the context of their lives. So often, these more medically orientated environments support the mere fixing of body parts, a paradigm of working, that for occupational therapists, reflects a structuralist paradigm (Hooper and Wood, 2002). I believed then and still do now in the pragmatic paradigm of people as human beings who are action orientated, "doing" with the mind as well as the body (Ikiugu and Schultz, 2006) engaging in tasks and activities that are meaningful in the context of their lives. The potential of occupation to transform lives is a belief that is central to occupational therapy (Kielhofner, 1997) and one that I wholeheartedly subscribe to.

I am not alone in my discomfort between these two paradigms which Hooper and Wood (2002) discuss as stucturalist- pragmatist tensions, it is a debate which has its roots in the history of the profession and one which occupational therapists are continually called upon to question (Gustafsson, Molineux and Bennett, 2015). It is a tension that was instrumental in shaping my choice to work in the field of neurological rehabilitation, where I believed I could practice within a holistic pragmatic paradigm. Continuing to question

my paradigmatic position and approaches to practice has informed not only my choices as a therapist, but also latterly as a researcher.

In the early 1980's I worked in the charitable sector at a neurological centre in London and also for Social Services in the community. I viewed myself as providing important "help" to people, supporting them to engage in occupation. However, over time as I engaged with people and their lives, I was exposed to the stigma and social injustices that many disabled people experience. Judgemental views on the sexuality of disabled people, the fear attached to the epidemic of HIV and AIDS, what it means to live on the poverty line due to benefit cuts, exposed me to the rawness of disabled people's lives. This challenged my idealistic view of occupational therapy being the answer to everything and opened my eyes to the reality of the challenges of life and living for many people. I began to pay attention to engaging with people where they were, rather than imposing my ideas of what occupational therapy "help" looked like and my belief that I could "remedy need" (McKnight, 1977, p.82). Enabling people to engage in occupation by working *with* people in their life context started to emerge as the focus of my practice, although the importance of this still took some time for me to fully recognise.

My 13 years of managing and leading a neurological rehabilitation occupational therapy service in a specialist regional centre, provided the opportunity to work as part of a strong multidisciplinary team to develop ways of working in order to provide effective treatment to adults with a neurological impairment including for example, head injury, stroke, spinal injury and multiple sclerosis. It provided the opportunity to draw alongside service users and their families at times of distress and loss, but also in times of personal achievement as they moved forward towards home and participation in their community. I hold these times with great pride and affection, establishing the credibility of the Centre was a team effort and the way the services were organised was the focus of much national and international interest (Barnes, 2003a,b). Much of occupational therapy intervention is provided at the level

of a person's limitation in activity, for example, self care, supporting participation in society and understanding environmental restrictions, as categorised by the International Classification of Functioning, Disability and Health (ICFDH) (WHO, 2001). Occupational therapy has much to offer service users who identify themselves as requiring advice and positive support in such areas, however, my personal discomfort lies in the professions broad embrace of such categorisation by the ICFDF. Through its use, service users themselves are categorised and risk becoming merely an object of assessment and intervention. The voice of the service user, their breadth of their life experience and what is meaningful to them can readily be lost. My commitment to ensuring the voice of the service user was heard both in treatment and in the development of the rehabilitation services as a whole led me to take a more political stance, creating spaces where service users could express their views about services without fear of retribution, build on their strengths and subsequently influence practice. These became spaces where, I hope service users felt acknowledged as people in their own right, as citizens with a voice and not merely as patients in receipt of care and treatment.

Service user involvement in service development and redesign became part of NHS policy from the late 1990's onwards (DH, 1999; 2006a; 2008a). It was a challenge to change culture that I couldn't ignore and became the Patient and Public Involvement Lead for the service alongside my continuing clinical and professional commitments. This in turn led to a secondment for a year to the National Centre for Involvement undertaking work with GP practice managers. Policy seemed to suggest that involvement was merely an "activity" that was undertaken by staff with service users (DH, 2008a), personally this did not reflect the passion I felt for ensuring that service users had a voice in their own care and the way that service were run. My stance was more in line with the definition of involvement outlined by INVOLVE (2017) which, whilst related to research, is also pertinent for health practice. It highlights the importance of "research [and practice] being carried out '**with**' or '**by**' [service users] rather than '**to**', '**about**' or '**for**' them" (INVOLVE,

2017). My passion for this approach to involving service users was not shared by all my colleagues and as with all evolutionary culture change, it took between 5-8 years to establish service user involvement in the mainstream of neurological rehabilitation organisational strategy and practice. It always baffled me that the values of client centred practice, which are enshrined in rehabilitation (DH, 2005a), stayed within the boundaries of the therapeutic relationship and at times didn't seem relevant to teams of practitioners, when thinking about the development of services. Whilst there were some important initiatives, on the whole, unless prompted, developing services remained the domain of practitioners, reflecting the assumption that practitioners are the experts and know best in relation to how services should be developed.

My own assumptions and practice as both a therapist and Service User Involvement Lead were significantly challenged through conversations with a disabled activist. I was exposed to disability theory first hand and presented with challenging conceptions of therapists as parasites. These were difficult conversations, but understanding this different perspective was pivotal in continuing to recognise the powerful position that I held as a professional when I make the assumption that I could enable someone else. That I might hold the power to allow or permit someone else to be "able" was quite abhorrent to her. However, without this critique, my assumption that my practice was right and was in accordance with professional thinking on enablement (Townsend and Polatajko, 2007), would have led me to continue to practice in the same way, oblivious to the perspectives of other paradigms of thought. Through being challenged, my awareness increased, not only of the power of my professional status and position, but also in relation to the powerful nature of practices that are accepted without question. Such a view mitigates that there might be another view point that can inform and transform a situation. Transforming practice by creating a space where service users and staff could share their different perspectives and assumptions could be challenged became central to my work. Working together with this critical friend we shared our leaning about collaborating in

14

practice with other occupational therapists (Atkin and Carter, 2008). We were an alliance that worked because of our shared passion to change practice to be more inclusive, our recognition of the value of our different perspectives and our willingness to engage with each other. She sadly took her own life; I have missed her sharp thinking, but her voice and inspiration lives through this study and continue to be influential through ensuring that the principles of inclusion and inclusive practice are embedded in both my practice and research.

1.5.2 Journey as researcher

Research within neurological rehabilitation services was predominantly quantitative, focussed on impairment and aimed at demonstrating the effectiveness of rehabilitation intervention. My engagement with this research paradigm felt problematic as it was about quantifying people rather than qualitatively exploring their experiences of rehabilitation and living with their long term neurological condition. My exposure to qualitative research came during my MSc project undertaken in 1998 which focussed on the clinical reasoning process staff used to predict outcomes in neurological rehabilitation. The link between this project and my PhD was not intentional, however, assumptions are inherent within the reasoning and thinking processes of therapists and are recognised as such by Mattingly and Fleming (1994, pp. 333-342). It was a link that remained unrecognised until I started to explore the literature informing this study and saw the connection, particularly in relation to the call for practitioners to be more critically reflexive about their thinking and reasoning in practice (Trede, 2012).

My desire to change practice through dialogue between staff and service users led me to embrace service improvement models and evaluation tools that supported a collaborative process. Experience Based Design (Bate and Robert, 2006), Appreciative Inquiry (Cooperrider, Whitney and Stavros, 2003) and participatory evaluation (Chambers, 2002) all guided my practice and chimed with an inclusive way of working, drawing staff and service users together to discuss their experience and discuss how practice could be

changed. Using these approaches reflected my political commitment to participation and change. This commitment to a participatory paradigm has continued and whilst undertaking and writing this thesis, additional projects have served to reinforce the importance of working *with* service users and/ or staff in research (Cook et al. 2011; Atkin, Brandon and Thomson, 2014; Thomas, Atkin and Thomson, 2015),

1.5.3 The view from the other side

My personal experiences as a user of cancer services and as supporter of my Mum who lived with the consequences of a high-level incomplete spinal injury from the age of 70 have had a profound influence on my journey towards and throughout this study. Personal experiences of health care can be a roller coaster, comprising any combinations of the good, the bad and the ugly. Two specific situations had a particular influence on my thinking and hence ultimately this study.

Treatment for cancer is never pretty, but it can be made more tolerable by being involved in treatment decisions and being treated as a human being. My own experience highlights the contrasting approaches between a doctor who was prepared to listen, answer my questions and respond in a timely way, with a doctor who gave little credence to my personal experience, dismissed my questions and responded to my symptoms in a technical fashion. My response to the latter professional was initially to acquiesce to his purely technical approach. However, despite being particularly unwell, I rapidly changed tack, questioning his approach and articulating the negative impact this was having. This was met with a brusque, unhelpful response; making the possibility of any further constructive communication even more remote. I considered making a complaint, but at the time didn't feel strong enough. At the heart of this disparity in expected approach, were our assumptions. We both held very different assumptions about the most appropriate approach to communication and the style of how treatment should be delivered. The outcome of this was a feeling of exclusion from having any say about my treatment. I could have complained or made a

fuss, but I wasn't in a place physically or mentally to take this matter forward. I just wanted to be respected, treated as a person and get better. This mismatch of assumptions led to an air of dissatisfaction, defensiveness and distrust, none of which were conducive to effective treatment. As I looked around the large waiting room, it was full of people who were, like me, undergoing gruelling and often very unpleasant treatment for cancer. At this time, when we were at our most vulnerable, understanding and respect were vital. The whole process of my radiotherapy treatment left me both frustrated and saddened and it became one of the main drivers towards wanting to highlight the importance of assumptions in influencing experiences of inclusion or exclusion and to change practice.

The way that people view their relationship to professionals has historically been one of deference. This is particularly noticeable in the older generation. My Mum acquired a spinal injury when she was 70 and as an older person, always made the assumption that "doctor knows best" and became flummoxed when asked what she wanted to happen. Despite support and facilitation, the assumption continued to manifest itself through the usual response "you just decide". I have been struck as to how difficult it must be for practitioners to work together with someone who is adamant that the professional has the expertise, that such a balance of power is not to be disturbed and theirs is the only decision that matters. Disagreement or even discussion is seen as "upsetting the applecart" and the perceived "natural order" of things must prevail at all costs. Such a stance means that the possibility of including people in their own treatment is very difficult when there is little recognition of the importance of their own voice and assumptions. Instead, they defer to their assumption that the dominance of professional expertise, status and power take precedence.

Such personal experiences increased my awareness of the important impact assumptions can have on how I relate to other people. Furthermore, I recognised the importance and the influence of assumptions on whether people felt included or excluded in interaction, their engagement in

intervention and ultimately their participation as citizens in the wider social sphere. I also recognised that we all hold assumptions. They are how we make sense of the world around us, without the need to consciously process the vast amounts of information we are faced with in our daily lives. They shape my own and other people's views of knowledge, whose knowledge is important and why. They influence how we *are* with each other, whether we view each other as an object to be categorised, measured and experimented upon, or as people who act to influence each other's lives and worlds. By investigating the influence of assumptions on others and raising awareness of assumptions in neurological rehabilitation practice, I hope that service users and practitioners will gain a better understanding as to how they influence experiences of inclusion. Ultimately, it is hoped that this may lead to changes in neurological rehabilitation practice.

1.5.4 Personal research paradigm

My preferred paradigm of research practice draws on my personal and professional experience and recognises that social reality is something that is constructed together. My way of knowing about the world is to connect with others, to see other perspectives and in understanding a different viewpoint, reconsider my own. It supports the creation of new connections and the generation of new ideas by working together. The enactment of this paradigm results in a creation of spaces where people can interact together, share their experiences and understand each other's perspectives through engaging in dialogue. It is a paradigm that is based on inclusivity, and the belief that everyone should have the opportunity to "do" and participate together, so benefiting the learning and understanding of everyone involved and ultimately change practice for the better.

My personal paradigm outlined above has influenced the generation of this study's research question and also my approach to conducting the research, as such social constructivism, the principles of participatory research and the pragmatism of doing and learning together are the foundations on which this

study has developed. Further exploration of the theoretical underpinning of my study will be outlined in my methodology chapter.

1.6   My position as a researcher in this study

Whilst I have clearly outlined in the previous sections above how my various life journeys have influenced the principles and values that underpin this study, further transparency is needed as to the evolution of my position as researcher in relation to the participants in the study. The literature suggests that such a commitment to transparency requires that I position myself as an "insider" or "outsider" in the study setting, thereby enabling my influence on the epistemology, methodology and ethics of the study to be clearly identified (Herr and Anderson, 2005, p. 29). On paper, this duality of position looks clear cut; however, in reality, it was much more complex. My history with Walkergate Park and longstanding relationship with so many of its staff meant that I seemed to straddle the boundaries that were artificially created by the notion of being "in" or "out". On paper I might be employed or not employed by Walkergate Park, but wherever I am formally positioned; my experience determined that I have knowledge about the staff, service users and the services that placed me in a very privileged position. The following sections unpacks the relevance of my positioning in relation to the conception and development of this study.

1.6.1 Insider within the organisation

At the outset of this study, I was employed as an NHS member of staff within the Regional Neurological Rehabilitation Centre where the study was based. I was an organisational "insider", sharing day-to-day experiences with fellow staff members, privy to strategic, operational and clinical information, influencing practice, particularly in relation to how the service user voice was heard (see Figure 1). This afforded me the opportunity to question established approaches to practice, and was a privileged position that I did not take lightly. This insider position within the organisation meant that I was well placed to collaborate with my colleagues and service users within the

Centre from the conception of the study. In addition, I was able to gain support with the logistics of the project, for example, accessing databases in order to implement the sampling strategy. Such goodwill may not have been possible as an outsider researcher, but as an insider I was able to generate enthusiasm, interest and support for the work.
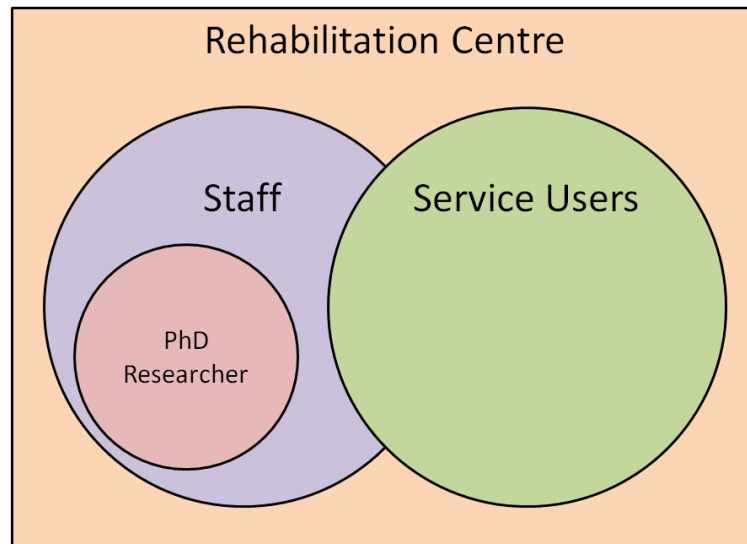
Figure 1. Researcher position at the outset of the study

Figure 1 illustrates my insider researcher position within the subset of "staff" in the context of the rehabilitation centre. The simplicity of the diagram belies the complexity of shifting identities, power relationships and their impact on knowledge production that have played out through the course of this study.

1.6.2 Insider within an externally funded research project

Whilst commonly insider / outsider researcher positions relate to the setting that is being researched, for this study it is also important to highlight my position in relation to the externally funded National Institute for Health Research previously referenced on page four. The funded research and this study took place at the same time, were built on the same participatory principles, utilised a similar methodology and data was generated at the same time for use by both the funded research and my study. My role was as a researcher on the funded project, at the same time as conducting my PhD, whilst also working in my NHS role. Holding these multiple "insider"

positions was problematic in the early days of developing this study, as I found it difficult to define the boundaries between the funded project and my PhD. I knew that being clear about my original contribution to knowledge, within a wider organisational research project was essential (Zuber-Skerritt and Perry, 2002), however, from this double "insider" position, the distinctive shape of this study took time to evolve. I felt as though I was contained by so many layers of complexity, like the smallest of the Russian dolls, I sat within an organisation, undertaking a study within a wider research project, wondering how I was going to break through these many layers and find a space that I could claim.

1.6.3 Outsider with insider experience

In the early stages of my PhD I made the decision to leave the NHS and work part time at Northumbria University, this shifted my position to being an outside researcher to the organisation, but yet, I still had insider knowledge. Whilst I was collaborating with my ex-colleagues, it could be argued there was a "reciprocal collaboration" (Herr and Anderson, 2005, p. 31) between myself as an "outsider", with "insider" colleagues and service users. This new position gave me insider privileges. I knew the systems, processes and challenges of the practice context and yet I was now distinctly apart from my ex-colleagues, with a very clear allegiance to research ethics of confidentiality. Staff participants stated that they were able to talk to me about things that they were unlikely to tell anyone else because they knew I understood the challenges of practice. However, there was also a confidence that as an "outsider", confidentiality would not be breached. These perceptions of my position as an "outsider" were seemingly influenced by my previous credibility within the service and that I still had current knowledge about the day to day working and politics of the services.

Not being able to continue conversations about the study and therefore generate improvement and change at an organisational level was perhaps the biggest impact of my change in position to that of "outsider". Whilst I had considered this prior to starting my PhD, I perhaps had not fully appreciated

its impact. My experience highlights that as an "outsider" engaged in participatory research; there is a need for strong collaboration with "insiders". Given the time this PhD has taken to complete, the challenge as an "outsider" is now to form new collaborations with "insiders" in order to explore the potential impact of this study beyond the transformation of personal assumptions that took place during the study, to the wider consciousness of neurological rehabilitation services.

I recognise that my own voice is usually "heard" as a facilitator of inclusive and participatory processes rather than necessarily contributing to the topic that is being discussed. Asking critical questions that act as an intervention in order to make assumptions explicit (Wadsworth, 2006, p. 329) does not always come naturally to me and it is perhaps because of this, that I proactively try and create spaces for people to become aware of their assumptions through dialogue. I believe that it is in hearing the perspectives of others and understanding the world through different viewpoints that assumptions can be disrupted and positive changes towards practice becoming more inclusive can occur. It is hoped that in presenting this study, the authentic and varied perspectives of participants are heard and the importance of actively working with assumptions in neurological rehabilitation practice is recognised. The following section will outline the structure of the thesis and provides a brief summary of the content of the chapters.

1.7   Outline of subsequent chapters

Chapter Two presents some of the relevant literature in the field, this conceptualises assumptions, articulates their role in influencing thought and action, outlines how they can be explicated and explores their potential for change. Neurological rehabilitation is then considered through the perspectives of both service users and staff, drawing out assumptions that inform the nature of their relationship and interactions. Finally, conceptualisations of inclusion are explored, identifying the particular importance for neurological rehabilitation of inclusion generated through

interaction and critical dialogue. The gap in knowledge that intersects assumptions, neurological rehabilitation and inclusion is clearly identified.

Chapter Three presents the methodology, in which I articulate my rationale for a participatory paradigm that is underpinned by social constructivism and supported by the theoretical framework of symbolic interactionism. I explain how this has informed the study design, methods, data generation and data analysis and how my study relates to a National Institute for Health Research funded project.

Chapter Four presents an evaluation of the quality of the methodology, reflecting on this study in relation to the values, principles and validity criteria of participatory research. I closely examine my own position as facilitator and reflect upon how my own assumptions have influenced the validity of the study.

Chapter Five presents the findings. Particular attention is paid to the complexity of assumptions and how the different characteristics of assumptions can influence experiences of inclusion. Assumptions held by service users and staff about neurological rehabilitation are examined and their power to influence relationships, experiences of inclusion and outcomes of neurological rehabilitation articulated. Finally, I will identify the conditions that facilitate a change in assumptions, highlighting the importance of disrupting taken for granted thought through critical dialogue and generating an emotional connection.

Chapter Six discusses the findings and argues that an inattention to assumptions can lead to ineffective practice. A re-conceptualisation of neurological rehabilitation practice is proposed which reflects a critical relational ontology, through which assumptions of service users and staff can be explored by engagement in critical dialogue. This discussion challenges some of the accepted principles upon which neurological rehabilitation practice has been built and instead presents an ontology that supports

service users and staff to question "how do we work together" in practice. The chapter concludes by outlining the next steps following the completion of the study and the strengths and limitations of the study.

Chapter Seven concludes the study, in which I identify my unique contribution to knowledge. This includes a new framework for critically reflecting on assumptions and insights into the conditions that lead to change in assumptions. Most importantly, from the standpoint of the critical relational ontology proposed in this study, I argue that this has the potential to positively disrupt the status quo in neurological rehabilitation, making practice more effective and inclusive. The implications of this study for practice, education and research are outlined and the chapter concludes with a short reflection on my personal journey undertaking this study.

Chapter 2: Literature Review

2.1 Introduction

This chapter will provide a critical review of the three key areas that are of relevance to this study, assumptions, neurological rehabilitation and inclusion. The review of assumptions provides a critique on what they are, why they are important and the different approaches that are used to illuminate them. Following this, I will review the perspectives that are held by both service users and staff about neurological rehabilitation, this reflects the context in which the study was undertaken. The final part of this critical review will focus on inclusion, with particular reference to some of the complexities that are inherent within the term and two approaches, the rights based approach and social model approach to inclusion, that are of particular relevance to this study. Having explored these areas, I will highlight the gap in knowledge that sits at the intersection between these three concepts in which my study is located (Figure).
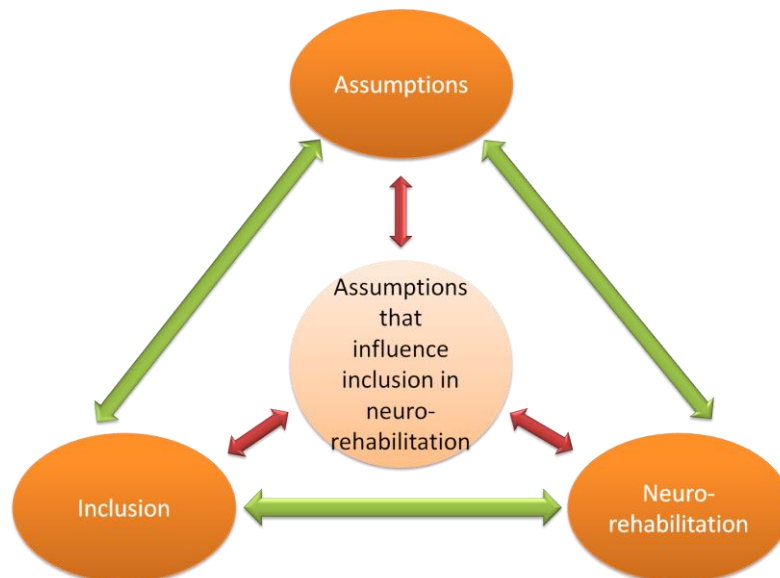
Figure 2. Literature review positioning the gap in current knowledge to the three key concepts of the study.

A critical review (Grant and Booth, 2009) has been adopted rather than a general literature review, due to the intention to focus the literature on the key authors whose work informs my research question. Using such an approach will help to develop an understanding of what is already known and then critique relevant authors contrasting ideas. The purpose is to offer a critical analysis of the literature rather than a mere description, draw together some common themes and highlight any gaps in knowledge (Jesson and Tracey, 2006). This focused approach requires me to be systematic in my approach to searching, but selective in the work that I will critique and synthesize.

This review draws from articles published in peer reviewed journals and reports written in English that relate to the topic of assumptions and their influence on inclusion within the context of neurological rehabilitation from the perspectives of service users and staff members. Searches were undertaken using the electronic databases at Northumbria University including AMED, Cinahl, ASSIA, Psycharticles, Web of Knowledge and Google Scholar. Searches were undertaken of abstracts using keywords (see Table 1), exclusion criteria included child or children and mental health. Combinations of terms relating to assumptions AND neurological rehabilitation AND inclusion were used, retrieving abstracts from papers between January 2000 and May 2017.

Table 1. Search strategy key words.

Assumptions	assumption*, perspective*, expectation*, belief*, model*, critical thinking
Neurological rehabilitation	neurological, rehabilitation, head injur* brain injur*, stroke, spinal injury, multiple sclerosis, service user*, professional*, staff
Inclusion	inclusion, inclusive practice, client centered, person centered, involvement, relationships, patient-professional

Hand searches of information provided by the Kings Fund, Department of Health policy, British Society of Rehabilitation Medicine, National Audit Office

reports and relevant texts from the data base searches were undertaken to ensure that the policy context and key texts written before the year 2000 were captured.

The search revealed a scarcity of empirical publications in relation to the concept of assumptions. Typically, literature on assumptions was presented in book chapters or opinion pieces and used critical and/or disability theory to critique existing perceptions of health care or educational practices. Searches were undertaken for empirical research underpinning the book chapters e.g. the work of Brookfield (1995). However, in the main, this proved impossible to locate through the wide ranging search strategies adopted in this study. This difficulty in locating empirical studies that directly investigate assumptions indicated a gap in knowledge that was ripe for research enquiry.

In making a judgement of the value of the literature to the focus of my study, I drew on the work of Jesson and Lacey (2006). These authors suggest that in a critical review, academic publications can be judged in relation to the author's reference to theory and the application of their work to further empirical research and wider theoretical discussion. This was particularly important in critiquing the literature on assumptions, as in the absence of empirical studies, this enabled ideas and concepts to be contrasted, current understanding of the issues outlined and gaps in knowledge identified.

Exploring concepts such as attitudes and beliefs was considered in the early stages of this literature review. The dictionary defines an attitude as "a settled way of thinking or feeling about something" (Oxford Dictionary, 2015) and a belief as "an acceptance that something exists and is true, especially one without proof" (Oxford Dictionary, 2015). These definitions suggested a sense of permanency and thinking being deeply engrained. On face value, the definition of assumptions was similar, that is "something that is certain to happen without proof" (Oxford Dictionary, 2014).   However, examples provided by the Oxford Dictionary (2014) of how assumptions are used in

day to day life, for example "every now and again you read a book that shatters assumptions you have held for a very long time" indicated that instead, assumptions are open to question and reconsideration. It was this potential for change in thinking that I found particularly interesting and this provided the grounds for beginning my quest for a deeper understanding of assumptions. Therefore, further investigation of the concepts of attitudes and beliefs was not pursued in order to ensure a clear and tight focus on assumptions.   Making the conceptual distinction between these three concepts has the potential to be valuable in future studies in order to promote greater conceptual clarity.

Due to the participatory nature of my research, I wanted to keep an open mind on the focus and nature of the literature, therefore whilst a broad overview of the literature was undertaken at the outset of the research; this critical review was embarked upon following the completion of data analysis and the Findings Chapter. This approach made space for the emergent nature of knowledge and is relevant to the participatory action research nature of this project (Green, 1999). Engagement with the literature therefore has not been a 'one off' event, but there has been a continual process of seeking to understand who has contributed to the body of work in which I am seeking to locate my research, up until the time of submitting my thesis.

2.2   Defining and contextualising assumptions

Several authors have explored assumptions, describing them in a number of different ways in the literature dependent upon their particular standpoint or genre. For example, they are referred to as mental models in organisational practice (Senge, 1990) and schema in applied neuroscience (McBean and van Wijck, 2013). In research, Creswell, (2012) adopts the concept of worldview, that is set of philosophical beliefs and assumptions that guide practice, the same concept is used in other genres including medical education (Tilburt and Geller, 2007). The breadth of different interpretation across genres and disciplines makes identifying literature pertaining to

assumptions quite a challenge. However, other authors, for example Mezirow, (1990), Paul, (1993), Paul and Elder, (2006) and Brookfield, (1990, 2009) explore the role of assumptions in critical thinking and critical reflection. With particular attention to how this influences learning and can change thinking in adults. This connection with my research project informed the literature selected for this section of this critical literature review.

2.2.1 What are assumptions?

Assumptions are so fundamental to how we think and act and interact that we seldom think about them consciously (Berman, 2001). In the academic literature, their influence on how we frame situations and make claims about the validity and accuracy of our thinking is viewed as warranting exposure and exploration (Brookfield, 1992; 2013; Fook, White and Gardner, 2006; Hammell, 2006; 2009). The way assumptions are thought about in the literature varies, depending on the particular focus of the author. Brookfield (1992) suggests that there are three ways to think about assumptions. Firstly, as taken for granted beliefs, secondly, as rules of thumb that guide action and thirdly, as common sense beliefs and conventional wisdom. He states they are:

> "the taken for granted beliefs about the world and our place within it that seem so obvious to us as not to need stating explicitly" (Brookfield, 1995, p.2).

This taken for granted world of assumptions is one of the key characteristics that are recognised by academics. Ennis (1982) in his seminal text was one of the first to devote attention to the implicit nature of assumptions, identifying their importance as the taken for granted basis for developing an argument. Indeed this is also reflected in the Oxford Dictionary (2014) identified previously which defines an assumption as "something that is certain to happen without proof". Assumptions therefore are so implicit and embedded in our thinking and feeling that they generally remain hidden and difficult to identify (Claxton, 1999), but also may be acted upon without attention being paid to their contextual validity and accuracy (Brookfield,

1992). Indeed Brookfield (2012) also states that because they are so contextually dependent, using the terms right or wrong assumptions is unhelpful, rather, they are merely more of less accurate depending on the information that has been available or used at the time.

Mezirow (1990) also argues that assumptions are inherent in how we make sense out of our experiences or "make meaning" (pp.1-2). He suggests that there are two dimensions to structuring meaning, both of which have relevance to understanding assumptions. The first dimension he calls "meaning schemes" (pp.1-2), these are the implicit rules we have for interpreting situations, which are often based on the link between cause and effect. The second are "meaning perspectives" (pp.1-2) these are networks of beliefs about expectations of role for example as a staff member or service user. He states that these meaning perspectives refer to the "structure of assumptions within which new experience is assimilated and transformed by past experience during the process of interpretation" (p.2). This view would seem to suggest that assumptions are highly complex and whilst they may operate in a singular and linear fashion, they are more than just a response to a situation, they are informed by beliefs and values that shape thinking in response to the situation and context. The terms assumptions and beliefs are often used interchangeably, indeed, both are based on the premise that something is true without the proof that this is necessarily the case, however, beliefs are also defined as a "firmly held opinion" (Oxford Dictionary, 2015). It would seem therefore that it is the degree of strength and certainty with which a belief is held that marks the difference, indicating that beliefs are less open to influence and change.

In relation to assumptions, categorising them into different types is seen to be an important part of being able to identify and understand them (Kies, 1995; Nwake and Morrow, 2016). Brookfield (1995) identifies three types of assumptions that we hold in either text or speech; paradigmatic, prescriptive and causal. They are described as follows:

- Paradigmatic assumptions: the basic axioms or accepted truths with which we organise the world around us
- Prescriptive assumptions: what we think ought to be happening or should be happening
- Causal assumptions: how things work or can be changed, usually expressed as if *x*...then *y* (Brookfield, 1995, pp. 2-3).

This generic description of assumptions is helpful in that can be applied to any subject area; however, it is not clear from the literature how Brookfield established these categories, nor how he has utilised them in further research. The simplicity of the framework is useful in categorisation; however, it fails to acknowledge the reality of the complexity of assumptions that is how they inter-relate to each other to form wider meanings and how they inter play with the assumptions of other people. Eliot (1937) in his well-known early study identified the category of predictive assumptions which included "...hypotheses, prognoses, reputations, stereotypes, conceptions of role, definition of the situation [and] myths" (p. 508). However, he suggested that it is not merely the categorisation of an assumption that is important, but also how assumptions are evaluated, responded to and acted upon, both by the person making the assumptions and others who are interacting with that person. Eliot (1937) identifies that those assumptions which are readily corroborated by others can rapidly become cultural norms and accepted reality. His work identifies assumptions as being based on patterns of thinking associated with firstly, cause and effect and secondly, the subsequent confirmation or refutation of the original assumption. This early attention to causal patterning is also reflected in Brookfield's (1995) categorisation of assumptions; indeed both authors make a considerable contribution to the field of critical thinking.

2.2.2 Assumptions and critical thinking

In the field of critical thinking, there is a large body of work providing an understanding of assumptions. Critical thinking is recognised as being underpinned by logic, a theory that enables conclusions to be reached on the

basis of rational reasoning and argument (Eliot, 1937; Ennis, 1982; Paul and Elder, 2008; Cotterall, 2011). Logic theory clearly places assumptions as an integral part of our thinking and reasoning process, as outlined by Paul (1993, pp. 34-36) (Figure 3).

The object to be figured out	Experiencing an object and deciding on the information/data we use to understand the object
Reason for wanting to figure it out	What is the purpose or goal of reasoning? This provides a clear focus for thinking
Question or problem we want solved	An area of concern that requires explanation
An initial sense of what we take for granted	**Assumptions: these are the starting points for reasoning**
Some ideas by which we make sense of it	The use of ideas and concepts that are constructed by the mind and which shape and organise thinking
Drawing of conclusions about the thing	The inferences and conclusions we make are based on the concepts and assumptions that are held
What follows from our interpretation	Implications and consequences of the reasoning process
Point of view or frame of reference	Constructions of the human mind that form the framework for our reasoning. This may be too narrow and lead to error.

Figure 3. Elements of thought (adapted from Paul, 1993).

Paul's logic model places assumptions at the centre of our thought processes, it clearly identifies that they are the very starting point for our reasoning and thereby influence the conclusions we reach about an object or situation. They are the axis on which our subsequent thoughts can divide depending on the assumption that is held. Situating assumptions within a logic framework clearly indicates the influence they have on our interpretation and framing of situations and therefore subsequently on action.

There are however, critics of the logic approach, it is suggested that it runs the risk of constraining thinking (Bailin and Siegel, 2003) and pays little attention to the role of emotion in influencing experience and perception

(Nussbaum, 2001). Indeed several authors have explored the importance of emotion in human experience and in particular its influence on thinking and learning (Brookfield, 2001; Goleman, 1996; Eraut, 2004; Dirkx, 2008). These authors identify that a focus purely on cognitive rationality neglects the recognition of our emotional laden experiences in real life. Brookfield (2001) uses examples from health care practice to illustrate that it is often an emotional encounter with a service user that "forces someone to examine their own beliefs" (p.48) and thereby ones assumptions. He suggests that such situations are pivotal in triggering a reflective process which can ultimately result in knowledge and professional thinking being adapted and reorganised. It would therefore seem that whilst assumptions do have a pivotal role to play in a logical thought process, it also needs to be recognised that our interpretation of situations can seldom be reduced to mere cause and effect, and to do so would be to belie the complexity both the situations themselves, the role of our emotional interpretation and the wider social and ideological context. What is also evident from the literature is the inherent role that assumptions play in our thinking and learning and as such have an important influence on how we interpret situations in everyday life.

2.2.3 Influence of assumptions

The literature indicates that assumptions can influence situations both positively and negatively. For example, Adair (2009) asserts that assumptions that are made consciously actually encourage exploratory and creative thinking. This is on the basis that assumptions that are held "deliberately and temporarily" create the opportunity to use the imagination to consider what might be possible (Adair, 2009, p.61). He distinguishes these from assumptions, which are unconscious, which he argues hinder innovative thought. His emphasis on the positive role of assumptions, is outweighed by other authors, who suggest that assumptions have a negative influence, particularly in relation to health care. It is suggested that in health care, assumptions are used to stereotype disabled people (Abberley, 1987; Barnes and Mercer, 2003), can be dangerous when related to good

intentions (Bell and Salmon, 2012), harmful when unexamined (Auger, 2004) and lead to professional entrenchment when not probed (Hammell, 2009, 2011). Their influence is thought to be so detrimental to effective communication between disabled people and clinicians, that it is asserted that professionals should start with the premise 'make no assumptions' (Iezzoni, 2006, p. 212).

It would seem that tacit assumptions that go unrecognised or are ill considered can have unhelpful effects, posing a risk to forming effective relationships and interactions. However, Iezzoni's (2006) suggestion that assumptions should be suspended seems to imply that it is possible to almost erase personally held assumptions. This highlights an interesting conundrum. In order to suspend assumptions, so that their negative effects are not felt by others, they need to be made explicit, either internally explicit through reflexivity (pp. 38 - 43 will explore reflexivity more fully) or externally explicit by verbalising them. If assumptions remain implicit or tacit, they are not consciously accessible to us and therefore it is not possible to suspend them. Iezzoni's article appropriately highlights that assumptions can be problematic and constraining in the practice context. However, the broader theoretical literature seems to indicate that assumptions are so fundamental to our thinking processes that it is not cognitively possible to start from the assumption that it is actually feasible to "make no assumptions" (Iezzoni, 2006, p. 212).

Hooper (1997) asserts that personal assumptions held by a therapist can also positively influence clinical reasoning and have a constructive effect on the therapist's relationship with the service user and the treatment provided. This is one of the few projects that specifically researched the influence of therapist assumptions in practice. The therapist in this single case study is a Hindu. Hooper identified that her personal pre-theoretical assumptions about reality, life and death, human nature and knowledge, were based on her religious beliefs and did influence her clinical reasoning and the subsequent occupational therapy practice.

It would seem that in explicating the hidden world of the clinical reasoning process, Hooper has clearly identified that deeply held personal assumptions can influence thinking and behaviour. Hooper's choice of a single case study and the combined methods of observation and interview methods enable her to capture the complexity of how pre-theoretical assumptions influence reasoning. Her claim that the model she has developed has application in teaching clinical reasoning skills is questionable as the transferability of findings from single case study's warrant further verification.

Overall, these studies identify the way that assumptions are perceived to have both a positive and negative influence thinking and acting towards situations, other people and in clinical practice. It is apparent that the influence of assumptions can be explored and understood when they are made explicit; therefore, finding ways to illuminate assumptions is important in order to determine their validity.

2.2.4 Illuminating and changing assumptions

The process of illuminating assumptions so that they can be adapted or changed requires that tacit knowledge be brought to the fore. This enables assumptions to become "objects of knowing and learning", making them explicit so that they can be critiqued and evaluated in line with the evidence and context in which they are held (Claxton, 1999, p.192). Indeed, Nkwake and Morrow, (2016) argue that the explication of assumptions is essential in order to understand the false expectations that can be generated particularly during the design and evaluation of new services or programmes of work. The challenge of illuminating assumptions has been explored in a wide range of academic literature, with particular attention to the use of critical theory (Brookfield, 2001, 2005, 2009; Mezirow, 1997); reflection, critical reflection and reflexivity (Kinsella, 2012; Brookfield, 1998, 2009; Fook, White and Gardner, 2006; Finlay, 2008) and importance of group work (Brookfield, 1992; Fook, 2012).

Using critical theory to illuminate assumptions

In the field of critical thinking and transformative learning in adults, critical theory is advocated as the basis for challenging and illuminating assumptions about societal structure and systems that both perpetuate social inequality (Brookfield, 2009) and also influence personal experience (Mezirow, 1990). Critical theory takes the view that "societal conditions are historically created and heavily influenced by asymmetries of power" (Alvesson and Skoldberg, 2009, p.144), these are shaped by "social, political, cultural, economic, ethnic and gender values [that have] crystallized over time" (Guba and Lincoln, 2005, p.193). It is recognised for its ability to challenge the status quo of accepted thought and practice (Cotty, 1998) and is built on the assumptions that Western democratic societies are inherently unequal, dominant ideologies are readily accepted as inevitable and understanding these issues is a precursor to changing them (Brookfield, 2009, p. 298).

Brookfield states that it is through our accepted hegemonic assumptions that we attribute meaning to people, objects and problems, thereby using assumptions as a guide to make judgements and decisions that are based on dominant societal ideologies (Brookfield, 1995, 1998, 2009). Based on his work predominantly in teaching practice, he argues for a criticality that is rooted in ideology critique in which people develop an awareness of the belief systems and assumptions that maintain inequality (Brookfield, 2005, p.13). When applied to the field of physiotherapy, Trede (2012) argues that critical theory holds the potential to highlight paradoxes in practice by "scrutinizing the assumptions and motivations that create current practices" (p. 468). She suggests that by doing so, the use of critical theory not only offers a means of critiquing practice but also holds the potential for emancipation by raising awareness of the taken for granted inequalities and injustices that exist in the structures and systems of health practice. This view also reflects the principles of Friere (1970) who advocated for an approach to learning that views people as active subjects in their own

struggle to free themselves from oppressive systems, as opposed to merely passively accepting the status quo.

The work of critical theorist Habermas (1984, 1987) is of particular influence for clinical researchers searching for a theory to help them critique the social nature of their practice (Trede, 2012), in particular his theory of communicative action (Habermas, 1984, 1987). This is built on the notion of communicative rationality, which involves "reflecting on our background assumptions about the world" (Scrambler, 2001, p. 2) through the process of open debate and dialogue, involving the mutual questioning and testing of each other's ideas (Habermas, 1984). This is distinct from instrumental rationality (Habermas, 1984), whereby background assumptions are taken for granted and there is a linear process of working directly from a problem to a solution (Scrambler, 2001). It is this rational communicative approach which Habermas (1984) argued should create spaces for the "ideal speech" situation, where everyone should have an opportunity to enter into dialogue and question any assertion that is held by others (Habermas, 1984). It is an approach that is orientated towards understanding rather than technically orientated solutions and success which Habermas identified as strategic action (Scrambler, 2001).

The health literature particularly draws on Habermas' concepts of "lifeworld" and the "system" (Habermas, 1987) to illustrate the tensions that exist between the lived experience of the service user and the systemic bureaucracy inherent within the NHS (Greenhalgh, Robb and Scrambler, 2006). These Habermasian concepts are an integral part of his theory of communicative action (Habermas, 1987). The lifeworld is described as "the frame of the human beings lived life, a horizon of "taken for granted" knowledge, norms and expectations...which connects the dimensions of the objective, the social and the subjective worlds" (Walseth and Schei, 2008, p. 83) and the system consists of the economy and the state (Habermas, 1987). As such, both market forces and systemic bureaucracy are seen as "colonizing" the lifeworld, reducing people to commodities or objects and

subjecting people to organisational infrastructures which operate in line with financial and bureaucratic pre-determined conditions of success (Greenhalgh, Rob and Scrambler, 2006; Kemmis, 2001).

These concepts have been used to illustrate how biomedical approaches can overshadow the lived experience of the service user leading to them feeling invisible and powerless (Damsguard et al. 2016) and similarly how the lifeworld of the service user is readily colonised by the system, through organisational processes and medical or professional language (Mikkleson et al. 2008; Scrambler, 2001). Consequently, these authors were in a position to be able to challenge existing assumptions about healthcare that is driven by the system and advocate for practice that prioritises the lifeworld of the service user.

Habermasian critical theory provides a tool through which to explore and reflect on the complexities of practice, in particular those aspects that are traditionally taken for granted (Trede, 2012, Mikkleson et al. 2008). Trede (2012) suggests that the application of critical theory to practice requires professionals to commit to reflection on their practice. However, her study notes that some practitioners remained "unconvinced" of the value of using critical theory in practice to uncover their assumptions about professional power. Instead, it merely reinforced their existing professional position which from a critical theory perspective ran the risk of depersonalising practice. The term reflection is interpreted in a variety of ways across different disciplines (Fook, White and Gardner, 2006) and the difference between them can go unrecognised so that they are often used interchangeably without attention to their meaning and purpose (D'Cruz, Gillingham and Melendez, 2007).

Using reflection, critical reflection, reflexivity and critical reflexivity to illuminate assumptions

The literature indicates that assumptions are one of the primary foci for the practices of reflection (Bolton, 2009; Kinsella, 2012), critical reflection

(Brookfield, 1998, 2009; Fook, White and Gardner, 2012), reflexivity (Finlay, 2008, Bolton, 2009) and critical reflexivity (Cuncliffe, 2004). It is because of this apparent lack of clarity that it is important to briefly unpack these terms in order to understand their relationship to assumptions.

The practice of reflection is broadly viewed as a process of learning from experience in order to make sense of what has taken place with the aim of acquiring a new awareness about oneself and or practice (Boud, Keough and Walker, 1985; Eraut, 2004; Bolton, 2009). In his seminal text Schon (1983) alludes to assumptions by asserting that through reflection it is possible to uncover tacit understanding. This is on the basis that reflection helps to make "new sense of situations of uncertainty" (p.61) and counteracts those aspects of knowledge and action that have become taken for granted and automatic and on which assumptions are based. Schon (1983) argues that reflection on practice can take place both after an event and in the action of the event itself, stating that such reflection may focus on the "tacit norms and appreciations which underlie a judgement, or on the strengths and theories implicit within patterns of behaviour" (p.62). This focus on "tacit norms" has clear resonance with assumptions, as that, which is taken for granted.

It is also suggested however, that this raised awareness or consciousness is not sufficient in itself to change practice and Kinsella (2012) argues that within the practice of reflection, there needs to be a link to action, which is often referred to as praxis. This element of praxis is viewed as moving beyond the mere delivery of technical action, that is action based on the mechanical delivery of a skill, to a coalescing of reflection and action, which is informed by the values of social justice (Friere, 1970, p.48). This would seem to suggest that for some authors reflection is more than a mere review of the "nuts and bolts" of practice (Brookfield, 2009, p.293) or formulating an action plan (Stonehouse, 2015), but is a complex concept that links together reflection, action and values.

Brookfield (2009) states that mere reflection can only "uncover" assumptions (p.294), suggesting that its purpose is to make practice run more smoothly, however, he contends that the investigation and analysis of our assumptions requires the process of critical reflection. He states that this is not merely a process of reflecting more deeply, but one that commits to researching assumptions with particular reference to critical theory and the power and hegemony that are inherent within societal systems and structures (p.295). Alongside other authors, he articulates the need for a clear distinction to be made between reflection and critical reflection, in order to acknowledge the theoretical heritage of critical reflection (Brookfield, 1998, 2009; Fook, White and Gardner, 2006) and recognise the personal work that is required to be aware of the assumptions of power that are inherently embedded in relationships and practice (Brookfield, 2009).

 Fook, White and Gardner (2006) identify the importance of questioning the origins of assumptions in critical reflection, stating that it is the process by which people:

> *"...identify the assumptions governing their actions, locate the historical and cultural origins of the assumptions, question the meaning of the assumptions, and develop alternative ways of acting" (Fook, White and Gardner, 2006, p.12).*

Alongside Brookfield (2009), these authors emphasise that critical reflection is at best informed by critical theory, thereby enabling the person to get beneath the surface of analysing the mere logic of an argument, but instead to get to the heart of the social and political context and the root causes of assumptions. It is suggested that this approach to critical reflection holds the potential for such new knowledge to influence personal perspectives and inform future action.

Brookfield, (1998) draws attention to four lenses that can be used by critically reflective practitioners to constantly research their assumptions. He suggests that these lenses are firstly, analysing our autobiography as

learners to uncover why we do the things we do. Secondly, seeing ourselves through the eyes of the learner [or service user], thereby enabling a view from the other side. Thirdly, talking to colleagues or peers about what we do in order to gain a different perspective and fourthly, drawing on the theoretical literature in order to shine a different light on practice. It is interesting to note that in this earlier work, Brookfield does not make any specific reference to critical theory; it would seem that this has been a theoretical development as his work on assumptions and critical reflection has matured and he has viewed it as important to clearly locate his work in relation to critical theory.

Finlay (2002) states that reflection and reflexivity can also be confused and suggests that they are viewed as a continuum with reflection, that is thinking about a subject or an object at one end and reflexivity, which is viewed as a dynamic self-awareness, at the other end (p.532-533). She cites Mead (1934) as one of the first to consider reflexivity who from a symbolic interactionist perspective described it as the turning back of one's experience on oneself whilst interacting with others. Fook (2002) suggests that reflexivity is:

> *'...the stance of being able to locate oneself in the picture, to appreciate how one's own self influences. Reflexivity is potentially more complex than being reflective, in that the potential for understanding the myriad ways in which one's own presence and perspective influence the knowledge and actions which are created is potentially more problematic than the simple searching for implicit theory. (Fook 2002, p. 43)*

Whilst Fook (2002) and Finlay (2002), clearly treat reflection, critical reflection and reflexivity as separate entities, Brookfield (2009) suggests that there is a close link between reflexivity and critical reflection. He argues that critical reflection is in itself a reflexive habit, which occurs when there is an ongoing commitment to unpacking the assumptions of power and hegemony in professional practice (Brookfield 2009, p. 298).

Finally, Cuncliffe (2004) working in the field of management describes critically reflexive practice as a process of thinking more critically about our own assumptions and actions in order to develop more collaborative and ethical ways of working. She suggests that the notion of critically reflexive practice places a strong emphasis on praxis, arguing that such ethical action requires personally taken for granted assumptions to be questioned and contradictions and dilemmas in practice to be exposed. For Cuncliffe (2004) critically reflexive practice is not a technical approach to thinking about practice, it is a philosophy of practice that enables tacit assumptions to be highlighted and requires us to "explore how our own actions, conversational practices, and ways of making sense create our sense of reality" (p.414). Theoretically, Cuncliffe (2004) does not state that she situates her work in critical theory, but instead draws on the critical pedagogy of Friere (1970) and social constructionist theorists for example Berger and Luckman (1967). In doing so, she uses Friere's work to emphasise the importance of the need to think consciously about social reality and act on it in order to be able to transform it and social constructionism to recognise that we all hold subjective understandings of reality (Cuncliffe, 2004).

These different approaches to reflection, confirm the view that there is considerable blurring between the definition of terms and their application in practice (Fook, White and Gardner, 2006; D'Cruz, Gillingham and Melendez, 2007). The literature would seem to suggest that whichever reflective or reflexive approach is adopted, there is a strong focus on assumptions. It would appear there are two issues that influence which term is adopted, the first relates to the purpose behind illuminating assumptions, whether this is merely to identify assumptions and name them or whether it is also involves analysis and a commitment to praxis. The second is the theoretical commitment to the investigation of assumptions. It would certainly seem that there is considerable variation in the use of the term "critical", however, as in the work of Brookfield (2009), Fook, White and Gardner, (2006) and Cuncliffe, (2004) where the underpinning theory is clear, then the purpose

and goal behind exploring and investigating assumptions is also clearly articulated.

Illuminating assumptions by thinking alone or being in dialogue with others

Whilst much of the process of reflection and critical reflection is regularly undertaken on one's own in the context of working life (Eraut, 2004), Brookfield (1998) argues that such solitude is not an effective way of shining a light on those assumptions that are hidden in the depths of our being. This is because no matter how well we think we understand ourselves "we always use our own interpretive filters to become aware of our interpretive filters" Brookfield (1998, p.197). This view implies that when we think about and reflect on a situation, there is the risk that we merely provide an explanation that continues to be based on our own view of the world and therefore we validate our personal view. In support of this perspective, Fook (2012) and Yancher and Slife (2004) use critical discussion in social work and psychology education respectively to unearth previously unrecognised assumptions. Fook (2012) highlights the importance of critically reflective group work to bring together multiple perspectives, which are potentially contradictory. She notes that understanding different viewpoints can raise awareness and bring clarity to one's own thinking (p.224). However, she also recognises that such intense group work can create ethical dilemmas in relation to emotional risks to participants where experiences of emotional pain and shame can be experienced. Fook (2012) argues that whilst assumptions can be successfully explored using group discussion, it does require a safe space. It is only in this safe space that participants can comfortably commit to a process of co-researching each other's experience and generating a dialogue within the group context. These important issues of group dynamics are not recognised by Yanchar and Slife (2004) whose approach is based on cognitive rationality, where assumptions are valued as part of developing critical thinking. Students are supported to understand the implications of their assumptions and defend their position effectively, but there is no commitment to action or praxis.

43

These two papers clearly illustrate similarities in terms of a commitment to the benefits of group dialogue for illuminating assumptions, but also highlight differences in their interpretations of criticality. On the one hand, Yanchar and Slife (2004) emphasise the importance of assumptions in rational analysis and argument and on the other, Fook (2012) addresses the need to illuminate and reflect on assumptions in order to expose dominant ideologies and accepted practices. It is the latter approach to critical reflection which also holds a commitment to evaluating and changing both assumptions and practice.

Changing assumptions

Several authors have shown that personal assumptions are able to change particularly when there is a particular focus on learning and critical reflection (Bowe et al., 2003; Brookfield, 1993; Lamiani et.al. 2008). van Langenhove and Harre (1999) subscribe to the view that assumptions and stereotypes are located within discourse, thereby holding the possibility that they can be made visible and once visible they can be influenced and potentially changed. They state that this is opposed to belief systems, which are located 'inside' people and are therefore more difficult to change. Berman (2001) identified that the biggest resistance to changing assumptions is that of a 'closed mind', which includes for example lack of awareness, limited time to assimilate information and not recognising the complexity of the situation. It would therefore seem that changes in assumptions are not inevitable in all situations, however dialogue and the opportunity and openness to view a situation from a different perspective positively influences their ability to change. The Habermasian theory of communicative action regards knowledge as fallible and therefore always open to challenge, critique and evaluation (Habermas, 1984), this suggests that there is the potential for change in thinking and assumptions. Indeed this has been verified in health care practice, Walseth and Shei, (2011) used the Habermasian concepts of the lifeworld and rational communication through dialogue to change assumptions about lifestyle in relation to medical conditions. The authors discovered that "verbalising reasons for one's preferences may increase

awareness of values and norms, which can then be reflected upon, producing decisions rooted in what the patient perceives as good and right behaviour" (p. 81). Their work suggests that it is possible through dialogue to bring to the fore aspects of the lifeworld that are normally hidden, exposing assumptions and preconceived ideas. In line with Habermas (1984), once verbalised and explicitly expressed this knowledge can become the focus of discussion. Walseth and Shei (2011) illustrate that it is through such honest dialogue that assumptions hold the potential to be exposed, contested, re-evaluated and can subsequently change health behaviour. This example would seem to suggest that there are many taken for granted beliefs and assumptions that are deeply embedded in the lifeworld and therefore are difficult to change. However, in line with van Langerhove and Harre (1999) once these are made explicit and exposed in discourse, there is the potential to consider them more fully.

Other studies have also concluded that adopting a Habermasian critical theory approach holds the potential to change assumptions, particularly in practice development (McLain, 1988; Manley and McCormack, 2003; Lamiani et al., 2008;Trede, 2012). Trede (2012) used an action research approach to examine how Habermas' ideas could be applied to physiotherapy practice in a hospital setting including neurological rehabilitation. Nine physiotherapists were introduced to Habermas' work and asked to articulate their strategy for the implementation of emancipatory practice, which they subsequently trialled. Trede (2012) found that therapists who worked reflexively with Habermas' ideas questioned their practice based assumptions leading to increased awareness of professional power and prejudices and re-thinking communication and decision making practices (p.471). However, she also identified that for some therapists, the Habermasian utopian idea of critical rationality and communicative action were so far removed from the reality of health care practice that it was too hard to operationalise.

Habermas (1984) suggests that our well established, taken for granted assumptions require an "earthquake" (p.401) to bring them into consciousness in order to be able to change them. Whilst this metaphor may be a useful one to indicate that disturbance is required in order to shake the foundations of what we traditionally accept without question, it suggests that a major event is required in order to bring about a change in assumptions. In contrast, Cook (2004a) argues that changing what is traditionally taken for granted, does not happen as a one off disruptive event, but requires reflection over time and in collaboration with others. Indeed it would seem that this is more of a ripple effect, enabling an incremental building of understanding of both personal and organisational assumptions. Both Habermas (1984) and Cook (2004a) therefore indicate that disruption, be it singular or incremental is required to disturb what is generally perceived as stable and certain. It would, therefore, seem that without such disturbance, whether this is through critical reflection (Trede, 2012) or critical dialogue (Walseth and Shei, 2011), a change in assumptions is not possible.

Drawing together the different conceptual approaches to assumptions presented in this literature review, I generated the following working definition of assumption which constitutes the basis of reasoning in my PhD:

> *A taken for granted interpretation of the world, which is held with a sense of certainty until challenged through interaction with a different perspective and evaluated through a process of critical reflexivity. They are founded on past experience and are often tacitly held, influenced by both emotion and rational thought and are fundamental to reasoning, sense making and subsequently to behaviour and action.*

Neurological rehabilitation practice has not traditionally been recognised for its attention to critical reflection, particularly on the lived world of people's experience (Hammell, 2006; Trede, 2012). As such many aspects of practice are often taken for granted as assumptions go unquestioned. Paul's (1993) elements of thought outlined in Figure 3, suggest that assumptions sit

within the context of an area of concern or problematic issue requiring explanation, which in turn informs what assumption is held. The following section will seek to highlight these areas of concern by focussing on the perspectives of both service users and staff in relation to neurological rehabilitation. There was no specific literature that investigated assumptions in neurological rehabilitation, therefore understanding the perspectives of service user and staff gives an indication of how neurological rehabilitation is both thought about and experienced.

2.3 Perspectives on neurological rehabilitation

This section will provide brief critique of the key models that inform neurological rehabilitation, which sets the context for the clinical delivery of services and an overview of service user perspectives, highlighting in particular the important role that relationships with staff play in service user experience. Finally, I will review the literature relating to staff perspectives, paying particular attention to the practices of goal setting, teamwork and being person centred, which staff identify as important to their working relationship with service users. There is a small but growing body of knowledge that seeks to critique taken for granted practices in neurological rehabilitation. Hammel's (2006) critical synthesis of the theory and research informing rehabilitation, draws upon a wide range of perspectives and is therefore of particular value in informing the context for this study.

2.3.1 Perspective on models of practice in neurological rehabilitation

Historically, rehabilitation was based on what is referred to as the medical model, which viewed the patient is a victim of a disease or illness, treatment therefore being needed to alleviate the symptoms in order for a return to health (Wade and Halligan, 2011). This model positioned the practitioner as the expert in providing treatment solutions (Hammell, 2006), and assumes that there is an optimal level of functioning that the service user can achieve (Leplege and Hunt, 1997). The medical model has been strongly criticised by disability academics for its emphasis on labelling people as a condition or

47

disease, thereby viewing them as a tragedy (Swain and French, 2004), rather than an autonomous human being (Sim,1998). Instead, the disability community predominantly supports the social model, which argues that attitudinal and environmental barriers disable and exclude people from society and treatment rather than their impairment (Oliver, 1990). However, the medical model is still seen as having value by medical academics who argue that conceptualising disability as being socially constructed is unhelpful, suggesting that denying disability and refusing to attempt to "lessen the burdens and discomforts of stroke...spinal cord and head injury" lacks coherence from a bioethical perspective (Banja, 2015, p. 562). Leplege, Barral and McPherson (2015) argue however, that there is no single medical model and the medical model that disability theorists in particular refer to is instead an individualistic model. They suggest that rather than seeing medical approaches to rehabilitation in opposition to the social model of disability, there is instead a greater need for integrative models of rehabilitation which recognise the "individual...[and] their experience of impairment, disability, health or wellbeing" (p.37).

More recently, the bio-psycho-social model has been adopted in neurological rehabilitation practice. This model acknowledges the broader biological, emotional and social needs of the person but lacks recognition of the influence of the environment (Wade, 2015). Whilst this model has brought a person centred orientation to practice that have been well received by rehabilitation practitioners, service users and their families (Wilson and Gracey, 2009 ;Salminen, Kanelisto, and Karhula, 2014; Nieuwenhuijsen, 2009), it is recognised as not yet being fully embraced by some professions (Rousch and Sharby, 2011). Additionally, it remains contentious, particularly with disability academics for its tendency to individualise the problem of disability (Hammell, 2006).

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is founded on the bio-psycho-social model and aims to provide a classification of health and measurement of health and disability, which

additionally recognises the position of the environment in influencing health and disability. It is a model that is welcomed by many clinicians and academics, being seen as valuable to rehabilitation by providing a "unifying model of human functioning" on which rehabilitation practice and research can be based (Stucki, Cieza and Melvin, 2007, p. 279). However, it is also criticised for its emphasis on the categorisation of difference and the marginalisation of people who are deviant from what is perceived to be "normal" (Hammell, 2004, p. 409).

Hammell (2004; 2006) suggests that health care practitioners have a tendency to be uncritical about the models they use in practice, thereby accepting the perceived wisdom of the majority and holding assumptions about practice that are not critically analysed and debated in relation to their congruence with espoused professional values or critical theories that provides an alternative lens on practice. She advocates for the adoption of disability theory in order to critically reflect on practice from a service user perspective and shine a light on practitioner assumptions.

2.3.2 Service user perspectives

There is a relatively small body of literature concerned with service users' perspectives on neurological rehabilitation. What we know is based on work by disability academics who use disability theory to take a critical stance towards neurological rehabilitation and professionals who specifically investigate service user perspectives on neurological rehabilitation. The literature reveals that receiving effective interventions and making good progress in rehabilitation is important, however, what is of more importance to service users is the approach and attitude that is adopted by staff.

Over the past 30 years, several academic service users have contested traditional practitioner constructions of both disability and rehabilitation (Oliver, 1990; Davis, 2004; Swain, French and Cameron, 2003). Within neurological rehabilitation specifically, criticism has been levelled at the ideology and the power relationships within it (Oliver, 2003, Abberley, 2004). Taking the perspective of the social model, Oliver (2003) writing in response

to a book chapter written by a rehabilitation consultant (Barnes, 2003b) states that practitioners have little awareness that neurological rehabilitation is underpinned by assumptions of professional power, expertise and control. This results in a failure not only to acknowledge the perspective of the service user, but to recognise where the control really lies, for example in the pivotal process of goal setting. In his critique of Barnes (2003b), Oliver (2003) contends that rehabilitation reflects the "ideology of normality", for example the assumption of a return to walking (p.38), stating that this promotes an uncritical view of the purpose and aims of rehabilitation, perpetuating the categorisation and classification of disabled people. Indeed, some disabled academics have suggested that such assumptions held by practitioners lead to a parasitic relationship with service users, building careers on constructions of helplessness rather than engaging with disabled people in their struggle for equality (Davis, 2004). However, not all disability academics share such a negative perspective of healthcare practitioners in rehabilitation. Shakespeare (2005) and Shakespeare, Iezzoni and Groce, (2009) contend that rather than view health practitioners as self-interested parasites, it should be recognised that they merely act out of ignorance, holding assumptions about disability which can be dangerous, but nevertheless can be revised. From a practitioner perspective, Hammell (2004, 2006) concurs with the issues raised by Oliver (2003) and uses disability theory to provide a strong critique of professional practice in rehabilitation. She argues that practitioners do collude with the oppressive categorisation of disabled people, for example in their use of the International Classification of Functioning Disability and Health (2001); she clearly identifies practitioner power as a major issue in shaping service user experience of rehabilitation. However, she also concurs with Shakespeare in suggesting it is this lack of awareness of the influence of power and paternalism that is the point of greatest concern (Hammell, 2006).

Shakespeare would seem to be more conciliatory towards practitioners than other disability theorists. Whilst he does not dismiss the important issue of the power imbalance between service users and practitioners, he recognises

the need for education and raised awareness. He advocates that practitioners working in rehabilitation should aim to adopt practice that reflects both an understanding of disability studies and a human rights approach. He states that practitioners should practise in line with the principles of 'respect, dignity, equality and non-discrimination in their interaction with disabled people' (Shakespeare and Officer, 2014, p.1488). Shakespeare and Officer (2014) would seem to suggest that the combination of critical reflection and positive principles for practice hold the potential to increase awareness of assumptions in practice.

In the professionally led literature, Lewinter and Mikkelsen (1995) were some of the first academics to recognise the value of the service user perspective of neurological rehabilitation. Their work in a newly developed stroke unit highlighted that service users' particularly valued physical intervention and the peer support of other service users, though some participants also reported that more attention needed to be paid to the social and psychological consequences of stroke. However, it is interesting to note that they did not refer to the influence of staff approaches and attitudes on their experience, but reflected mainly on the content of the programme of rehabilitation that was offered. Given that more recent literature suggests that service users' experiences of neurological rehabilitation is heavily influenced by staff attitude (Peoples, Satink and Steultjens, 2011; Luker et al. 2015), this raises questions about the methodological approach that was adopted. This study used a qualitative methodology and semi structured interviews, which were carried out with service users 3 months to 1-year post discharge. The broad categories of interview questioning focussed predominantly on the service user experience of the technical delivery of stroke rehabilitation, for example, the "amount, style and intensity of training...usefulness of exercises, techniques and assistive devices..." (Lewinter and Mikkelsen, 1995, p.5). Other than the final question which asked "what might improve rehabilitation" (p.5), it would appear that the structure of questions has missed an opportunity to draw out service user perspectives on the quality of their experience, thereby getting beneath the

surface of the mere technicalities of the delivery of rehabilitation. The paper does suggest that the purpose of the interview was to allow service users to talk about their experiences of using stroke services in an unstructured way, however, as Hammell (2001) notes, where research questions and priorities are structured by experts, there is the risk that participants are rendered powerless and the assumption is held that practitioners are well placed to define the issues that are important to service users (Hammell, 2001). After Habermas (1984; 2008) it would therefore seem that such power asymmetries do limit the potential for honest conversations, as service users are less able to say what they really mean. Instead, there is the risk that they are unconsciously coerced into saying what they think other people may want to hear.

As one of the first people to investigate user perspectives of the meaning of client centred practice, Cott (2004) conducted a qualitative inquiry, sampling 33 service users of which 14 had long-term neurological conditions. She found that of most importance to service users was practitioners treating people as individuals and tailoring rehabilitation to their needs. However, less positive experiences highlighted that people felt practitioners categorised them according to their condition, holding assumptions that were made on the basis of diagnosis rather than reflecting on personal strengths and capabilities. Service users felt that they had to battle for their individual voices to be heard, both in the central rehabilitation process of goal setting and in decision-making. Cott (2004) highlights that the rhetoric of client centred practice is not matched by reality and suggests that client centred practices will not be realised unless practitioners and service users are able to work to a shared agenda particularly within the goal setting process. She notes with irony that "for all that has been written about client centeredness very little is based on client perspectives" (p.1412). Hammell (2013) in her critical review of client centred practice concurs with this. She highlights that its realisation in practice requires an awareness of the power inequalities between service users and practitioners. She notes that definitions of client centred practice that merely place the client at the centre lack, recognition of

the need for client autonomy and respect; she argues that therapists who adopt such a stance are disempowering service users.

Two recent qualitative systematic reviews of user perspectives of stroke rehabilitation established that service users clearly value some aspects of rehabilitation but that experiences can also be negative (Peoples, Satink and Steultjens, 2011; Luker et al. 2015). In relation to intervention, they identify that service users' value making good physical progress, particularly in relation to walking; in fact they wanted more of this physical approach to rehabilitation and were disappointed when this was not available. In relation to feeling empowered within the rehabilitation process, they valued being treated as an individual, considered with respect and able to work collaboratively with practitioners. It was equally evident that the opposite of these experiences resulted in feelings of disempowerment. The attitudes of practitioners were particularly viewed as having a strong negative impact on experiences of rehabilitation. Such practitioner behaviours included indifferent responses to participants' goals and authoritarian and paternalistic attitudes that had the impact of reducing control, autonomy and diminishing confidence and motivation for rehabilitation. This literature would appear to support Oliver's (2003) view that practitioners exercising power over service users continues to be a problem for service users and their engagement in the rehabilitation process. Luker et al.'s (2015) review captures the views of 560 stroke patients aged 18 years and above across 32 documents. Whilst their aim was to represent the service user voice in stroke care, an aspect of practice they felt had previously been missing, they nevertheless failed to include people with cognitive or communication problems, thereby limiting the transferability of their findings to all people with stroke. The importance of the relationship between the practitioner and the service user to either empower or dis-empower the service user is not restricted to stroke rehabilitation. These issues are consistently reported in the literature, including generic rehabilitation settings, (Wain, Kneebone and Billings 2008; Lui, Thompson and Playford, 2004); spinal injury (Hammell, 2007); traumatic brain injury (Darragh, Sample and Kreiger, 2001; D'Cruz, Howie and Lentin,

2016) and in the process of goal setting (Rose, Rosewilliam and Soundy, 2016; Rosewilliam et al. 2016; Young, Manmathan and Ward, 2008).

Whilst there is evidence of positive aspects of interventions in neurological rehabilitation, ultimately the literature seems to show that service user experiences of neurological rehabilitation and engagement in its process are influenced most strongly by the way they feel disempowered by practitioners through their approach and their attitudes. This theme of service users feeling alienated from their own care and treatment is also reiterated in policy. Darzi (DH, 2008b) in his report High Quality Care for All stated that service users "feel like a number rather than a person... [and they] lack 'clout' inside our health care system" (p.6). Such statements reflect service user assumptions about their lack of power and influence in their own care. Similarly, Colin-Thome (2007b) formerly National Clinical Director for Primary Care highlighted the need to move towards a patient centred approach rather than a reactive system based approach when working with people with neurological long term conditions. Emanating from his experience as a General Practitioner, Colin-Thome recognised the need for quality patient care that was "not a bureaucratic exercise in box ticking" (DH, 2007b, p.10). Indeed, one of the quality requirements of the National Service Framework for Long Term Conditions (2005a) also states that service users should be at the very centre of their rehabilitation. However, more than 10 years on from the launch of this policy, there are still difficulties with its implementation (National Audit Office, 2015; Sixsmith et al. 2014), and recognition of the need for a change in culture in order to fully realise the involvement of service users in their own care and treatment (Foot et al. 2014). This culture change is viewed by Foot et al. (2014) as requiring a response from practitioners, service users and managers alike, whereby practitioners need to let go of their established and taken for granted practices, service users need to consider responsibility for their health and care and systems need to become more responsive and human. They state that tackling this requires a "radical realignment of the current power dynamic away from paternalistic, expert approaches in the consulting room, to a more collaborative, shared

decision-making relationship..." (p.57). Such comments by Foot et al. (2014) highlight the problematic nature of assumptions held by staff about the privileged nature of their practitioner role and expertise and the negative impact this can have on service user experiences.

The literature provides evidence of a clear aspiration from service users, academics and NHS policy makers to redress the balance of power between service users and professionals and create a system that is more person focussed. Whilst there is evidence of good practice, it is apparent that the practice and approach of professionals that leads to service users feeling empowered within neurological rehabilitation it is not systemically implemented. The apparent lack of awareness by practitioners of how their attitude and approach influences the service user experience, alarms disabled service users, academics and policy makers alike.

2.3.3 Staff perspectives

Over the past 30 years, professional academics and clinicians have expressed their perspectives on neurological rehabilitation predominantly through the focus of their research or through commentary and opinion papers. Traditionally, there has been a strong emphasis on intervention and measurement and outcome studies. However, in the past two decades academic inquiry has demonstrated a greater awareness of the need to engage differently with service users and question the nature and purpose of rehabilitation. These studies and commentaries particularly reflect a need for practitioners to understand the lived experience of service users (Diller, 2005; Roscigno and Van Liew, 2008; Cicerone, 2012); understand and respect their strengths (Rowlands, 2001; Yllvisaker, Jacobs, and Feeney, 2003); recognise the need for greater collaboration between practitioners and service users (Doig, Fleming and Kuipers, 2008) and rethink taken for granted conceptions of rehabilitation (Palmadottir, 2006; Hammell, 2006, 2013; McPherson, Gibson and Leplege, 2015). Research studies that specifically investigate practitioner perspectives are less evident and there is very little published research on the perspectives of staff who work in

neurological rehabilitation but do not hold a professional qualification for example therapy assistants or reception staff. Research relating to therapy or nursing assistant's focuses predominately upon their perceptions of their role within a rehabilitation team (Robinson, DePalma and McCall, 1994; Stanmore, Omrod and Waterman, 2006), however, their perspectives about the process of neurological rehabilitation itself and their engagement with service users is not evident in the literature.

Perceptions of goal-setting and team work

Goal setting and team work are core rehabilitation practices that are generally perceived by practitioners as times when service users are listened to and actively involved in their rehabilitation as an integral part of the multi-disciplinary team (Barnes, 2003a,b). This is however, not always the case and practitioners cite cognitive impairment as one of the main barriers to working collaboratively with service users in goal setting (van de Weyer, Ballinger and Playford, 2010; Rosewilliam et al. 2011; Sugavanam et al. 2013) and excluding them from the team (Suddick and De Souza, 2006).

This stance suggests that the assumption is held that service users are the problem and the main obstacle to successful goal setting, as opposed to practitioners reconsidering their own approach in order to provide the service user with the necessary positive support to fully engage and participate. Other authors contend that it is actually the responsibility of the practitioners to maximise the active engagement of the service user (van den Broek, 2005; Hunt et al. 2015). Kayes and McPherson (2012) take this further and propose that collaboration with service users is not dependent on what practitioners '"do" with service users, but upon "who we are and how we are" with service users (p.1907). Their work suggests that a better understanding of this therapeutic alliance between the service user and the practitioner and its influence on rehabilitation is yet to be fully investigated. However, their early exploration of related literature indicates that participation in rehabilitation and rehabilitation outcomes are heavily influenced by how service users and practitioners relate to each other and collaborate together.

This theme of practitioner responsibility in taking a person centred approach to practice is further explored by Bright et al., (2012) and Mudge, Stretton and Kayes (2013) in the following section.

Perceptions of person-centred and client-centred approaches

Much has been written in the literature about both person centred and client centred approaches to practice which reflect a commitment to working with service users (Law, Baptiste and Mills, 1995; Corring and Cook, 1999; Cott, 2004; Sumison and Law, 2006). As has already been identified, the terms client centred and person centred are regularly used in practice, but whether they are fully realised in practice is hotly contested by academics and service users alike. Surprisingly little has been published which focuses specifically on practitioners undertaking personal enquiry into implementing person centered approaches in neurological rehabilitation. This would enable greater understanding of how practitioners perceive they influence neurological rehabilitation.

Bright et al. (2012), however, did adopt such an approach and used an auto-ethnographic methodology, to understand the socio-cultural influences on their practice whilst implementing a client centred goal setting programme in traumatic brain injury. Their research formed part of a wider programme, which used a clinical trial to introduce innovative person centred goal setting techniques. Through their co-inquiry, Bright and her colleagues developed an awareness of the impact on service users of positioning themselves as an expert and taking a deficit approach to the assessment and treatment of impairment. These insights enabled them to understand how their assumptions of professional expertise and their unintentional paternalism created barriers to developing an effective therapeutic relationship. Their stance rendered them blind to what was meaningful to service users, ignoring their strengths and aspirations. The requirement to work in a new way as part of the clinical trial on goal setting, led them to articulate a new philosophy of practice that aspired to work *with* service users in a way that

was empowering. They noted that their assumptions shifted and their starting point for engagement with the service user changed from:

> *'"what can I do for this person" to "who is this person and what do they need"...[which] promotes a client-centred partnership with shared power' (p.1003).*

They suggest that by adopting this approach therapists will move from focussing purely on the technical, intervention aspects of rehabilitation, to prioritising what is actually important for the service user.

Their findings have clear resonance with the work of Hammell (2013), Cott (2004) and Mortenson and Dyck (2006) all of whom articulate the need for practitioners to undertake critical reflection of the power relations between themselves and the service user in the practice context. These authors suggest that such critical reflection will move practitioners from the rhetoric of good intentions and holding assumption about what is important to the service user, to finally prioritising in clinical practice what really matters to the service user.

Mudge, Stretton and Kayes (2014) took part in the same clinical trial as Bright et al. (2012). They also used auto-ethnography to reflect on their experiences as neurological physiotherapists engaging in an overtly person-centred paradigm of practice. Through their investigation of their own practice, they uncovered a tension between their traditional biomedical model of physiotherapy practice and a person centred approach. They clearly experienced considerable emotional discomfort when using person centred approaches to goal setting which focussed on the social, psychological and ethical dimensions of practice and therapeutic relationships. Their reflection below highlights their deep distress at recognising the impact of their usual physiotherapy practice:

> *"I think we have both been quite shocked at the paternalism that we recognise in ourselves. We think we have embraced client centred*

practice, but we haven't; we don't have a clue about it" (Mudge,
Stretton and Kayes, 2014, p.460).

This honest and personal investigation led the authors to suggest that this
tension between their usual physiotherapy practice and a person centred
approach need to be recognised and acknowledged by the wider profession.
They state that the body as machine philosophy adopted by physiotherapy
limits the possibility of fully adopting a person centred approach due to its
lack of recognition of the holistic needs of service users. Therefore, they
suggest that physiotherapists need to embrace strategies that actively seek
service user perspectives in order to compensate for the professions
mechanistic approach. This study highlights the importance of
understanding how historical and taken for granted assumptions and theories
of practice influence the relationship between staff and service users.
Additionally, it reinforces the importance of staff undertaking a critical
analysis of their practice in order to recognise those assumptions and
understand how and why is affects the adoption of more person centred
philosophies of working.

This tension between client centred practice and adopting assumptions that
are based on a positivistic paradigm is replicated in other professions and
can also be seen in research practice. Gillen's (2010) review of neurological
rehabilitation studies in occupational therapy highlights an emphasis on
quantitative studies and as such reflects the prioritisation that is given to
knowledge that is constructed by practitioners. This reflects the lack of
reference to service users in identifying and prioritising research topics as
well as the dismissing the potential for knowledge to be built in accordance
with service users' personal experiences of neurological rehabilitation. Such
a stance is built on the assumption that service user experiential knowledge
is not valid in research that is clinically orientated and privileges practitioner
expertise. Indeed, in a subsequent review of studies in neurological
occupational therapy, Powell (2016) argues that neurological rehabilitation
research, which focussed on the priorities of service users, would actually
lead to better crafted service delivery. It would seem therefore, that despite

the rhetoric of client centred practice, practitioners continue to hold assumptions on behalf of service users about what matters to them, thereby reinforcing traditional hierarchies between service users and practitioners.

There is evidence of wide range of practitioner perspectives on neurological rehabilitation, from those that emphasise a commitment to ensuring the service user is in receipt of effective intervention, to those that espouse a philosophy of client or person centred practice. The literature seems to suggest that practitioners are strongly influenced by the culture within which they practice, whether this is their own professional culture or the neurological rehabilitation context. Davies and Mannion, (2013) state that it is in such cultures that patterns of shared assumptions are held, suggesting that the culture of practice influences how practitioners view their relationship to the service user and how they work together with them. The studies discussed in this section suggest that critical reflection is important in order to raise awareness of the impact of practitioners' taken for granted professional ways of working. Some academics specifically exhort practitioners to engage in dialogue about the tension and disconnect between practitioner paradigms and espoused person centred approaches. This suggests that without critical reflection, changes in practice that attend to the lived experience of service users are less likely to take place.

2.4   Defining and contextualising inclusion

Inclusion is conceptualised in the literature in a variety of ways, depending upon the particular perspective that is being adopted and the context in which it is being discussed. As such, inclusion can be viewed as valuing difference or alternatively merely expecting people to fit into existing systems and services (Swain et al. 2003). The words social inclusion and inclusion are often used interchangeably; the former usually refers to groups of people who are excluded from society or social support (Buckmaster and Thomas, 2009), whereas the latter recognises that inclusion is important to all of us as individuals in our daily interactions with each other (Goodin, 1996). The literature pays significant attention to issues of social inclusion of minority

groups for example the inclusion of disabled people (Swain et al. 2003; United Nations, 2007); the importance of inclusion through interaction is particularly evident in relation to the education of disabled young people (Cook, 2004b) and people with learning disabilities (McPhail and Freeman, 2005; Wallmesley and Johnson, 2003). However, there is only very recent evidence of its importance specifically within neurological rehabilitation (Cook et al., 2011). Despite an increasing use of the rhetoric of inclusion within health policy (United Nations, 2007; DH, 2001; 2005a), Cook, (2012) argues that the differences in meaning that are attached to the term inclusion creates ambiguity that is misleading and unhelpful. As such, a clear distinction between inclusion and integration is called for (Swain et al. 2003). The following sections will critically review the literature on inclusion, its definitions, some of the complexities that that exist in the term inclusion and some of the different perspectives that are held about inclusion that are particularly relevant to healthcare and this study.

2.4.1 What is inclusion?

Inclusion is viewed as a complex notion, thereby defying easy definition (Buckmaster and Thomas, 2009; Bigby, 2012). Indeed, it is this lack of clarity around these definitions and meanings of inclusion that is in itself problematic (Cook, 2012) and can have the unintentional consequences of leaving people feeling marginalised (Hyder and Tissot, 2011). What is apparent from the literature is that it is a concept that really matters to people because its primary purpose relates to our fundamental need to participate with other people (Lombe and Sherriden, 2008). For example, the importance of inclusion to people with learning disability is stated as:

> " [Inclusion] means being able to participate in all the aspects of
> community – to work, learn, get about, meet people, be part of social
> networks and access goods and services – and to have the support
> to do so" (DH, 2009, p.20).

The literature indicates that inclusion is informed by a set of principles that recognises:

- Everyone has a right as a citizen to be included in society on an equal basis with others (United Nations, 2007; Hammell, 2015; Young, 2000).

- "...everyone has something to contribute" (Lombe and Sherriden, 2008, p.204).

- Everyone's differences are celebrated and valued (Swain et al., 2003; Swain, French and Cameron, 2003).

- The diversity of people's needs is recognised (Swain et al., 2003).

- Removal of attitudinal or physical barriers to inclusion (Oliver, 1996; French and Swain, 2008).

- A commitment to communication through the "endeavour of ...forging shared understandings" (Cook et al. 2011, p.15; Habermas, 1984; 2008)

Studies suggest that these principles can have a beneficial influence on people, enabling choices to be made about the way they live their lives (Cook et al. 2011) and the way they feel connected to their communities (Goodin, 1996). Additionally, rights as citizens can be enacted (Whiteford and Pereira, 2012) and people experience a lack of oppression, marginalisation or exclusion from participating in society or interactions with others (Young, 2000; Buckmaster and Thomas, 2009; Oliver, 1996, Swain et al. 2003).

Drawing on their work in the UK education system and the requirements of disabled young people as they moved from special school to mainstream school, Cook and Swain (2001) provide a helpful summary of inclusion that synthesises some of its fundamental principles. The authors suggest that inclusion is:

"... based on a philosophy of the positive valuation and celebration of difference. An inclusive [environment] is barrier-free and is accessible to all in terms of the buildings and grounds, curricula, support systems and methods of communication" (Cook and Swain, 2001, p.187).

This view of inclusion as "a philosophy" (Cook and Swain, 2001, p.187), suggests that it is a way of being, thinking and doing together. This commitment moves beyond the mere delivery of a technical skill of including people or the easy fix of requiring people to fit into or be "integrated" into existing services or established systems (Swain et al. 2003, p. 115). These authors would therefore seem to imply that inclusion is based on a set of principles that guide thinking and behaviour in relation to society and the nature relationships and interactions. Not all authors share this view of inclusion, a point that will be revisited later in this section. Inclusion is viewed by a number of authors as a challenge, it is stated that it is "a struggle" (Swain et al. 2003, p.115) or a concept to be "grappled with" rather than necessarily solved (Labonte, 2004, p.121). Viewing it in these terms highlights what Labonte (2004) calls the "dialectical dance" between the hope of inclusion against the inequality of exclusion (p.120). This binary logic between inclusion and exclusion appears to be generally accepted in the literature, but which comes first remains a point of discussion and debate (O'Reilly, 2005). Indeed Labonte, Hadi and Kauffman (2011) working in the field of social exclusion even suggest that there is little clear distinction between these concepts of inclusion and exclusion, other than "one represents an undesired state [exclusion] and the other it's desired reversal [inclusion]" (p. 7). So does it matter which comes first, inclusion or exclusion? In her seminal work on deliberative democracy, Young (2000) argues that inclusion arises out of a position of exclusion, she states:

> *"Calls for inclusion arise out of experiences of exclusion – from basic political rights, from opportunities to participate, from the hegemonic terms of debate. Some of the most powerful and successful social movements of this century have mobilized around demands for oppressed and marginalized people to be included as full and equal citizens..." (p.6)*

Her work postulates that a democracy that is inclusive is not merely about the equality of political rights, but also requires attention to be paid to the voice of under-represented groups of people who experience social or

economic inequalities. Similarly, other authors who have a concern for social justice also start from a position of seeking to understand exclusion in order to create a more inclusive society (Levitas, 1996; Levitas et al. 2007; Kitchin, 1998) and inclusive health care (Jackson, 2000).

In the field of inclusive education in the UK, initiatives to develop education for children and young people who are traditionally marginalised started from a place of addressing issues of exclusion (Barton, 1997). Over time however, increasing emphasis was paid to what inclusion means to young people and their parents and how this could be embedded in school policy and practice (Baker and Zigmond, 1995; Cook, Swain and French, 2001; Cook and Swain, 2001). The literature suggests that by paying primary attention to inclusion rather than exclusion, it has been possible to construct positive principles of practice and engage in critical dialogue in order to change practitioner thinking and ultimately action (Cook, 2004a). However, Levitas et al. (2007) in their critique of the policy Every Child Matters question whether taking an approach, which is positive, seeks primarily the wellbeing and inclusion of the child, actually ends up placing too much responsibility for inclusion on the individual. They suggest that such an approach actually limits the chances of inclusion, because it does not get to the heart of structures and issues that act to exclude.

Cameron (2006) however argues that it is because inclusion lacks definition that attention has focussed on the problems of exclusion rather than the possibilities of inclusion.   In relation specifically to social inclusion he states that it is because inclusion is viewed as "mainstream" and "self-evident" that it is predominately both measured and defined against conceptions of exclusion (p. 397) and therefore it lacks critical understanding. Such differences in definition are illuminated by Vorbura's (2000) account of inclusion. Unlike the authors cited in the preceding paragraphs, he holds the assumption that institutions can define inclusion. Here, gatekeepers, act as the arbiters of inclusion or exclusion, provide access to systems and services for example a doctor providing access to medical care or therapies. Indeed,

other authors would view such an assumption, which requires people to fit into systems, as exclusion or possibly at best mere nominal inclusion (Oliver, 1996; Swain et al. 2003). Vorbura's (2000) view would seem to imply that inclusion is reduced to either being 'in' for example medical care or 'out' of medical care. Goodin (1996) suggests that such a delineated view marks "the endpoints, the boundaries, the margins of our stay" (p.347). He suggests, that such boundaries inherent within the term inclusion are also reflected in the way it is used in politics and wider society. People are merely pushed "just over the line" (Goodin, 1996, p.349) and therefore whilst the assumption is held that they are included, in actuality, they are merely nominally included and remain on the border line or at the margins of society or groups.

It would seem that the literature does indeed indicate that the binary between inclusion and exclusion is inescapable; however, whether inclusion or exclusion should be the starting point of enquiry about exclusion or inclusion is a continuing debate, which is in part influenced by the perspective of the author. As identified in the work of Cameron (2006), it is the lack of clear conceptual definition and our assumption that inclusion is a "social expectation" (p.397) which means that inclusion can therefore only be identified through negative experiences. Additionally, this lack of conceptual clarity risks the development of an "illusory consensus" (Edelman, 1964; Cook, 2012) and it is only on digging beneath the surface that this is revealed as a mere superficial agreement rather than a shared understanding. Despite the problematic nature of the term and its multiple meanings, there is an overarching consensus of the need for social inclusion and inclusive interactions with others, to ensure that those people who are on the margins of society have the opportunity to be included and actively participate within society and the communities that are meaningful to them (Labonte, 2004).

Having explored some of the overarching debates and complexities inherent in academic inquiry in the field of inclusion and social exclusion, the following

sections will address some perspectives that are of particular relevance to neurological rehabilitation, these include perspectives on: inclusion in relation to UK policy, inclusion as a right, inclusion and integration and inclusion through critical dialogue.

2.4.2 Inclusion in UK policy

In neurological rehabilitation and rehabilitation policy more broadly, inclusion is not the preferred term. Instead, references are made to person or client centred practice (DH, 2005a), shared decision-making (General Medical Council, 2013; DH, 2010) and service user involvement, particularly in the design and shaping of services (DH, 2008a; 2015). In 2005 however, in its policy document "Improving the Life Chances of Disabled People" (Prime Ministers Strategy Unit, 2005), the government situated inclusion at the heart of its programme of action for disabled people. This stated that the purpose of the programme was to:

> *"...bring disabled people fully within the scope of the "opportunity society". By supporting disabled people to help themselves, a step change can be achieved in the participation and inclusion of disabled people" (p.7).*

The programme aimed to address and remove barriers that prevented inclusion and create a culture of support and empowerment. Inclusion was viewed as the vehicle through which disabled people would have access to opportunities, whether this was in the transition from childhood to adulthood, gaining employment or engaging in the local community. Inclusion was seen as an important principle underpinning health practice that held the potential to promote "choice and control" in both the design of products and services as well as in treatment (Prime Ministers Strategy Unit, 2005, p.64).

Reference in this policy was also made to inclusion within schools. Indeed, this is where the principle of inclusion was first embedded within policy and subsequently implemented, as Local Education Authorities sought to find a

way to manage the reorganisation of the school system and avoid the segregation of disabled pupils (Cook and Swain, 2001). These education initiatives subsequently helped inform health policy for people with learning disability and inclusion became central in policies that shaped both services and practice for that particular group of people (DH, 2001; 2009; Emerson and Baines, 2010). However, as the Winterbourne View report (DH, 2012a) into the abuse and ill treatment of people with learning disability indicates, it cannot be assumed that a policy on principles of inclusion through rights, equality and choice means that these principles will necessarily be embedded in practice. The failure to fully deliver on inclusive policy for all people with learning disability is widely acknowledged (DH, 2001) and there is recognition that in order for inclusion to be realised, an ongoing commitment from all sectors of government, practice and the wider community is required (DH, 2009). Indeed, Clegg et al. (2008) argue that inclusion as a policy for people with learning disabilities failed because it lacked attention to what actually matters to learning-disabled people and their families is a sense of belonging and being able to participate in activities that are meaningful. It would seem that assumptions held by policy makers and professionals about what is important to learning-disabled people are prone to error. Clegg et al. (2008) argue that the markers of inclusion laid down by policy for people with learning disability merely place a young person "somewhere" rather than support them to "become someone" (p, 93). This view challenges the conceptualisation of inclusion in policy as an outcome or endpoint (Goodin, 1997) and argues for an articulation of inclusion that is more strongly based in relationships and interaction.

An inclusive practice initiative in mental health aimed to address the issue of both inclusion in society and inclusion in the interactions between service users and professionals: The Capabilities for Inclusive Practice (DH, 2007a) document placed the values of for example "working in partnership; respecting diversity, practicing ethically; challenging inequality; identifying people's strengths and needs, providing service user centred care..." (p.2) at the heart of everyone's job from commissioners to grassroots staff. This

document viewed the NHS workforce as essential in opening up opportunities for inclusion to be realised for people with a mental health issue and, therefore, called for staff commitment to reflection on the values outlined, in order that practice might be challenged and changed (DH, 2007, p. 1). Whilst values such as client centred care continue to be evident in subsequent NHS policy, for example the NHS Constitution (DH, 2015), the link between inclusion and the capability of staff to reflect and challenge their own practice is not an obvious thread in subsequent policy initiatives. As Cook (2004a, p. 93) identifies, such commitments to personal reflection and change do not have ready tangible and measurable outcomes and therefore are often side-lined in favour of a quantifiable output. In the health service, these are often associated with performance targets and service efficiency (National Audit Office, 2011). However, these are also recognised as problematic in the delivery of quality care within the NHS (Ham and Murray, 2015).

In recent years, inclusion no longer appears as a central tenet of UK health policy. Instead, the rhetoric emphasises the need for service users to be increasingly involved and control of their own health care (DH, 2014) based on the assumption that these are of benefit to service users. This emphasis on involvement in one's care and treatment has increased in intensity with initiatives to support service users to self-manage their condition (DH, 2005b; 2006) and more recently their own services, through the introduction of personal budgets (DH, 2012b). However, Warsi et al. (2004, p.1648) argue that self-management programmes, which aim to educate service users about their condition and give them more control over their health (DH, 2005b; 2006b), are "conceptually appealing... [and] a means of empowering patients", but that evidence shows that they are not necessarily effective in either their achievement of empowerment or reducing the costs of health care or improving outcomes. There is some recent evidence of the self- care agenda giving more control to service users and their families (D'Silva, 2011). However, it would also seem that there is an assumption that self-care programmes work for all service users. Such a "one size fits all"

approach belies the complexity not only of an individual person's condition, but also of the broader social context of people's lives and can easily lead to service providers interpreting service-users' lack of engagement with self-management programmes an "non-compliance"(Kendall and Rogers, 2007; Trappenburg et al. 2013). Indeed, Wanless (2002) suggested that service users should become more fully engaged with their treatment, not necessarily for the benefit of the service user, but to reduce the costs of service provision, particularly for people with long term conditions. Not surprisingly, Swain et al. (2003) have criticised this assumption that it is possible for "one size to fit all" in the management of health, as reflecting not the inclusion of service users, but merely service-users' integration into the existing expectations and requirements of NHS services and their providers (Swain et al. 2003).

On the other hand, Foot et al. (2014, p. 57) suggest that the recent changes in health policy towards more service user control in the management of their health, heralds a new relationship between service users and practitioners that requires a less paternalistic approach, greater emphasis on collaboration and attention to the imbalance of power. It would certainly appear that there is increasing recognition that service users are experts through the experience of living with their health condition. However, Cook et al. (2011) argue that merely giving service users control in a clinical situation does not necessarily mean to say that they have control over the choices they wish to make about what is important in their lives. In their study, Cook et al. (2011) identify that service users do not necessarily want control over everything, but instead, would like to choose what they have control over, with the recognition that this may also change during the course of treatment. They suggest that it is this dialogue about choice and control that is so important to inclusion, rather than the control itself.

In recent years the term 'involvement' rather than inclusion has become increasingly embedded in NHS policy leading to the use of phrases such as "Real Involvement" (DH, 2008a), "Nothing about us without us" (DH, 2010)

and the "right to be involved" in care, treatment and the planning of health care services (DH, 2015). Such terms recognise the importance of experiential insights of service users to practice and research (Glaseby and Beresford, 2006) and are based on the assumption that service user involvement is a good thing (Beresford, 2002). The concept of involvement, however, has been viewed as problematic in health care practice, in part, due to its lack of clear definition (Hui and Stickley, 2007) and the way in which it sustains traditional power hierarchies between service users and staff (Stickley, 2006). This suggests for example, that merely inviting service users to be a part of the agenda of the organisation, does not necessarily mean that service users are meaningfully involved and have a voice in their own health and influencing services (Ocloo and Matthews, 2016). Policy generally appears to promote involvement as an "activity" (DH, 2008a, p.16), something that staff are required to "do" with service users. Viewing it solely in this way, suggests that the assumption is held that involvement is merely a product or an output rather than a process of engagement. This runs the risk of neglecting any philosophical discussion about the value of different kinds of knowledge that are essential in informing the construction of both health and social care interactions and service development (Beresford and Croft, 2001).

The policy documents that have been referred to highlight that in health care, the notion of inclusion draws together under one banner many of the values and principles that NHS staff, policy makers and service users hope will be delivered on a day to day basis in practice. However, its place within health policy is, patchy, and reference to inclusion in recent years is less evident, perhaps indicating that it is a term favoured by some governments and policy writers and not by others. It is also apparent that the term involvement is preferred over inclusion, suggesting that developing and adopting policy with inclusion at its heart is not an easy option and one that is only occasionally actively pursued. Despite this lack of focus in UK health policy, internationally, the assumption is held that inclusion is a right, particularly for disabled people (United Nations, 2007).

2.4.3 Inclusion as a right

Awareness of inclusion as a right is not a recent development in international policy, indeed despite the term not being used specifically, the ideal of human dignity, equality and the freedom to participate in society Universal Declaration of Human Rights 1948, speaks to many of the principles outlined at the beginning of this section on inclusion. It is a right that is reiterated for disabled people in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007) which states that disabled people should have the right to:

> *"full and effective participation and inclusion in society" (United Nations, 2007, p.13).*

Whilst each country has a responsibility to promote the legislation and combat negative stereotypes towards disabled people, it would seem that assumptions that the presence of legislation results in its realisation in practice, could not be relied upon. Indeed, a recent review of the convention in the UK (Equality and Human Rights Commission, 2014) identified that there is little evidence that disabled people have a say in the societal issues and community services that concern them, access to buildings, transport and information remain problematic. The report also suggests that current welfare reforms are actually reducing the opportunities for disabled people to be included in society, suggesting that these may even potentially deny disabled people their right and choice to live in the community as opposed to living in residential care. These fundamental changes in welfare are effecting disabled people's right to inclusion in both the issues of daily life and work. They are seen as having their roots in assumptions that the disabled person is the problem that needs to be fixed, rather than a recognition that there are societal and attitudinal barriers to inclusion that need to be addressed (Shakespeare, Watson and Alghaib, 2016).

A number of authors identify that a rights based approach to health care is not sufficient in itself to ensure the inclusion or involvement of service users, they advocate that attention also needs to be paid to the interactive process

between service users and professionals (Harra and Salminen, 2015; Lewis, 2009). Harra and Salminen (2015) investigated the rights of people to be included in the Finish health system. They argue that that even if rights based legislation is in place, the respect and inclusion of disabled people requires changes to be made not only at organisational levels, but also in the interaction with health practitioners. They identify that there are both internal and external barriers to a disabled person implementing their right to be included in their own health care. Internally, these include negative attitudes towards oneself and the volition to act, both of which can be influenced by professional assumptions of service user capacity and capability. Externally, alongside the requirement of an accessible environment, the ingrained assumptions, taken for granted rules and habits of significant others can historically influence the roles that are traditionally adopted by the disabled person and the degree of autonomy with which these roles are enacted. The authors suggest that "therapeutic collaboration" which includes building reciprocal relationships, deliberative judgement and implementing choice, should be framed within the context of the human right to inclusion and are central to this interactional process (Harra and Salminen, 2015, pp.98-99).

Lewis (2009) analysed the discourse relating to involvement in treatment and services in mental health, she identified that despite the values of a rights based approach being adopted, labelling people as service users marked people out as different from others, which in turn had a marginalising effect supporting exclusion rather than inclusion. Lewis (2009) identifies that "non-recognition and disrespect", (p.261-266) and "misrecognition [in relation to] authority and credibility" (p. 266-269) are key issues if the rights of people with mental health issues, to be included in their own health care, are to be realised. She highlights that even within a rights based framework, service users often held the assumption that they were inferior to others, thereby highlighting the insidious nature of power to undermine the voice of service users. She argues for recognition of the systemic cultural and societal inequalities that exist within the traditional hierarchical relationships in healthcare and particularly the impact of a medicalised model of intervention, which views the individual as the problem to be solved. Indeed, she

advocates for a social model approach to be adopted in order to disrupt the taken for granted schemas of medical discourse in mental health (Lewis, 2009). This call for the disruption of assumptions through the application of disability theory is a consistent theme throughout the literature when the need for a change towards more inclusive ways of working in practice is identified.

2.4.4 Inclusion or integration?

The words inclusion and integration are often used interchangeably (Cook et al. 2011) as evidenced in Labonte, Hadi and Kaufman (2011, p.7), however it is suggested that there is a significant difference in the meaning between the two terms (Swain et al. 2003; Cook et al. 2011). The origin of the notion of integration relates to people being integrated into the labour market (Levitas, 1996, p.5), but was later adopted by the disability community and viewed as the requirement of disabled people to fit in to existing services or systems (Oliver, 1996; Swain et al. 2003). Inclusion on the other hand is viewed as involving society making changes in order to meet the needs of disabled people Swain et al. (2003). Swain et al. (2003) suggest that the primary differences between integration and inclusion are outlined in Table 2.

Table 2. The difference between integration and inclusion. After Swain et. al. (2003. p.115).

Integration	Inclusion
- Is a product - Non problematic and taken for granted - Requires professionals to acquire special skills - Requires the acceptance of disability as a personal tragedy - Dominant value is what is perceived to be normal - Is professionally led and can be delivered by professionals	- Is a process - Problematic, raises issues and questions about service provision - Requires professionals to commit to accessible services - Requires a positive valuing and celebrating of difference - Dominant value is the value of the diversity of need - Involves struggle, negotiation and is partnership led

Whilst there is continued debate about these terms, Cook et al. (2011) suggest that integration 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" (p.35).

In contrast, they state that inclusion is.

"...a process that involves society making changes, both physical and attitudinal. It embraces diversity. It enables people to be in control of their lives and the choices they make in relation to their lives" (p.35)

Such clear differences between the meaning of the terms are influenced by the social model of disability that has already been advocated as supporting a perspective of inclusion that attends to the social context (Kendall and Rogers, 2007) and recognises the individual (Lewis, 2009). Evidence for the integration of disabled people and service users is rife within the rehabilitation literature due to its reference to the medical model (Hammell, 2006). In his seminal paper, DeJong (1979), noted that the medical model traditionally holds the assumption that the medical practitioner is the expert and assumes that the service user will take a compliant role. In his seminal paper which critiques a medical model approach to rehabilitation DeJong (1979) states that such an approach determines that the individual is the problem because they are no longer able to carry out an "adequate performance" (p.442). The best outcomes of rehabilitation are therefore perceived as a return to a previous level of skill in activities of daily living and return to work. The medical model argues that interventions supporting these aims can only be diagnosed and carried out by an appropriately trained person. It would seem that DeJong's critique mirrors many of the issues raised by Swain et al. (2003) in their presentation of "integration" as outlined in Table 2. It could therefore be postulated that a medical model merely acts

to integrate service users into existing NHS systems and hierarchies and it is the service user who is required to the adapt and fit in, rather than the specific needs of the person being met.

Similarly, the view that the individual is the problem is reflected in the perspective that disability or impairment is a "personal tragedy", as such, disabled people are viewed as being victims of circumstance, dependent on others and unable to make decisions for themselves, thereby requiring the help and charity of benevolent others (Oliver, 1993; Swain and French, 2004). This conceptualisation of disability is constructed by non-disabled people who fear that they may become impaired (Swain and French, 2004) and as such need to reinforce their own position of superiority in order to bring stability to the situation (Hughes, 2012). Hughes argues that holding this assumption that disabled people are dependent can result in their invalidation as people. This implies that these assumptions of dependence mean that inclusion are not based on the notion of equality, but merely leads to the dominant person or people defining the boundaries of choice. They therefore also impose their conceptualisation of what inclusion looks like and feels like. Shakespeare (2006) also supports the view that charitable giving situates the person in a position of dependence. He notes that charity "paradoxically undermines the goal of acceptance and inclusion" (p.155). He argues that such assumptions of dependence do not address social inequality and the barriers that exist to inclusion, but merely reinforces the dominant view of what it means to be disabled and dependent. He does however raise the point that many charities now adopt policies that engage in the political struggle for the inclusion of disabled people and are indeed service user led (Shakespeare, 2006), it would therefore seem that such an approach brings them more in line with the conceptualisation of inclusion as outlined by Swain et al. (2003).

Disability academics view inclusion as a positive process by which people actively participate with others (Swain et al. 2003). As such, the process of inclusion is therefore closely connected with the relationships and

interactions between people in health care or society more broadly and these interactions play a significant role in experiences of inclusion (Cook et al. 2011). Some disability scholars have been interested in the importance of these micro interactions in influencing how people perceive themselves and therefore construct their identity, particularly their negative impact (Thomas, 2004a; Reeve, 2002). Thomas (2004b) identifies that conceptualising disability as arising from interactions between powerful non-impaired groups and people who have a physical or cognitive impairment can readily lead to oppression and exclusion, resulting in feelings of powerlessness and worthlessness. Reeve (2002) argues that such negative and invalidating interactions or "disablism" (p.494) contribute to the "internalised oppression [that is] the ways in which disabled people internalise the prejudices and assumptions held by non-disabled people about them" (p.501). It would seem therefore that where one party assumes that their perspective is more valid than another, this influences these micro-interactions and relationships, playing a vital role in determining whether people feel included or excluded during their engagement with practitioner, services or other groups of people in society.

This view that the identity of disabled people is formed by the assumptions of others is contested by Watson (2002) who argues instead that identity is constructed through dialogue and therefore disabled people have a choice, refusing to be categorised on the basis of their impairment or reflexively accepting other people's definition of them. Whilst the detailed arguments around such identity politics are not the focus of this review, this brief overview highlights the influence of assumptions in the micro-processes of interaction and identifies the importance of positively valuing difference (Swain et al. 2003). This celebration of difference is also reflected in the literature that views inclusion as a process, which is constructed by people reflecting and learning together with others.

2.4.5 Inclusion as working together with others

People working together and thinking together has been recognised by Cook (2004a) as integral to the conceptualisation of inclusion. She therefore, does not view inclusion as a diverse range of people merely nominally grouped together, but sees it as a process of active co-labouring. She states that such this process requires:

> *"...a complex mix of trying to understand both self and others, personally and professionally, and at all levels of the hierarchy. It entailed accepting that the complexities of human diversity and the importance of recognising diversity are a means to working with and including others*" (Cook, 2004a, p.95).

Cook (2004a) argues from the evidence of a number of small action research projects that such a commitment to working together in this way holds the potential to challenge existing assumptions and taken for granted conceptions of practice, paving the way for change at a micro level. This conceptualisation of inclusion reflects the valuing and celebration of difference and the commitment to partnership previously outlined by (Swain et al. 2003). However, it would seem, that Cook's (2004) notion of inclusion goes beyond this and her subsequent work in neurological rehabilitation is based on the assumption that inclusion is realised through communication and dialogue, which is forged by service users and staff co-labouring together (Cook et al. 2011). The authors argue that such an inclusive approach enables people to have real choices rather than merely choice from a pre-prepared menu devised by someone else, supports shared decision making, promotes personal agency and control and recognises the person at the heart of the process (p. 16).

This connection between inclusion and critical dialogue, which presents an interactional approach to inclusion, is also reflected in the work of Habermas, particularly his ideal speech situation (Habermas.1984; 2008). Habermas (2008) identifies four key elements that support honest, critical dialogue

between people in pursuit of democracy.1) Inclusiveness: Anyone who can make a relevant contribution must be included; 2) Equal rights: Everyone must have the same opportunity to speak; 3) No deception: Participants must mean what they say; 4) Absence of coercion: Raising issues and critiques must be unconstrained (Habermas, 2008, p.50)

Habermas (2008) seems to suggest that inclusion is a deliberate act, one that is based on responsibility, reciprocity and engaging with each other. The additional elements of no deception and the absence of coercion require those working together in such a dialogue to be cognisant of how positions of power and privilege can constrain and coerce. If taken on its own, his statement about inclusiveness initially appears somewhat inadequate, particularly in the light of Cook (2004a) and Cook, et al.'s (2011) conceptualisation of inclusion. However, combined with the other elements of the ideal speech situation, together these more closely reflect Cook, et al.'s (2011) view of inclusion.

Aspiring to Habermas' ideal speech situation, Bowen, Yeates and Palmer, (2010) advocate for a relational approach to the rehabilitation of brain-injured adults. Such an approach recognises that creating positive and inclusive social interactions and social environments are crucial to how people re-construct their lives after brain injury. However, Gillespie et al. (2014) suggest that the context of health care does not readily support Habermas' ideals of dialogue that have inclusion at its heart. They give the example of communication strategies adopted by people with aphasia (difficulty in comprehending or producing speech) and their families, identifying that whilst family members recognise the right of people to speak for themselves, in reality the ideal speech situation is not possible. They suggest that this is influenced by not just the challenge of including the person with aphasia, but carers themselves will often deceive by covering up their true feelings. Consequently, this negates the opportunity for honest conversations between themselves and their partners. The authors advocate that the realities of such asymmetries of power in health care be recognised. This

requires that difficulties in achieving the ideal speech situation are acknowledged and attention be paid to how people constrain dialogue in order to manage difficult and challenging situations.

These studies highlight the importance of actively working and collaborating together so that inclusion itself is constructed by those involved through interaction and dialogue. It would seem that if based on the Habermasian ideal speech situation finding ways of working together is more challenging and there are questions about whether this can be fully realised particularly for people who have communication needs. Drawing on a social model approach, Cook et al. (2011) however argue that inclusion can only be realised through an approach to practice that is inclusive in itself. This means that whilst there are barriers to inclusion these are engendered through a lack of appropriate and effective support, organisational systems that require people to 'fit in' and beliefs about NHS practice culture that can lead to both service users and staff having fixed views about their inclusion in neurological rehabilitation practice. However, Cook et al. (2011) do not unpack these fixed views and assumptions about neurological rehabilitation and how they influence service user and staff experiences of inclusion, which will be the purpose of this study.

2.5   Summary

This literature review had identified the centrality of assumptions to thinking, behaviour and action and the importance of developing an awareness of assumptions through critical reflection and critical reflexivity. It has highlighted the importance of the relationship between service users and staff in the neurological rehabilitation process, recognising that this holds the potential to be either empowering or disempowering for service users. This is influenced by a lack of awareness particularly from practitioners of the influence of embedded cultural practices on their relationship with service users. The relational focus of inclusion supports the importance of service users and staff working together collaboratively, in a space where diversity is both recognised and celebrated. The concept of inclusion has only recently

been explored in neurological rehabilitation; however, it would appear to be part of small but growing interest in the importance of the relational aspects of neurological rehabilitation practice.

The literature highlights that there is a lack of empirical studies that specifically investigate assumptions in relation not only to neurological rehabilitation, but also more broadly in health care. Additionally, there is no evidence in the literature of empirical studies which specifically address the intersection between the three concepts of assumptions, neurological rehabilitation and inclusion. There is some empirical evidence that identifies the conditions that lead to changes in assumptions; however, there are very few examples in the field of neurological rehabilitation. The combination of the identification by service users and members of the funded research group of the perceived importance of an investigation into assumptions and their influence on inclusion in neurological rehabilitation and the gap in knowledge identified through the literature review led to the construction of the aims and objectives of this study.

Aim: To investigate and unpack assumptions held by service users and staff about neurological rehabilitation practice and examine their influence on inclusion.

Objectives:

- Identify the nature of assumptions held by service users and staff
- Illuminate assumptions participants hold about practice
- Identify the influence those assumptions have on experiences of inclusion
- Explore the conditions that lead to changes in assumptions: What enables these changes to happen?
- Identify the implications for practice of the study's findings

This study will also contribute to the critical dialogue on assumptions in rehabilitation started by Hammell (2006) and add understanding to the new

sphere of work started by Cook et al. (2011) in relation to inclusion in neurological rehabilitation. The following chapter will explore the methodology, design and methods that will support my investigation into this gap in knowledge.

Chapter 3: Methodology

3.1   Introduction

This study uses a qualitative methodology in order to understand the nature of participant's assumptions about neurological rehabilitation and their influence on inclusion. This chapter presents the choices I made in this study regarding firstly my overarching methodology and secondly my methods. The first section explains the reasons for adopting a participatory paradigm as the guiding set of beliefs, which form the basis for this study, followed by a discussion about the epistemological, ontological, and axiological perspectives that form the philosophical underpinning of the study. Following this, I will discuss the choice of symbolic interactionism as my theoretical framework underpinning the qualitative methodology and identify its relevance to this study. Finally, I will articulate the participatory action research approach used in this study with reference to its core principles and criteria for judging the quality of this study. Figure 4 provides a visual overview of the methodology adopted in this study. A chapter evaluating the quality of the study in relation to the participatory paradigm will immediately follow this chapter.
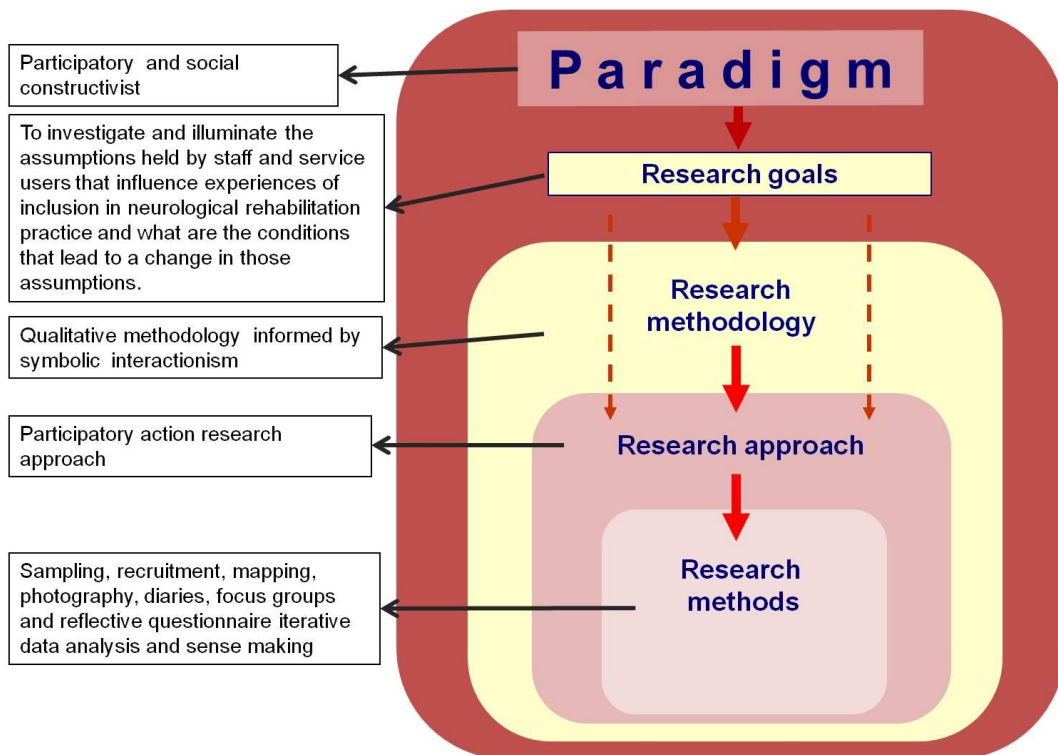
Figure 4. Overview of research methodology (Adapted from Higgs, 2001).

3.2 Participatory paradigm

"Maximis[ing] the participation of those whose life and work is the subject of the research process" (International Collaboration of Participatory Health Research, 2013, p.6) is at the heart of this study, and it is this commitment to participation that provides the "overarching paradigm or set of beliefs that guide action" (Denzin and Lincoln, 2005, p.183). Traditionally, participation has not been recognised as warranting a paradigmatic position in research (Guba and Lincoln, 2005). However, it has been argued that research that has participation at its core is not merely a technical method, but a specific orientation to research with its own principles and practices (Heron and Reason, 1997; ICPHR, 2013). This orientation is influenced by the attitude and approach of the researcher which determines "how, by and for whom research is conceptualised and conducted" (Cornwall and Jewkes, 1995, p.1667). It is an approach that reflects Freire's (1970) pedagogy of working *with* people rather than doing *to* people and offers a response to the critique

of disability theorists who have consistently argued that in rehabilitation, "the way [research] has been conceived, organised and conducted, as well as in the nature and use of results,... has been carried out by representatives of professional groups with little or no consultation with, or involvement of, disabled people themselves (other than as research subjects)" (Thomas, 1999, p. 152). Oliver (1992) maintains that such traditional concepts of research are based on the assumption that disabled people are merely passive objects of research or subjects in research, thereby reproducing the disabling conditions experienced in wider society

In contrast, participatory research provides a methodological approach that seeks to redress this criticism, aiming to give a voice to and collaborate with those people who are traditionally marginalised by dominant hegemonies in both research and practice (Kindon, Pain and Kesby, 2010). It is an approach that is inherently personal and political, valuing the knowledge and experience of participants and holds a commitment to creating positive change through the research process (ICPHR, 2013). Whilst participatory research has its roots in the emancipation of oppressed groups of people (Freire, 1970), more recently, a collaborative orientation to participatory research has been advocated which recognises not only the voice of the oppressed, but the experiences of all those who are affected by the area of study (ICPHR, 2013). This study recognises that service users and staff have knowledge and experience that are important not only to developing a new understanding about assumptions and how they influence experiences of inclusion, but also in the design of the study which enables those understandings to be accessed. This study, therefore, has a commitment to a participatory paradigm and is a collaboration particularly between service users and staff, but also recognises other key stakeholders who were involved in shaping the design and process of this study.

The core beliefs that guide this study and form its participatory paradigm are articulated in Table 3 as follows:

Table 3: Principles of participatory research (Adapted from ICPHR, 2013).

Principles of participatory research	
Participatory	Maximise the participation throughout the research process of those people whose life or work is the subject of the research
Locally situated	Research located in a social system
Collective research process	All group members are participatory researchers, investigating together the area of concern
Collectively owned	Ownership lies with the group
Aims for transformation through human agency	Aims to create positive change by empowering group members
Promotes critical reflexivity	Consider issues of power and powerlessness, leading to questioning and potential change
Produces knowledge which is Local, Collective, Co-created, Dialogical and Diverse	Knowledge created reflects what is known through local experience, reflects multiple ways of knowing, is created together through dialogue incorporating a wide range of perspectives
Strives for broad impact	Aims for social change that occurs throughout the process, not merely at the end

These key principles articulate the ideal set of beliefs that guide participatory research practice and have methodological and ethical implications for how my study is conducted and how people relate to each other. They are, therefore, fundamental in guiding the ontological and epistemological stance of this study.

3.3   Ontological perspective

My commitment to a participatory research approach recognises that social reality is created through social relationships and is developed in interaction between the participants and the researcher (Alvesson and Skoldberg, 2009). This is opposed to reality existing externally to participants. Such a stance accepts that there is not a single reality that is waiting to be discovered, but it is the participants and researchers who hold multiple realities through which meanings are ascribed to the situations of which they are a part (Guba and Lincoln, 2005). This view of reality informs the participatory approach which is central to this research and views data as being generated together rather than merely collected. In addition, I take the view that the existence and meaning of assumptions is actively created in

interaction, through the interpretation and negotiation of meaning associated with, for example, people, language and gesture.

This constructivist perspective of reality views participants as people "who use knowledge, who have theories about their practice [and lives] and who behave according to those tacit rules and procedures" (Higgs, 2001, p.52). This clearly indicates that research participants hold personal and indeed multiple perceptions of reality. Participatory research holds the belief that it is in the interaction of these multiple realities that new reality can be co-created and lead to change (Heron and Reason, 1997). My role as researcher and that of the people collaborating with me on the study is one that does not seek to separate out our views from the research process, but actively values them, recognising that it is our personal realities and commitments that actively shape the research design and delivery of the research. It is argued that by standing back and not engaging with participants the research process runs the risk that researchers view participants merely as objects from which to gather data. Indeed, Blumer (1969, p. 86) stated that:

> *"remaining aloof as a so called "objective" observer and refusing to take the role of the acting unit is to risk the worst kind of subjectivism".*

It is, therefore, only as researchers get close to the complex realities of participants' life and work experiences that understanding develops. The subjective personal realities of both the participants and the researchers are integral both in understanding assumptions and in how they influence inclusion in practice. As multiple realities are drawn together in dialogue, personal realities are reconfigured, leading to the generation of new understanding and knowledge.

Vasilachis de Gialdino (2011) cautions that despite the best of intentions, researchers who have traditionally engaged with an objectivist ontology - thereby anticipating that there should be distance between the researcher

and the participants- may have difficulty shaking off this stance. This is a caution worth noting, as despite my commitment to a participatory approach, my lived reality as a professional is one of exposure to expectations of objectivity and external measurement in both research and practice. Whilst this is balanced with a commitment to understanding the complexities of people's lives and engaging service users in the issues that concern them, the potential influence of the tendency to move towards objectivity is acknowledged.

This study, therefore, adopts an ontological position that is informed by a constructivist paradigm, recognises the subjective experience of both participants and researchers and, thus, the multiple realities embedded within those experiences. Reality, therefore, is, constructed between people as they interpret their own and each other's worlds, generating meaning and understanding pertaining to assumptions, and how these assumptions influence experiences of inclusion within neurological rehabilitation practice.

3.4   Epistemological perspective

Epistemology and ontology are viewed as being closely related as what is perceived as reality will influence perceptions of knowledge, indeed it is argued that they often merge together (Crotty, 1998). Epistemology is concerned with the nature of knowledge and how what exists can be known (Higgs, 2001) and provides a basis for deciding what kind of knowledge it is possible to generate and how these claims to knowledge can be judged in terms of their quality and validity (Higgs, 2001; Guba and Lincoln, 2005).

In line with its constructivist ontology, this study views knowledge not as static, but as being co-created through an interactive and dialogical process between the participants and the researchers. Maguire (1987) argues that when knowledge is produced by the communities themselves, this also provides a more accurate view of social reality:

87

> *"Participatory research proposes returning to ordinary people the power to participate in knowledge creation, the power that results from such participation, and the power to utilize knowledge... Participatory research assumes that returning the power of knowledge production and use to ordinary and oppressed people will contribute to the creation of a more accurate critical reflection of social reality, the liberation of human creative potential, and to the mobilization of human resources to solve social problems"* (Maguire, 1987, p.39).

Maguire (1987) appears to suggest that in participatory research the experience of those who are traditionally marginalised are privileged in order that knowledge can be created about the issues that concern them and lead to social change. Participatory health research acknowledges that service users' knowledge might ordinarily be side-lined, however, it also recognises that staff often lack a voice and may feel oppressed by health systems and practices (ICPHR, 2013). Indeed, Somekh (2002) argues that:

> *"...knowledge constructed without the active participation of practitioners [and service users] can only ever be partial knowledge"* (p.90).

It is in this breadth of participant experiences that knowledge can be created, thereby holding the possibility of generating an understanding of the whole situation under investigation. This study actively draws upon both service user and staff subjective experiences of using and delivering neurological rehabilitation services, respectively, to create new knowledge and understanding about assumptions and their influence on inclusion.

Cook (2012), however, argues that new knowledge is not merely created, but indeed it is "actively forged through critical discussion" through a wide range of methods. The forging of knowledge in this way also recognises the different ways of knowing in which subjective experience is grounded. Reason (2001, p.185) describes these as:

"experiential knowing or knowing through empathy and resonance with a person, place or thing; presentational knowing which is based on experiential knowing, but is expressed through imagery; propositional knowing or knowing about something through ideas or theories and practical knowing or knowing 'how to' do something".

Recognising these different ways of knowing adds a deeper layer to understanding how knowledge is created and, therefore, informs my choice of visual, oral and group orientated methods within this study, based on the assumption that different methods hold the potential to both tap into and challenge personal preferred ways of knowing.

How then can assumptions be known, as often these are tacitly held and not open to ready identification? Brookfield (1998) suggests that we are unable to readily see our own assumptions because we only ever interpret situations from our own perspective. Indeed, McIntyre (2008) contends that:

"it is by participating in critical dialogue, in discussions in which people agree, disagree, argue, debate, are affirmed for their views and challenged for their views that participants truly experience the aha moments that come with self and collective scrutiny. It is that type of participation that provides the space for people to reflect on what is being discussed in the group sessions and then upon reflection, to take the necessary steps to improve their current situation" (p.32)

It is therefore suggested, that it is in these "aha" moments where people's multiple realities, different perspectives and different ways of knowing are brought together, that points of interaction and critical reflexivity will enable knowledge and assumptions that were once tacit to be brought out into the open and therefore "known". On this basis, this study sought to uncover service user and staff assumptions through the process of interaction, by bringing together multiple realities, different perspectives, different ways of knowing and supporting participants critical reflexivity. ?

3.5   Axiology

A participatory approach to research is recognised as being "rooted in the experience of the people it seeks to understand" rather than viewing research as the study *of* people (Titchen, 1994, p.15).Therefore, the relationship between the researchers and the participants in this study is one that recognises the importance of the interaction and inter-relations between all participants and researchers. It is a relationship that is historically rooted in an asymmetry of power between service users and staff (Hammell, 2006). Data generation, therefore, holds the potential for staff knowledge to be privileged over that of service users affecting the depth and honesty of disclosure during the research process. This study benefitted from the approach taken by the funded research, which, sought to create the space for honesty and disclosure by connecting service user researchers with service user participants and staff and academic researchers with staff participants. Studies adopting this approach are viewed as producing a quality of data that is honest and reliable (Staley, 2009). However, in her review of the evidence, Staley (2009) also identifies that having a shared experience can limit the depth of exploration of participant experiences. This observation is particularly pertinent in relation to assumptions, as it is difficult for assumptions to be illuminated and challenged when people share the same perspective (Brookfield, 1995; Claxton, 1999).

My own relationship to the context of this study has been previously highlighted in the introduction to this thesis. My interaction with service users holds the potential to perpetuate the power asymmetries between service users and staff. This is particularly problematic in creating honest conversations, if service users adopt a deferential position towards myself as the researcher. My interaction with staff during the research process, holds the potential to create a connection between three kinds of knowledge; propositional knowledge about neurological conditions and theoretical practice approaches, practical knowing through my experience of knowing how to act in certain situations and experiential knowing, in recognising how it feels to be faced with dilemmas or challenging situations in practice

(Reason, 2001; Higgs, Titchen and Neville, 2001).   The sharing of such knowledge holds the potential to generate data that is honest and credible, but also could render me blind to asking critical questions due to the degree of empathy and inability to stand back from the situation and see through a more critical lens. In addition, as a researcher I need to be mindful of how my knowledge and understanding of research theory and methods can influence the process of developing the study (ICPHR, 2013). Indeed, Townsend (2013) advocates that participatory researchers "expose the extent to which the participatory processes live up to ideals that they espouse" (p.339). With this in mind, reflection on the lived experience of facilitating the study against the espoused ideals of participation will be presented in Chapter 4. This will be set against Cornwall's (1996) continuum of modes of participation (Table 4). These present the nature of the relationship between the researcher and the people within the social situation being studied.

Table 4. Types of participation (Cornwall, 1996, p.96).

Participatory Methods: Means to What End?		
Mode of participation	**Involvement of local people**	**Relationship of research and action to local people**
Co-option	People are invited to join the agenda of others, but have no influence or power	on
Compliance	Outsiders decide the research and set the process	for
Consultation	Local opinions asked, outsiders analyse and set the course of action	for / with
Co-operation	Local people work together with outsider researchers determine priorities, responsibility remains with outsiders for direction the process	with
Co-learning	Local people and outsiders share their knowledge, to create new understanding, and work together to form action plans, with outsider facilitation	with / by
Collective action	Local people set their own agenda and mobilize to carry it out, in the absence of outside initiators and facilitators	by

Whilst there are a range of models that highlight different degrees of participation, this model provides the opportunity to map the intended degree

of participation against the key points of the research process in this study and where this assumption of participation is not attained, explore the reasons why.

Critical reflexivity is central to this process and recognises the interwoven relationship between the researcher and the participants. Indeed, Springett (2010) states that:

> "Engaging in true participatory practice also depends on ability and willingness to understand and reflect and to critically question as well as the skills to data collect and analyze" (p. 290).

Critical reflexivity holds the potential to uncover not only the assumptions of participants, but also my own assumptions and beliefs and understand how they might influence the research process. Specific examples of personal critical reflexivity will be presented throughout section 3.8.5 of this chapter and in Chapter 4, which evaluates the quality of this study.

3.6   Symbolic interactionism as a theoretical framework

The qualitative orientation of this research with its focus on the understanding and illumination of assumptions requires a theoretical framework that can support an enquiry into assumptions and the influence of human interaction on assumptions and subsequent action. Symbolic interactionism is a perspective recognised for underpinning qualitative research due to its underlying assumption that "individuals act on the basis of the meaning that things have for them" (Benzies and Allen, 2001, p. 541). The following section will outline this theoretical framework and its relevance to this study.

Symbolic interactionism (SI) provided the lens through which data was interpreted. It emphasises the centrality of interaction in the construction of meaning in the lifeworld of the participants, drawing attention to assumptions through the values of critical reflexivity. Symbolic interactionism is

recognised as a general perspective, rather than a theory; its emphasis on meaning and interpretation of meaning provides a useful framework for thinking about the assumptions that are held during interactions. Several authors have used SI as a framework to understand human interaction and behaviour in a social context following brain injury (Roscigno and Van Liew, 2008), in mental health (Saunders, 1997) and cancer rehabilitation (Handberg et al. 2015), supporting its relevance to health and neurological rehabilitation.

3.6.1 Premises of Blumer's symbolic interactionism

Blumer's (1969) work on symbolic interactionism is perhaps most widely recognised. Based on the work of pragmatist George Herbert Mead (1934) he suggested that symbolic interactionism is based on three over-arching premises:

> *"human beings act towards things on the basis of the meanings they have for them*
>
> *[the] meaning of such things is derived from, or arises out of social interaction*
>
> *these meanings are handled in and modified through, an interpretive process used by the person in dealing with the things he encounters" (Blumer, 1969, p.2)*

These premises indicate that individuals attach meaning to objects and act on the basis of the meaning rather than in relation to the object itself. They act based on the assumption that there is a shared understanding of meaning and individuals are independent agents, making choices and forming new meanings based on those choices and interpretations (Benzies and Allen, 2001; Handberg et al. 2015). Recognising and understanding different interpretations of the meaning of an object are, therefore, vitally important to this investigation of assumptions and their influence on inclusion.

3.6.2 Key concepts of symbolic interactionism relevant to this study

Whilst a full exposition of symbolic interactionism is not the purpose of this study, it is important to understand and provide a brief overview of the concepts of the symbol, the self, definition of the situation and role taking, which hold particular relevance to this study.

Symbol

Symbols are objects which hold meaning for those people who use them and they are used intentionally to communicate a message either to oneself or to others (Charon, 2011) and can include for example objects, words, colours and perspectives (Hewitt, 1988). Blumer (1969) suggests that it is when such a symbol holds the same meaning, understanding between people occurs. Indeed, I suggest that this is the point where both parties are also holding very similar assumptions about the meaning of such a symbol. However, it is also recognised that where symbols are used to represent a particular category, for example that of therapist or doctor, it is possible that the meanings associated with that symbol may be very different depending on experience and cultural differences (Hewitt, 1988). Indeed, although a concept such as inclusion might hold the shared meaning that it is something of importance and to be valued, there can also be a wide range of additional meanings associated with such concepts that can be readily glossed over, leading to misunderstanding or argument (Cohen, 1985). As such, it would appear that staff or service users are cautioned against assuming that symbols of neurological rehabilitation practice or of inclusion hold the same meaning for all concerned.

The Self

Central to symbolic interactionism is the idea that individuals can regard themselves as an object and, therefore, reflect upon their own actions, thoughts and feelings. This perspective views the self as a process, changing through interaction with others, rather than something that is fixed or static (Charon, 2011). Symbolic interactionists have built on the work of

Mead (1934) who suggested that the self is comprised of the "I" and the "Me". The "I" is the subjective self, which responds immediately and impulsively to an object or a situation. With growing awareness of the situation the "Me" phase emerges. The individual begins to see themselves through the eyes of others and enters into a dialogue with themselves about the situation, thereby providing a more measured and controlled response in line with social expectations (Hewitt, 1988). The self is, therefore, reflexive and in a constant inner dialogue in relation to the perceived meaning of situations, conforming to the perceived social expectations of others or choosing to act differently (Figure 5).

The reflexive self in interaction with society

The Self
"I"
(Subjective)

Me
(Objective)

1) "I" respond to the situation

2) Other people influence how I view myself within that situation

3) The "Me" acts towards the situation in line with personal decisions & goals

Society, other people, rehabilitation services etc.
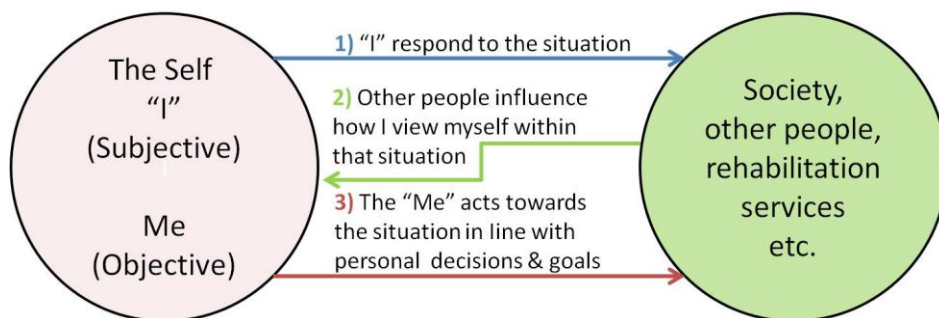
Figure 5. The Self in interaction with society.

Initial impulsive responses are not always controlled and in such situations the "I" remains dominant (Hewitt, 1988). People with cognitive impairment as a result of a neurological long term condition can experience difficulties in controlling impulsive behaviour, reading the social symbols of other people's emotions and gestures (Atkin, Wijck and McBean, 2013) and are therefore likely to experience some challenges in engaging in such reflexive behaviour. It could be argued, that the immediate response to a situation are the initial assumptions held by the "I", these are subsequently modified by the "Me" as the meaning of the situation is interpreted and develops through interaction

with others. The "Me" then draws together the information, evaluates it, and creates what symbolic interactionists term a "definition of the situation" (Charon, 2011; Cast, 2003).

Definition of the situation

Definitions of situations draw upon the information that is noticed by and relevant to the individual in relation to themselves, other people and the situation. It requires a judgement of oneself within that situation and an interpretation and evaluation of the interaction that is taking place (Charon, 2011). Indeed, Charon (2011) argues that how situations are defined is the starting point for action. This has resonance with Paul's (1993) logic model of thinking (p. 32, Figure 3) in which assumptions are viewed as the very starting points for reasoning. It would seem, therefore, that assumptions about oneself, other people and wider cultural expectations will all influence how situations are defined and subsequent attitudes and behaviour. Such definitions are not viewed as static, as in holding a one–off assumption about the situation, but rather a dynamic place of interaction which is "constructed and maintained" between the self, the people, objects and the range of meanings that are held about the situation (Park and Moro, 2006, p.101).

Role taking

This interactive process requires one person to be able to place themselves in the position of the other (Blumer, 1989), thereby imagining a situation from the perspective of the reality of the other person. The "other" can be both the person involved in the immediate interaction, or the "generalized other" who form the wider social group of for example friends, family and community (Charon, 2011, p.107). This group of generalized other generates the expectations, rules and norms which provide the mental guides for action.

This interactive process is important to this study as it provides a lens through which to investigate the nature of assumptions one person holds in relation to another through this process of imagination. Charon (2011) points out that "it is impossible to grasp the other's viewpoint; it is easy to be

96

inaccurate" (p.105), highlighting the ease with which assumptions about the perspective of the other person can be erroneous. Whilst role taking is recognised as forming the basis for action (Charon, 2011), it would seem that it is also a space where misinterpretation and misunderstanding is possible.

3.6.3 Symbolic interactionism and participatory research

The link between participatory research and SI is well established in research studies in which the focus and analysis of the research is on micro-processes or patterns of interaction (Genat, 2009; Burrows and Harkness, 2016; Eilertsen, Gustafson and Salo, 2008). The following table below (Table 5) highlights their commonalities:

Table 5. Assumptions shared by participatory research and symbolic interactionism.

Philosophical assumption	Assumptions of Participatory Research and Symbolic Interactionism
Ontology	"Reality" is situationally dependent. There are multiple meanings and therefore multiple realties.
Epistemology	Meanings and knowledge are collaboratively constructed in interaction and through dialogue. Knowledge is locally situated. Meaning is fluid and therefore constantly being constructed holding the possibility of change in and development of meaning and knowledge.
Axiology	Researcher and participants are interactive. Research is value laden with a commitment to action. Reflexivity is central to interpreting the interactions of others leading to questioning of roles and inequalities.
Methodology	Both prefer the use of a qualitative methodology, but not exclusively. The methods reflect the importance of understanding the meaning of a situation to the research participants

This methodological synergy between participatory research and symbolic interactionism provides a sound basis for the investigation of assumptions in the interactions between service users and staff in this study.

Participatory research is recognised for its attention to the oppression of societal structures on participants (Friere, 1970). However, one of the criticisms of Blumer's approach to symbolic interactionism is that is stresses the choice and voluntary nature social action (Atkinson and Housley, 2003, p.9) and as such pays little attention to how institutions and organisations constrain social action. Academics working in the interactionist tradition refute this lack of attention to structural issues of power arguing that symbolic interactionism:

> *"examines history and power in terms of the effects these have in the actual lives of the interacting individuals...look[ing] at how structures, ideology and power interact in concrete interactional sites and locales to produce specific forms of subjectivity, emotionality and lived experience" (Denzin, 1992, p.62).*

Such a view would indicate that symbolic interactionists can remain "alert to the indicators of social inequality and social injustice that undermine attempts at reciprocal perspective taking and cooperation" (Forte, 2007, p.405). In line with Denzin (1992) this study aims to illuminate the assumptions that are inherent in the interactions between service users and staff that relate to participants' taken for granted perceptions of, for example, power and role and generate findings that reflect their lived experiences of neurological rehabilitation and inclusion. It, therefore, views interaction as something that is fluid and dynamic rather than something that is fixed and unable to be influenced or changed.

3.7   Participatory Action Research (PAR) approach

Participatory Action Research (PAR) is defined as:

> *"a 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 and Munn-Giddings,2001, p.8).*

The link between participatory research and action research is a contested issue, as, whilst there is a central commitment to social change in both research approaches, action research does not necessarily actively engage participants or key stakeholders in the research process (Kindon, Pain and Kesby, 2010). It is widely accepted however, that the intention behind participatory research is to create change, be this at an individual or service level (ICPHR, 2013). As such, participatory researchers do not always include the action element in the naming of their approach to research, but action is accepted as implicit. As action research encompasses a broad family of research approaches (Kemmis and McTaggart, 2005), it is the following description that reflects the purpose of this research:

> *"Action research is a form of collective, self-reflective inquiry that participants in social situations undertake to improve: (1) the rationality and justice of their own social or educational practices; (2) the participants' understanding of these practices and the situations in which they carry out these practices...The approach is action research only when it is collaborative and achieved through the critically examined action of individual group members" (Kemmis and McTaggart,1988, p.5).*

This view of action research moves beyond the traditional view of action research as a simplistic cycle of fact finding, planning, action, reflection/ evaluation and refining the problem (Waterman et al. 2001), but views action research as an approach which aims to improve a social situation, is undertaken collaboratively, is educational for those who take part and is critically reflexive. Such an approach is therefore not merely a:

> *"...method or a procedure for research but a series of commitments to observe and problematise through practice a series of principles for conducting social enquiry" (McTaggart, 1996, p. 248).*

It is this commitment to systematically observing, and theoretically problematising both notions of participation and action that bring rigour into

this research approach. This study actively draws together participation and action research by supporting participants and researchers to be critically reflexive thereby facilitating increased awareness of personally held assumptions. It is based on the broad strategy of second person action research that aims to "inquire face to face with others into issues of mutual concern" (Reason, 2001, p.185) and is practically focused on "educating and enlightening [those who take part in the research] so that they can act more wisely and prudently" (Kemmis, 2009, p.468). PAR, therefore, forms the underlying approach to this research. Within it is the collaboration between service users and staff that is central to the generation of critical reflexivity and the design and delivery of this study. The inherent nature of action within participatory research has been outlined; consequently, the term participatory research rather than participatory action research will be used within this thesis.

3.7.1 Rigour in participatory research

Participatory research takes a very different view to rigour than quantitative research which emphasises the reduction of researcher bias, reproducibility and generalisability (Mays and Pope, 1995). Participatory research, too, considers rigour as critically important to the quality of the research, however, in line with its paradigm and principles, rigour is viewed as the "extent the research is facilitated as to make possible new, transformative insights which offer these fresh approaches for action" (ICPHR, 2013). This view requires that participatory research is designed with a political commitment to change at its heart (Cook, 2012), generated through bringing different perspectives together in critical dialogue, a place which may often appear "messy", and yields not consensus but the potential for transformation and understanding (ICPHR, 2013). This view of rigour in openly ideological research is also supported by Lather (1986, p. 67) who cites Cronbach (1980) to present a construction of validity.

> *"The job of validation is not to support an interpretation, but to find out what might be wrong with it. A proposition deserves some*

degree of trust only when it has survived serious attempts to falsify it".

Validity of participatory research is therefore evaluated against a specific set of criteria described by the ICPHR in Table 6. These criteria have provided guidance for the evaluation of the validity of this study, which in relation to data analysis will be discussed later in this chapter. An evaluation of the quality of the study as a whole is provided in Chapter 4.

Table 6. Validity criteria of participatory research (ICPHR, 2013).

Type of validity	Description
Participatory validity	Extent to which stakeholders take an active part in research process
Inter-subjective validity	Extent to which the research is viewed as being credible and meaningful by the stakeholders from a variety of perspectives
Contextual validity	Extent to which research relates to the local situation
Catalytic validity	Extent to which the research is useful in presenting new possibilities for social action
Empathic Validity	Extent to which the research has increased empathy among the participants
Ethical Validity	Extent to which the research outcomes and the changes exerted on people by the research are sound and just

3.7.2 Ethical principles in participatory research

As identified in the axiology section of this chapter, there can be significant challenges for everyone who engages in this kind of research as different perspectives are brought together and asymmetries of power brought to light. Ethical practice in participatory research is therefore, not seen as being a one off technical bureaucratic exercise, but a day-to-day commitment to democratic principles (Banks et al. 2013). They include, but are not limited to, mutual respect, equality and inclusion, democratic participation, active

learning, making a difference, collective action and personal integrity (Centre for Social Justice and Community Action, 2012). They differ from traditional ethical principles enshrined in the Hippocratic oath for health care practitioners, for example beneficence (provide benefit and protect from harm) and non malfeasance (avoid afflicting harm on others) (Hammell, 2006), place the duty of care on the clinician or researcher to protect and provide, that risks doing to or doing for others. In contrast, participatory ethics promotes change through process of mutuality and collaboration, where "some degree of power sharing" (Banks et al., 2013, p.266) is required. These ethical principles make room for dilemmas to be considered as they occur, rather than a more traditional approach, which suggests that the research facilitator is able to hold accurate assumptions about what might be harmful of beneficial to another. I will reflect on this further in Chapter 4.

This project also fulfilled the requirements of ethical approval from Northumbria University Ethics Committee, Northumberland Tyne and Wear NHS Foundation Trust Research and Development Committee and the NHS Research Ethics Service (Appendix 2). All participants in the study have been anonymised, and given a pseudonym as required by the University Research Ethics Guidelines (Northumbria University, 2017). Issues of anonymity can be a particular issue for participatory research as some participants may specifically wish to have their contribution recognised (Centre for Social Justice and Community Action, 2012). The choice to be anonymous could not necessarily be assumed, particularly on behalf of critical friends who contributed to this study. One critical friend, Ruth, who was a participant in this study, has adopted a pseudonym. However, the second Christine who was involved as a researcher with the funded research chose to be named. This reflects Christine's right to personal choice and agency, which is supported by the participatory values as outlined by the ICPHR (2013), which require that people involved with the study feel empowered through the process of taking part.

3.8 Study design and methods

The following section will describe my study design, highlighting its relationship to a funded research project and the procedures shared between the two projects. It will articulate the choices made in recruiting participants to this study and the methods of data generation, data analysis and sense making of data.

3.8.1 Study design

My PhD is an integral part of a funded National Institute for Health Research project whereby Dr Tina Cook was awarded £199,000 to conduct research. This research investigated whether there was a link between the way people with neurological impairments were included in the NHS community and the way they used knowledge from treatment to develop their skills and independence in their daily lives. An Executive Summary of this study, Towards Inclusive Living (TIL), can be found in Appendix 1 and the full report at:

http://awam.org.uk/ltnc/download_files/final%20reports/Oct_11/Final_Report _Inclusive_Living.pdf

In order to provide a clear context for my PhD study design, recruitment and methods, I will firstly present a brief overview of the design, recruitment and methods of the funded TIL study, then describe the relationship between the TIL research and my PhD study. Following this, my approach to recruitment and the methods used in this study will be articulated.

3.8.1.1 Towards Inclusive Living: study design, recruitment and methods

The funded TIL study recruited service users and staff from the Regional Neurological Rehabilitation Centre based at Walkergate Park. This Centre provides assessment and rehabilitation to people with neurological and neuropsychiatric conditions on an in-patient, out-patient and community

basis. 70% of people use neurological rehabilitation services and 30% neuropsychiatry services. One ward (14 beds) is dedicated to service users with neuro-behavioural impairment, one ward (16 beds) to service users with neuropsychiatric conditions and two wards (35 beds in total) are dedicated to service users who have a predominately a physical neurological impairment and are non-aggressive. As highlighted in the introduction to this thesis, neurological rehabilitation provided at Walkergate Park is categorised as complex specialised rehabilitation, defined by the British Society of Rehabilitation Medicine (BSRM) as including service users with high physical dependency, mixed disability and cognitive behavioural needs. These services are viewed as high cost-low volume, providing rehabilitation for people who would be too complex for district hospitals (BSRM, 2015).

In 2002-2007 there were approximately 400 inpatient placements across the services at Walkergate Park which were commissioned predominately from the North East of England. During that time, 10,000 people were seen as outpatients. Sampling and recruitment for the TIL study commenced in 2009, and service users were sampled from the NHS Trust's electronic database. The sample was randomised across inpatient, outpatient and community services, based on the percentage size of that service. As the TIL study did not fully reach its recruitment targets for service users, a secondary process of voluntary recruitment was introduced using poster displays around the neurological rehabilitation centre. In order to take part, service users needed to be over 18 years old, had to have used Walkergate Park services in the last year, even if they were currently discharged, and were able to understand the information about the study and had the capacity to consent.

Staff who were employed by the NHS Trust were recruited to the TIL study via an invitation letter, circulated using the NHS Trust's data base. They were required to be over 18 years of age and currently working at Walkergate Park.

There were no restrictions to participation; participants of all gender, ethnicity, religion, sexual orientation and neurological condition were invited to take part in the funded study. Participants were invited but not required to provide information on their demographics; this was in line with the emphasis of this research on inclusion rather than individual characteristics. Some participants did provide demographic information; this can be found in Appendix 3 of the funded TIL study (Cook et al. 2011). As the majority of participants chose not to provide demographic data, only limited information is provided as part of this PhD study (see section 3.8.2).

Service users and staff were sent a letter of invitation; this was made as accessible as possible, particularly for service users. The letter was only sent to in-patients if it was felt by the staff treating them that they had the capacity to consent. The process of supporting people to understand the study and what they were being asked to consent to was iterative. This began with the offer to meet and speak to people personally about the study. Consent to participate was fundamental to all stages of the research and, as advocated by researchers working in the fields of learning disability (Cook and Inglis, 2012) and dementia (McKeown et al. 2010), this was not treated as a one-off event.

Forty-two service users took part in the funded study. An additional six service users gave their consent but did not ultimately take part: two people died, one withdrew and three people did not respond when contacted. Twenty-four members of staff took part in the funded study. One withdrew citing the demands of her job.

The funded study had four key phases. Phase 1: planning the study in collaboration with service user, staff, carer and voluntary sector co-researchers. Phase 2: Data generation from homogenous groups (staff, only, and service users, only) and individuals. Phase 3: Validation of early findings using heterogeneous groups (mixed focus groups) and individual interviews according to participant preference, and the discussion of new

ideas around the key emergent themes. Phase 4: Big Conversation Day, during which the findings were presented for further validation by participants. Initial data analysis took place between phases 2 and 3. Further data analysis took place between phases 3 and 4, prior to the final phase of data analysis at the Big Conversation Day. However, it should be noted, that some of the data generated in this research referred to experiences of service users using other NHS and social care services.

These phases are illustrated in Figure 6 below. Phases 2, 3 and 4 described above provided the basis for recruitment to the assumptions study.

```
┌─────────────────────────────────────────────────────────┐
│                      Phase 1:                            │
│   Planning the Towards Inclusive Living funded research  │
└─────────────────────────────────────────────────────────┘
                            ↓
┌─────────────────────────────────────────────────────────┐
│                Phase 2: Data generation                  │
│ Interviews, photography, mapping, focus groups, diaries, │
│                       questionnaire                      │
│                   All groups homogenous                  │
└─────────────────────────────────────────────────────────┘
        ┌─────────────── Data    ↓    Analysis ────────────┐
┌─────────────────────────────────────────────────────────┐
│ Phase 3: Verification of themes and highlighting         │
│                    different viewpoints                  │
│                    Mixed focus groups                    │
└─────────────────────────────────────────────────────────┘
        ┌─────────────── Data    ↓    Analysis ────────────┐
┌─────────────────────────────────────────────────────────┐
│              Phase 4: Big Conversation Day               │
│  Final verification and discussion on implementation of  │
│                         findings                         │
└─────────────────────────────────────────────────────────┘
        ┌─────────────── Data    ↓    Analysis ────────────┐
┌─────────────────────────────────────────────────────────┐
│                      Dissemination                       │
└─────────────────────────────────────────────────────────┘
```

Figure 6. Design of the Towards Inclusive Living (TIL) funded study

3.8.1.2 The relationship of this PhD assumptions study with the Towards Inclusive Living study

In parallel with the planning phase of the TIL study (Phase 1) was the planning phase of this PhD study. Both studies used the same process to gain participants' informed consent: The intentions of both studies were articulated in the participant information sheet.

As a consequence, there are a number of commonalities between this PhD and the funded research. They share the same participatory paradigm; the critical conversations that took place to plan the funded research also informed my own research question relating to assumptions. I was involved in data generation in Phases 2, 3 and 4, the data of which was used for analysis by both studies, but with each study applying a lens specific to its aims and objectives. In Phase 4 I generated additional data that was specific to my PhD study. Throughout, data analysis and data sense making in respect of assumptions (that is for my PhD study) were undertaken independent of the TIL study. Figure 7 below illustrates the relationship between my PhD study and the funded TIL study.
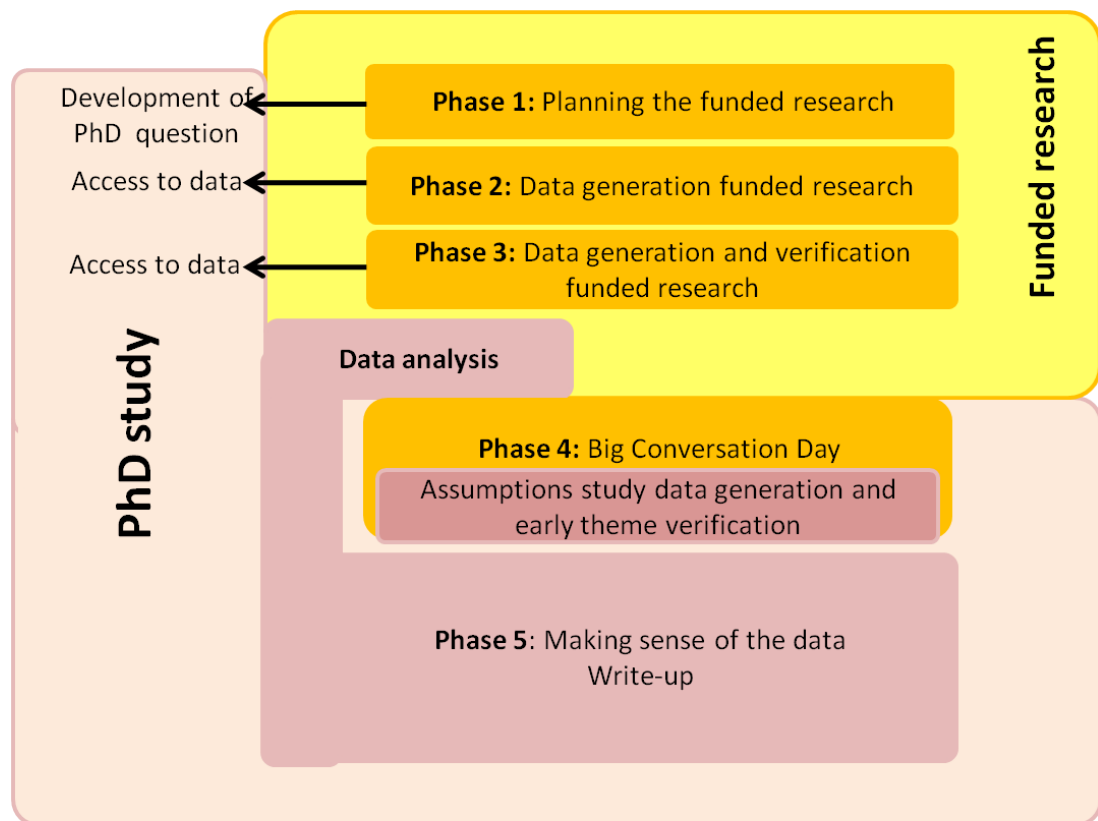
Figure 7. Relationship between PhD assumptions study and the funded Towards Inclusive Living study

3.8.2 Sample characteristics of the PhD study

Not all participants contributing to the overall data generation ended up contributing to this PhD study. I wanted to ensure the potential for illuminating service user and staff assumptions, to answer the aims and objectives of my PhD. Therefore, I chose to engage with data generated through methods which I identified as particularly encouraging critical reflexivity and dialogue, holding the potential for tacit assumptions to be brought to the surface (Cook, 2004a) and generating rich learning specific to my research question (Patton, 2002).

Blumer (1969) supports the argument for using small groups as method, suggesting that a "small number of individuals brought together as a discussion or resource group is more valuable...than a representative sample" (p.41). Table 7 outlines the people and methods used in the generation of data in this PhD study during the different phases. Many service users who took part in Phase 2 also took part in Phase 3. In total, for Phases 2 and 3, 15 service users and 15 staff took part. People who took part in the Assumptions Workshop were not connected to their original identification number, and therefore, could not be linked to any previous contribution in Phases 2 and 3. All questionnaires were completed anonymously; therefore, it was not known which of the previous participants had submitted a reflective questionnaire.

Table 7. The different phases and people contributing to the generation of data for this PhD study

Phase of the study	Method	Number of service users	Number of staff
Phase 2	Photography	3	1
	Diaries	2	0
	Mapping	5	6
	Focus groups	0	2
	Interviews	1	1
Phase 3	Mixed focus groups	8	8
	Interviews	1	0
Phase 4 (Big Conversation Day)	Assumptions workshop	5	3
	Reflective questionnaire	8	6

This purposive approach to sampling and generating rich data is congruent with my qualitative methodology, relevant to the focus of my study and provides the basis for a deep analysis and sense making of the data.

As previously highlighted in the section relating to the funded study, it was not the intention to explore the relationship of the individual characteristics of participants to the data generated for example, impairment, age or profession, and age. However, it was identified that service users had a wide range of acquired neurological conditions, which included, for example, traumatic brain injury, brain haemorrhage, spinal cord injury, and degenerative conditions such as multiple sclerosis. The majority of service users had been using services for between three and 15 plus years.

The gender characteristics of both service users and staff who took part in the PhD study are presented in Table 8.

Table 8. The different phases of my PhD study and the gender of participants

Phases of study	Service user		Staff	
	Female	Male	Female	Male
Phase 2	6	5	10	0
Phase 3	6	3	7	1
Phase 4	3	2	2	1

Based on their description during the data generation, two service users self-identified as having cognitive impairment, impacting on their daily lives. All service users identified themselves as having used inpatient neurological rehabilitation and/or community neurological rehabilitation services, though they often drew upon their use of other NHS or social care services to illustrate their personal experiences of inclusion and explore their assumptions. Staff who took part worked in a range of community, in-patient and/or outpatient neurological rehabilitation services, providing a range of clinical intervention, managerial and/or administrative support.

3.8.3 Study procedures shared with the funded research

Research procedures, which included the training of the research team who took part in the funded research and administrative processes such as sending out invitation letters, information about the research and consent to take part were all part of the processes of the funded research. Examples of the documentation relevant to this study are found in Appendices 3.1-3.5. Issues of ethical governance were also addressed by the funded research, which included gaining consent to take part, ensuring confidentiality and maintaining anonymity. I was an integral part of managing these processes for the funded research and there was no necessity to re-visit them for this study focussed on assumptions. However, additional information was produced for participants specific to Phase 4 of this assumptions study and can be found in Appendix 3.6. Despite the administrative processes for ethics having been addressed, supporting an inclusive space for participants to take part in the research required constant consideration and monitoring throughout all phases of this study. Taking a value orientated approach in the preparation and delivery of the research procedures and methods moves ethics from a mere top down procedure to an approach to research which prioritises the participant and respects their knowledge and experience. However, as illustrated in the following section, there are no 'quick fix' procedures for working inclusively in research; it is an iterative process requiring constant personal critical reflection as a researcher

3.8.4 Methods used for data generation

A wide range of methods were used to generate data in this study. In Phases 2 and 3 the selected methods used by the funded project were the source of data for this study. In Phase 4, methods were developed specifically in relation to this assumptions study. These phases of data generation are outlined below in Figure 8 and the key features of these methods are discussed.
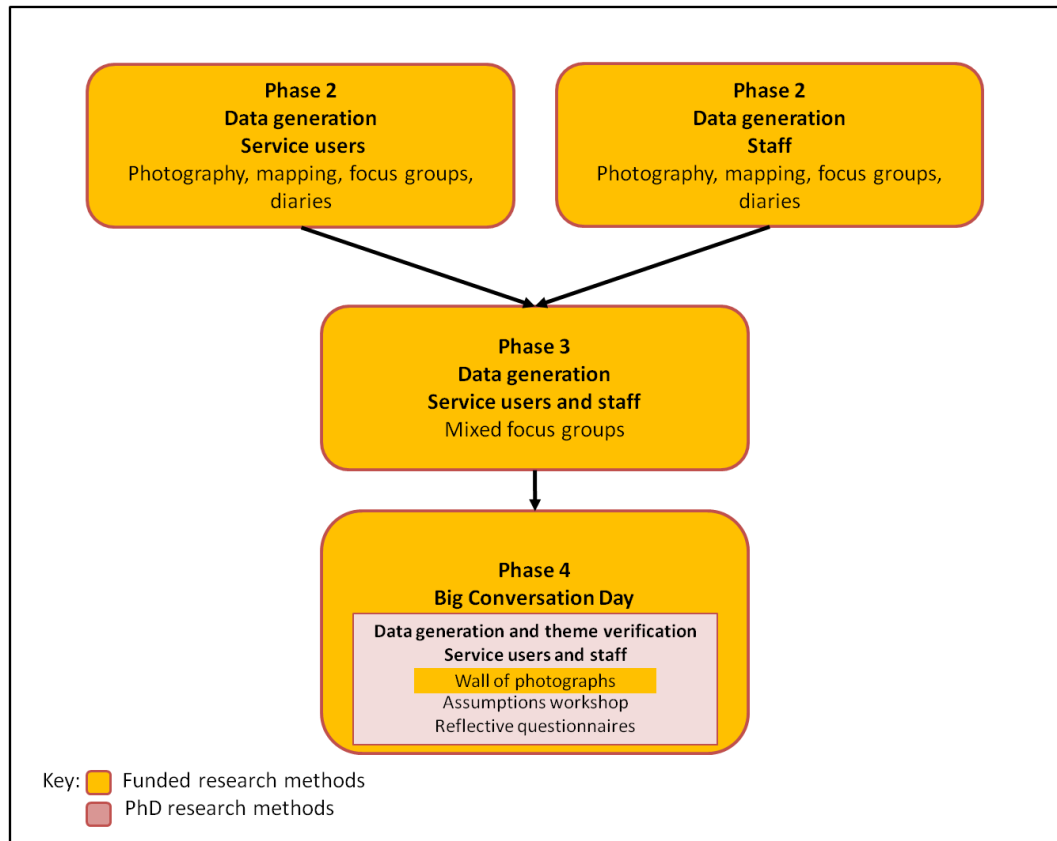
Figure 8. Methods of data generation.

3.8.4.1   Phases 2 and 3 methods

Mapping and focus groups offered participants a group discussion through which data was generated on a topic through interaction between participants and researchers, enabling viewpoints to be explored and contested (Kitzinger, 1995; Sim and Snell, 1996) and tacit assumptions illuminated (Kreuger, 1994). It is argued that the flow of conversation in focus groups can be most readily found in homogenous focus groups (Twohig and Putnam, 2002), however, in this study, focus groups that included a mix of both service users and staff (Phases 3) provided the opportunity for participants to contest each other's assumptions and understand different perspectives. Mapping is particularly recognised for its ability to move people from a mere description of the issues to theorising about them (Emmel, 2008) and can act as a valuable visual prompt to positively support people with memory impairment.

112

Photography offered an approach that ultilised participants' visual strengths to express their views, rather than being solely dependent upon language and communication skills. It is an approach to data generation that starts from the perspective of the participant (Wang and Burris, 1997), rather than being influenced by other group members. It enabled participants to capture their lives and showcase what was symbolically meaningful to them about inclusion. The symbolic nature of photography enabled meanings to be probed, thereby illuminating some of the assumptions associated with the choice of photograph. Similarly, diaries provided the opportunity to "capture life as it is lived" (Bolger et al. 2003, p.579) from the perspective of the participant, but provided a more descriptive account of experiences of living with a long-term neurological condition.

Interview data from the funded project was not a primary source of data and was only used on two occasions, when a participant's account was viewed as being particularly helpful to understanding assumptions and their influence on inclusion.

Mixed focus groups were another source of data for this study and were generated through Phase 3 of the funded research. These groups brought tougher service users and staff participants for the first time, creating a dialogical space whereby staff and service users could hear and question each other's perspectives. As a result, assumptions about each other and practice were highlighted. Examples were generated of how tightly some assumptions can be held and are presented in the findings section of this study. Where participants were unable to attend a group, an interview was offered as an alternative.

All methods except for diaries were digitally recorded using MP3 players and were 1 -1.5 hours in duration.

3.8.4.2 Phase 4 methods

A conference called the Big Conversation Day held by the funded research project provided the context for data generation in this phase. Three methods were used to generate data, the Wall of Photographs (Figure 9), the Assumptions Workshop and a reflective questionnaire.

Wall of Photographs

Participants who had taken photographs in Phase 2 were asked to provide captions for their photos, which were subsequently displayed and other participants were encouraged to talk to photographers about the meaning behind their photographs (Figure 9). Unfortunately, only one photographer was able to attend.

Figure 9. Wall of Photographs.

Discussions about the photographs were not recorded; however, based on feedback in one of the staff reflective questionnaires, it was evident that these discussions had a powerful effect in challenging and changing assumptions about inclusion and neurological rehabilitation practice.

Assumptions workshop: 'Absolutely Inclusion'

The Assumptions Workshop was the first method that was undertaken solely for the purposes of this study. The aim of the workshop was twofold, firstly for service users and staff to verify through discussion whether the key assumptions that had been drawn from the data had resonance with participants. This aspect referred to by Lather (1986) as face validity formed part of the process often referred to as triangulation that acts to verify the trustworthiness or quality of value orientated research (Lather, 1986). The second aim was to discuss the changes that would be required in practice in order to respond to these assumptions in order that practice might be more inclusive.

An information sheet about the workshop had been provided to participants on arrival at the Big Conversation Day as illustrated in Appendix 3.6, participants who attended made the active choice to come to the workshop. There was an evenly mixed group of service users and staff. 2 facilitators were present, myself and a member of the research team employed by the voluntary sector who was already known to some staff and service users in the group. The purpose of the group discussion was reiterated with participants, in order to check that everyone wished to remain. The workshop lasted 1 ½ hours and was recorded using an MP3 player.

The information presented to the group was the findings of an early analysis of the data generated in Phases 2 and 3. This was presented as four overarching assumptions and sets of related assumptions Appendix 4. These assumptions were presented to the group, for discussion and were subsequently ranked in order of importance in relation to creating an inclusive approach in neurological rehabilitation practice. A simple bean counter approach was used to facilitate the process, where participants indicated their first, second and third preferences. Taking the two most highly ranked assumptions as the starting point (Appendix 4: assumptions 1a and 2a), the group split into two and mapped the changes they felt needed to take place in order to that practice might be more inclusive. A map of the

outline components of the Theory of Change (Weiss, 1995; Anderson, 2006) was used in each group to guide discussion and support constructive and focussed interaction. An example (Appendix 5) was provided to enable participants to understand what was required.

The Theory of Change indicates that assumptions are integral to the ideas that we hold about change in practice and uses a mapping technique to identify the preconditions that are required to bring about a desired long term goal (The Aspen Institute, 2003). Examples of the use of the Theory of Change in practice (Anderson, 2006) suggest that it is important to recognise the main assumptions that are held at the outset of any change initiative and identify long term outcomes based at these assumptions. It is an approach that is viewed as being effective when participants know how the service actually works in practice and can work together to map the links between assumptions, ideas and practical planning (Hernandez and Hodges, 2006). Whilst I did not intend to use the Theory of Change approach in full, the practical mapping tool (Anderson 2003) enabled me to create a link between the assumptions that had been identified in the data and the process of discussing and planning change. The mapping tool asks participants to map their long term outcome and the preconditions, indicators and interventions required to develop change. The language of the mapping tool was adapted in order to make it more accessible to people taking part in the workshop. A detailed reflection on my facilitation of this workshop can be found in the Discussion Chapter.

Reflective questionnaires

Participants were asked to complete a short qualitative questionnaire (Appendix 6) at the end of the Big Conversation Day and hand this in prior to leaving (to ensure the best return). The questionnaire sought to engage participants in exploring their response to the research that had been undertaken under the umbrella of the funded research and identify changes in perceptions that had taken place as a result of taking part.

This reflective questionnaire was designed to capture qualitative data about the personal impact of taking part in the research process. It specifically asked for moments when tacit knowledge had been made explicit. 8 service users and 6 staff returned their questionnaires. One member of staff completed the questionnaire in great detail, generating rich data about a change in her assumptions. This will be explored further in the Findings Chapter.

3.8.5 Methods used for data analysis

This section will discuss the methods used during the process of working with the data. It will outline the tools used to assist the analysis process and provide a critically reflexive perspective on the process of making sense of the data.

3.8.5.1 Tools used in the analysis process

NVivo 8, 9 and 10, computer assisted qualitative data analysis packages were used to manage the data during the analysis process. Its facility to store considerable amounts of qualitative digital, photographic and written data in a password-protected space supported the wide range of methods used to generate the data, enabling them to be imported into one place. One of the key features of NVivo used in this study was its capacity to create codes under which the appropriate sections of the data could be labelled under a "node". These nodes were subsequently developed into "trees of inter-related ideas" (Bryman, 2008, p. 567) which enabled connections to be made between the nodes. These connections of nodes were subsequently categorised to form a theme. It is suggested, that NVivo uses a grounded theory type approach, which enables theory to emerge from the data (Welsh, 2001). Whilst my study did not use a grounded theory approach, ensuring that I kept myself grounded in the experiences of people who had generated the data, the contexts within which their accounts were constructed and my interpretation of this data was crucial to the analysis process. Additionally, holding the data and the memos I generated about the data in one place helped to provide me with some continuity of thought over the time frame of

this study. The memoing facility enabled me to record my interpretations of the data in relation to the assumptions of each participant, potential themes and connections between themes. These were not used in line with traditional grounded theory guidelines as detailed by Charmaz (2006). As someone who readily pays considerable attention to detail, I found that NVivo drew me further and further into creating more and more nodes, as I dissected the text for assumptions. I needed to find a way to step back and see the broader picture. Mind mapping provided the facility for me to do this and I used them on a regular basis in conjunction with the memos and node facility in NVivo in order to develop the structure of my themes and subthemes. An example of mind mapping can be found at Appendix 7. This eclectic use of data analysis tools enabled me to use the strengths of each approach and also accommodate my own personal working style.

3.8.5.2   Making sense of the data

Patton (2002) describes data analysis as a process which "transforms data into findings. No formula exists for that transformation. Guidance, yes. But no recipe" (p. 275). Indeed, it is perhaps this lack of "formula" that leads to data analysis being described as the mysterious "black box" of the research process from which themes and findings magically emerge (Schiellerup, 2008, p.163). However, it is suggested that there is a distinct lack of transparency in relation to the analysis process (Bailey and Jackson, 2003), and researchers are called upon to articulate their analysis process (Patton, 2002). It is this transparency that is challenging to articulate in the complexity of making sense of the data. However, the following section aims to unpack the analytical process undertaken in this study.

The data analysis process undertaken during this study was long and protracted, as I sought to get to the heart of the assumptions participants held about neurological rehabilitation that influenced their experiences of inclusion. The iterations of analysis presented in this next section reflect my commitment to getting beyond this mere description and grapple both with how to unpack the "black box" of data analysis and how to make sense of

what was inside it. What is presented here is an honest journey that is creative and responsive to the data and the context of the research. It does not go straight from A to B, but is messy and complex. It is more akin to "making sense" of the data, a term that is used by Miles and Huberman (1994), and reflects the distinction made by Coffey and Atkinson (1996) between the technical task of data analysis and an interpretive and creative approach.

> *"For some authors, analysis refers primarily to the tasks of coding, indexing, sorting, retrieving, or otherwise manipulating data . . . From such a perspective, the task of analysis can be conceived primarily in terms of data handling . . . For others in the field, analysis refers primarily to the imaginative work of interpretation, and the more procedural, categorizing tasks are relegated to the preliminary work of ordering and sorting the data" (Coffey and Atkinson 1996, pp. 6–7).*

My engagement with the data analysis process is summarised in the following diagram (Figure 10). Whilst presented in a linear format, it was a messy process, which has been challenging to capture. It is rooted in critical reflection that views data analysis not as a one-off process that follows a technical procedure, but one that focuses on what I could learn from the data, how I could continue to be collaborative and how each stage of interpretation and understanding might inform the next (Winter and Munn-Giddings, 2001, pp. 238-241). As such, my sense making process has been rooted in interactions with the data, theory, research participants and critical friends. Whilst this process has been inherently interpretive, it has been a process that has continued to be informed by social constructivism, through collaboration with others and a high degree of critical reflection through the process of writing multiple drafts. Points of questioning, dilemma and discomfort have formed what I have referred to as my way-markers for this process. These provided the reference points for important new directions for thinking and interpretation of the data. The concept of way-marking is not new; cairns or stones have guided the way of walkers and travellers who are

lost or disorientated in remote places for many years. Weick, Sutcliffe and
Obstfield (2005) connects it to the concept of sense-making in organisations,
using contextual cues as way-marks to set the direction of travel as opposed
to following a prescriptive map for service delivery. My way-markers were
questions that drew me into the next phase of analysis, leading me to
continually investigate the relevance and focus of my sense making process.
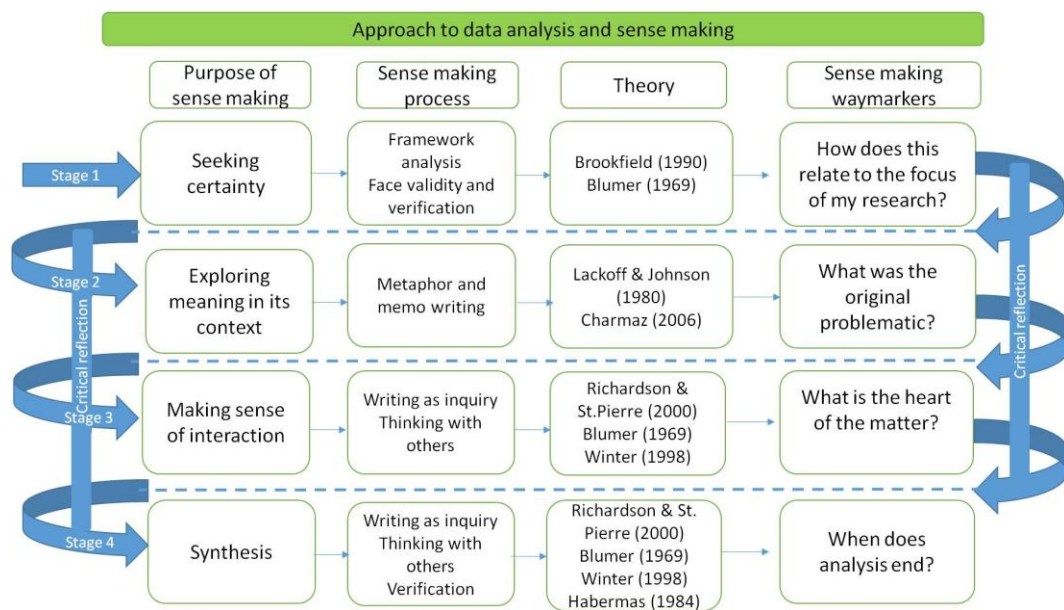
Figure 10. Process of data analysis and sense making.

The data sources that link with each stage of the analysis and, therefore,
influence the sense making process and ultimately the findings of this study
are summarised in Table 9 below. A detailed account of the data analysis
and sense making process is given in sections 3.8.5.3 to 3.8.5.6 of this
chapter.

Table 9. Link between phases of data analysis, data sources and the outcomes of analysis

Stage of data analysis and sense making	Data source for analysis and sense making	Outcomes of analysis and sense making
Stage 1	Analysis pilot of 3 service user and 3 staff data	Identification of 5 key assumptions underpinning inclusion
Stage 2	Analysis of the full data set of all service users and staff from the sample included in my PhD study. Focus of analysis remained on inclusion rather than assumptions.	Early themes of the influence of assumption on: cultural challenges to inclusion; whose knowledge counts; values and meaning of inclusion; disruption in challenging assumptions. Also identified were the emergent conceptual themes of role, knowledge, power and empathy
Stage 3	Reworking of first draft of findings with a focus on assumptions rather than inclusion. Additional use of full data set as in stage 2 to explore emerging concepts more fully and to develop analysis on the complexity and nature of assumptions	Development of conceptual themes and sub-themes relating to concepts of role, knowledge, power, empathy and changing assumptions. Development of themes and subthemes relating to the complexity of assumptions
Stage 4	Draft findings chapter	Validation of findings with critical friends

The following sections provide a descriptive account of each stage of the data analysis and sense making process.

3.8.5.3 Stage 1: Seeking certainty: Identifying key assumptions

The first stage of my sense making was informed by the design of the funded study, particularly the timing of both data generation and the Big Conversation Day. My initial goal had been to undertake an early analysis in order to use the mixed focus groups to explore the credibility of this early analysis. This aimed to ensure that the findings were congruent with participant experience. Due to time constraints, this process was started instead at the Big Conversation Day in the Assumptions Workshop.

In order to begin the process of understanding how I might recognise assumptions in the data, I met with fellow researchers from the funded research team. We looked together at examples from the data where they felt that assumptions were clearly articulated or identifiable. Links were particularly made between the idea of "expectation", that is, what participants felt should or ought to be happening, and assumptions. Assumptions were also viewed as influencing how concepts such as service user involvement and inclusion were interpreted.

At this early stage I viewed data analysis more as a process of managing the data through coding and categorising, rather than an active engagement with people's experiences from which meaningful sense could be constructed. In my uncertainty and inexperience of qualitative analysis, I sought a degree of certainty, desiring an approach that would provide clear guidance and lead me to the 'answer' and would be viewed as credible by participants. This search for certainty reflects something of the positivistic perspective on practice that is inherent within the broad culture of neurological rehabilitation practice. This was also fuelled by the pragmatic requirement to deliver this early analysis in line with the timeframe of the research design. The relationship between time and certainty seemed to reflect whether certainly for a novice researcher, the focus of analysis was related to a mechanistic delivery of an output or a process of sense making.

In this search for "certainty", I explored 2 ways of analysing the data. The first was to draw on the literature for guidance that would enable me to systematically interrogate the data for assumptions. Mezirow's (1990) work on meaning schemes and meaning perspectives (pp. 2-4) and Brookfield's (1995) categorisation of assumptions into causal, conditional and paradigmatic (pp. 2-3) provided an early thinking framework as I read through the transcripts and familiarised myself with the data (Appendix 8). Resonance between the literature and the issues identified by the research group was reassuring. Once familiar with recognising assumptions in the data, the simplicity of Brookfield's categorisation enabled me to use this as a framework to generate an initial analysis of the data from Phase 2 of the research.

Secondly, an exploratory analysis of one transcript in line with symbolic interactionist "root images" (Blumer, 1969, p.6;) was undertaken, this included concepts such as the nature of objects; the nature of social interaction and the human being as an acting organism. This exploration highlighted, for example, differences in the meaning of locked church door held by a service user and a church official. Additionally, it illustrated how the use of symbolic, emotive language used by the service user during interaction, ultimately seemed to facilitate a shared understanding of the situation. A reflection drawing on Blumer's (1969) root images of symbolic interactionism in relation to this scenario can be found in Appendix 9.

I had worked professionally with one of my critical friends, Ruth, over twenty years previously, she was a participant who had shown a specific interest in my study on assumptions and had offered her support. She was invited to read these two different approaches, following this early analysis of her data. That is using Brookfield's categorisation of assumptions (Appendix 10) and my reflections based on my application of symbolic interactionism. She was specifically asked to comment on clarity and resonance. She expressed that she could clearly follow my reasoning using the work of Brookfield as a guide, but was somewhat bemused by my application of symbolic

interactionism and found my interpretation difficult to follow. This approach to member checking moved beyond merely checking the accuracy of the transcript, to checking the face validity of this early data analysis. Face validity is described by Lather (1986) as satisfying the "truth-value criterion" or whether the findings chime with the participant's experience. This approach specifically supported the participatory quality criteria of inter-subjective validity, which aims to ensure that the research is meaningful to participants (ICPHR, 2013).

Consequently, a preliminary process of data reduction through ordering and sorting the data (Coffey and Atkinson, 1996) using Brookfield's categorisation of assumptions was undertaken in collaboration with Ruth. Three service user and three staff transcripts were used as the basis for this work, the purpose of which was to generate early findings that could be discussed, developed and potentially validated at the Big Conversation Day. Over 100 assumptions were identified and perceived as relevant to inclusion. These were reviewed for repetition and similarity, reducing the data to 30 key assumptions (Appendix 11). These assumptions were reviewed with Ruth for their relevance to inclusion, similarities and differences with other assumptions and potential resonance to a wide range of service users and staff. These were presented at the Big Conversation Day as causal if-then assumptions, my view being that such an approach would help provide clarity, aiding understanding and discussion. These early themes of assumptions underpinning inclusion were discussed, contested and prioritised.

Detailed descriptive writing of these preliminary findings provided an early indication that my interpretive process was leading me back to writing about inclusion, which was the focus of the funded research, rather than assumptions. Whilst at the time this insight was merely a small way-marker, full recognition and understanding would not be realised until Phase 3 of this sense making process.

3.8.5.4 Stage 2: Moving from coding and categorisation to exploring meaning in context:

The full data set was analysed using Brookfield's categorisation; however, this did not capture the creative or conceptual representations of participants' experiences, reflecting a deep-seated response to situations that moved beyond a mere description. As such, metaphor is recognised for its ability to capture automatic thinking that we are not normally aware of (Lakoff and Johnson, 1980, p.3) and is viewed as valuable in highlighting assumptions (Deshler, 1990). Rorty (1991, p, 170) describes metaphor as being "unfamiliar noises", suggesting that they can convey a causal network or express internal belief systems that are usually tacit, thereby reinforcing their relevance to the exploration of assumptions. A detailed exploration of the linguistic structure of metaphor is beyond the scope of this study, however, of particular relevance to making sense of the data, was an appreciation that metaphors have source and target domains. That is, we aim to understand a target domain for example a social organisation through the source domain of a plant, an example might include "the company is growing" (Kovecses, 2010, pp. 4-10). Particularly useful to this research was the recognition of the use of metaphor expressed in terms of structure, orientation and ontology (Lakoff and Johnson, 1980). Structural metaphors are where a complex abstract concept is explained using a more concrete concept thereby acting as a guide to its meaning. For example in the data, the notion of empathy is explained as "putting yourself in someone else's shoes". Orientational metaphors provide a concept with a spatial orientation for example the description that life is *"an up-hill struggle"* sets an orientation of "up" being classed as a difficult experience. Recognising this in the context of the data was important, as for some people the concept of "up" may be a positive one. Ontological metaphor is illustrated when participants identify their experiences as specific entities, which can be identified and reasoned about (Lakoff and Johnson, 1980, pp. 25-35). For example, one participant described her experiences of exclusion whilst using a swimming pool hoist and used the concept of the "ducking stool". Her choice of metaphor made the intangibility of her experiences tangible, so that they could be more

125

readily discussed and understood. Similarly, inclusion was described as being able to *"fit into the circle"* the circle is imposed as a physical object with boundaries and an in/out orientation, which requires someone to fit in to it. Even the notion of "fitting in" has at its source an element of force as one person effects change on another. The use of metaphor here clearly highlights the challenges particularly of describing inclusion, but also identifies an underlying assumption that some degree of power and control may be involved in some perceptions of inclusion.

Key metaphors were entered into an Excel spreadsheet and analysed in relation to their potential source and target. Whilst the detail of this exploration of metaphor were not used in the analysis beyond this point, this understanding of the basic characteristics of metaphor was valuable as part of the sense-making process of the data. Data was subsequently coded in NVivo using the categories of paradigmatic, causal, prescriptive and metaphor in order to understand the foci of the assumptions. Multiple codes were generated - for example, communication, enablement, knowledge, attitudes and environment. Within these codes were multiple sub-codes. As I worked with the data, it became increasingly apparent that the focus of my findings related to inclusion, rather than addressing my research question relating to assumptions. A second detailed descriptive account of the data was written at this point. This document acted to reduce the data and formed part of the basis for the reworking of the data in Phases 3 and 4.

In response to the realisation that inclusion remained my focus, I sought to capitalise on my growing understanding of how to identify the assumptions and additionally the resonance I held as a researcher with the participants' accounts and life contexts, by using the tool of memo-writing. Memo-writing is usually viewed as a process that enables the elaboration of codes (Charmaz, 2006), however, I found it useful to step back from the detail of previous coding systems and through memo-writing (Appendix 12) return to participants' lived experience and gain a perspective on what I now recognise as being the broader conceptual themes. Indeed, Silverman

(2011, p. 62) suggests that an intense focus on a limited amount of data can provide a "grasp of the phenomena with which you are concerned". The conceptual themes of assumptions pertaining to role, knowledge, power and agency were evident in the data, however, at the time I was unable to capitalise on the patterns I was beginning to recognise and understand. However, I did recognise that my analysis continued to focus on inclusion rather than assumptions; assumptions remained the elusive lens through which to view my data. Returning to the original problematic of my research was essential in recognising that there is a context around how and why an assumption is held that influences the way in which people interpret situations, interact with each other and ultimately experience inclusion. This way-marker led me to return once more to the data with the purpose of exploring what participants said about assumptions and the context around those assumptions. At this stage of the analysis, my focus remained on investigating assumptions underpinning inclusion.

3.8.5.5   Stage 3: Making sense of interaction using the lens of assumptions

Whilst Brookfield's categorisation had been very helpful as an initial starting point, using a predetermined framework from literature is recognised as a deductive approach, which runs the risk of determining what can be seen in the data, reducing the opportunity to see the unexpected (Gale et al. 2013). References to assumptions and their associated concepts, for example expectations and perspectives, highlighted similar categories to those of Brookfield. However, it was in the writing of multiple drafts and questioning the data that my understanding of the importance of the context within which assumptions are held and why some assumptions are more firmly held than others, began to take shape. The combination of seeing writing as inquiry (Richardson and St. Pierre, 2000) and returning to the original problematic that inspired my research, that people make assumptions based on their interpretation of a face value encounter, were critical in moving my analysis forward.

I asked the question, if the inclusion of A is an issue, then what is it about the assumptions that are being held that makes a difference to whether A is included or not. It was not necessarily only *what* participants were describing, but it was also the nature of their interaction and the levels of interpretation that were critical to an understanding of assumptions. This led to the articulation of a framework that recognised the relationship between interaction and assumptions. This framework of assumptions was reflected in the context of the types, strength and formation of assumptions providing an overview of how and why assumptions influence thinking and practice. This formed my overarching framework of assumptions and is described in my Findings Chapter.

These ideas and their interpretation were explored through dialogue with critical friends, a process that is described by Winter (1998) as "thinking with others" (p. 67). These dialogical collaborations provided the space for considering other perspectives and were a significant part of my ongoing process of critical reflection and sense making of the data. Unfortunately, they were seldom documented as they often took place on car journeys, but they required me to articulate my ruminations for scrutiny and re-consideration. This organic sense making process led me to recognise the importance of understanding how and why the meaning of assumptions influenced interaction; how symbolic gesture and words could be used to express assumptions which were interpreted through the assumptions of others; how situations were defined through assumptions and how all of these, in turn, influenced action. I had come full circle to framing my analysis using symbolic interactionism as a guide (Blumer, 1969; Handberg et al. 2015), recognising that the assumptions inherent within micro level interactive processes have a considerable influence on experiences in healthcare.

I returned to the conceptual themes identified at the end of Stage 2, of role, knowledge, power and empathy. Using my new framework of assumptions and the premises and key concepts of symbolic interactionism, began to

explore the data in previous iterations of writing in relation to these themes. Significant to the final stage of my analysis was the recognition that my research question did not actually reflect my research problematic. The assumptions that influenced participant's experiences of inclusion were much broader than those that merely underpinned inclusion itself. Consequently, the focus of my research changed to:

"Exploring the assumptions held about neurological rehabilitation practice and investigating their influence on inclusion"

In action research, this shift in research focus is not unusual, as Winter (1998) articulates:

"action research's emphasis on knowledge generated by particular contexts entails an assumption that once the inquiry is under way and once one begins to learn from the first phases of the work, the focus and the scope of the inquiry are likely to change" (Winter, 1998, p.63).

I had, indeed, learned from these first phases of working with data and engagement with critical friends and supervisors. It should be noted that this sense-making process adopted during data analysis was guided by a constant return to the data, specifically data that had formed the basis for my first written draft of my findings. Where I needed further context or sought a different perspective, I returned to the main data set, but my deep familiarity with the data was primarily developed through the working and reworking of writing drafts and using mind maps in order to stand back and see new patterns and relationships in the data.

The conceptual themes highlighted at Stage 2 were modified slightly and the data was developed into subthemes. Writing once more became the facilitator to setting down another sense making way-marker. This was not only a shift in undertaking a final synthesis of the data from descriptive writing to interpretive and analytical writing, but marked a positional shift for

myself as a researcher from wanting to merely describe what people had said to being prepared to interpret the data and own that interpretation.

3.8.5.6 Stage 4: Synthesis and validation of the findings

The final synthesis of the data continued to be informed by the process of writing, symbolic interactionism and collaboration with others. The writing became a synthesis of the many layers of thinking and interpretation described in the previous sections that was firmly embedded in the data itself. The subsequent generation of a writing draft focussed on the question that was at the heart of my research problematic, was grounded in the data and informed by theory. However, the final process of sense making was, undertaken with the critical friends who had journeyed with me thus far. The Findings Chapter were emailed to them asking for comments relating to whether the findings held face validity, that is, were they deemed credible and meaningful (Lather, 1986; ICPHR, 2013). Critical friends were asked:

1. Do the overarching themes about assumptions make sense in relation to the quotes that are given? Are there examples when the findings 'jar' with you a little or don't make sense in relation to the data presented?
2. Are these findings meaningful and if so in what way?
3. Are these findings useful for bringing about change in practice and if so in what way?
4. From reading the findings, do you think that the study increased empathy and understanding between participants, if so in what way?

Ruth responded

"The overarching themes about assumptions do make sense – I did have a bit of a double-take in pondering about 'plasticity'. When I thought of 'flexibility' alongside plasticity, it helped a little to understand more of where you were coming from... but all in all they

do chime with life experience, my own assumptions and that
wonderful sense of inclusion" (Email, 20.02.2016)

I had originally used the term plasticity to reflect that assumptions held the potential to change. The value of critical friends in creating such a reflexive space provided a challenge to my construction of the findings, drawing them into question and providing a platform for further consideration. Ruth's comments caused me to stop critically reflect and reconsider my choice of language. Christine also described plasticity as a word that "jars" against the spirit of the rest of the findings, however, at the time we were unable to find a word that captured the very essence of the potential of assumptions to change in response to experience and the environment, although the use of the word malleable was explored. Alevesson and Skoldberg (2010) argue that it is possible for the researcher to "be captivated by their own language games" (p.308) which can be related to their own research paradigm. The language of plasticity was part of my neurological rehabilitation vocabulary capturing the brain's ability to change and adapt in response to new stimuli. Perhaps the use of plasticity was part of my language game, given that the quality criteria for participatory research emphasises the need for it to be meaningful to participants (ICPHR, 2013). I kept the term plasticity until the thesis was close to completion, finally deciding that it was not a language that held meaning for many of the service user participants in particular. Instead, I have returned to the term malleable, as this does capture the essence of the change potential of assumptions and is a word that is more commonly used in everyday language.

In line with the collaborative nature of this research as outlined in this chapter, validating these findings with a focus group of original research participants was considered. This would potentially have added value in terms of the participatory validity by further checking the credibility and meaning of the findings and in checking out the usefulness of the study to create social action or catalytic validity (ICPHR, 2013; Lather, 1986). However, there were a number of issues influencing my decision not to go ahead with such a focus group. As the data analysis had taken place over a

three to four-year period, running an additional focus group with the purpose of verifying my research findings was not perceived to be either practical or ethical. It was deemed impractical due to the length of time available in a focus group itself to communicate and receive informed and meaningful feedback on the findings. Staff and service user participants had not engaged with the research since the Big Conversation Day in 2010 and considerable time would need to be taken to familiarise them with the study, a process that may be particularly challenging for participants with cognitive impairment. This would leave little time to explore, contest and develop the findings in line with the ethical principles of mutual respect, which values diverse perspectives and ways of knowing (Centre for Social Justice and Community Action, 2012). Ethically, using a participatory approach also requires a commitment to democracy at all stages of the research, enacted through "...encouraging and enabling all participants to contribute meaningfully to decision-making..." (Centre for Social Justice and Action, 2012, p. 9). Running a focus group where there was not sufficient time to discuss the essence of the research findings in a way that respected each person's contribution ran the risk of reducing validation to a mere 'tick box' exercise. Such an approach may run either the risk of participants potentially feeling coerced into agreeing with findings as presented or as Barbour (2001) suggests as the researcher, I may disregard my layers of complex interpretation in order to accept the face value interpretation of one of the participants, thereby unwittingly invalidating the time spent immersed in the data. Indeed, McTaggart (1998, p. 225) cautions, "any one account is just one amongst several defensible accounts which might be presented". Not having sufficient time to engage people meaningfully would, in my view be worse than not engaging with the wider group of participants at all at this stage of the research. Whilst I do not subscribe to the stance suggested by some researchers that validation with participants is "more trouble than it is worth" (Barbour, 2001, p.1117), I do adopt the stance that where participation is not feasible, transparency of decision making as a means of maintaining researcher integrity is an ethical way of being in participatory research.

The process of the validation of findings undertaken with critical friends was deep and detailed requiring us all to engage in understanding the concepts presented in my writing. This sense making process has resulted in my findings being validated for their credibility and meaning (Lather, 1986; ICPHR, 2013), but additionally the analysis process has been organic, educational and transformative in terms of both the development of the findings themselves and also personally. One of the critical friends reflected on the impact of our discussions:

> *"Its made me more self critical, realising how easy it is to fall into the trap of making assumptions...there is a need for constant watchfulness" (Phone conversation 26.08.2016).*

The findings have been validated beyond merely my own interpretation and generated changes in thinking in individuals - participants, myself and critical friends - and hold the potential to generate social change. Such catalytic validity is recognised as being important in participatory research that is values-based (ICPHR, 2013; Lather, 1986). Moreover, I am confident that my depth of engagement with the data has reached a point of "interpretive sufficiency", a term usually used in ethnographic research, which argues that interpretations of the data "should possess the amount of depth, detail, emotionality, nuance and coherence that will permit a critical consciousness to be formed by the reader..." (Denzin, 1997, p.283). Similarly, (Winter, 2002, p.145) refers to the "persuasiveness" of the text, which enables it to be relied upon by the reader.

Feedback from critical friends, too, would indicate that this has been accomplished; indeed, the way-mark of the 'ending' of this phase is perhaps most appropriately summed up by Ruth who commented that my findings "...*made sense*..." in relation to both assumptions and inclusion. This is my way-marker for my analysis having been sufficiently interpreted. This is also, however, the starting point for the next stage, which will be to make these findings public and begin a new conversation about their relevance to other situations and contexts (Winter, 2002). Further issues relating to the quality

of this study are captured in more detail in the following chapter. However, providing a critique on data analysis fits more appropriately in this section.

3.9   Summary

This chapter has discussed the participatory design and methods adopted in this study. Using a participatory research approach had an influence on the way the study was designed and the choice of methods in order to support the inclusion in the study of everyone who wished to take part and fulfilled the inclusion criteria. As has been illustrated, the analysis process was particularly detailed and lengthy to ensure that my interpretation of the data got to the very heart of the assumptions of service users and staff underpinning neurological rehabilitation and their influence on inclusion. The following chapter will explore the quality of the methodology adopted in this study in more detail.

Chapter 4: Evaluating the Quality of the Study

4.1 Introduction

This chapter builds upon the validation of findings presented in the previous chapter, critically reflects on the quality of the methodology and considers more broadly, the extent to which the study has met the validity criteria for participatory research (International Collaboration for Health Research (ICPHR), 2013). The quality of a participatory research study is recognised as being associated with its alignment to the core values and principles of participation (Springett et al. 2016). The ICPHR (2013) articulate these values and principles as follows: maximising the participation of those people who are engaged in the research which is locally situated; recognising all participants are researchers investigating a shared area of concern; having shared ownership of the research process; aiming for positive change through human agency; promoting self-questioning through critical reflexivity; producing knowledge that reflects diverse ways of knowing and is created through dialogue; aims for social change. Adherence to these values and principles will be considered throughout the chapter, the empathic and catalytic validity of the study will be explored. Issues of face validity introduced in the previous chapter will be built upon through a critical reflection on the Assumptions Workshop and ethical validity will be explored in relation to facilitation in a mixed focus group.

4.2 Evaluating the extent to which participatory values were realised

The active participation of service users and staff was espoused and aimed for throughout all stages of the study. To my disappointment I found that it was not always possible to realise this aspiration, due to time constraints

imposed by both the PhD process and undertaking this study as part of a wider funded research project. However, wherever possible, the participation of service users and staff has been embedded and facilitated throughout the course of this study. My perception of the variance in the participation of the people who took part in the study is summarised in Table 4 using Cornwall's (1996) modes of participation which have previously been outlined on p.91 in the Methodology Chapter.

Table 10: Evaluation of modes of participation in this study (Adapted from Cornwall, 1996 and Cook et al. 2012).

Modes of participation in this study						
	Research Question	Research Design	Data Generation	Data Analysis [1] / Data sense making [2]	Action	Dissemination
No participation						●
Co-option						
Compliance						
Consultation				●[1] ●[2]		
Co-operation	●					
Co-learning		●	●		●	
Collective action						

(Left axis label: Mode of participation)

[1] Data analysis; [2] Data sense making

Places of co-learning promoting the participatory values of critical reflexivity and the co-creation of knowledge based on the diverse perspectives of service users and staff were realised during the design of the study and data generation. At these stages in the research process, service users, staff and researchers alike developed an awareness of their own assumptions about neurological rehabilitation and also, how the assumptions of other people could influence their experiences of inclusion. Whilst inclusion was the focus of the discussion between participants and researchers, the design and facilitation of these discussions were successful in encouraging participants to not merely share their stories of inclusion or exclusion but also to explore their thinking at a deeper level. For many participants, this enabled them to develop new understanding not only about inclusion, but also about

themselves, their behaviour and practices, as they learned from people who held a different perspective. This personal learning and change is reflected in the action element of Table 10 and will be explored further in this chapter in relation to the catalytic validity of the study.

Developing the research question as outlined in Chapter One, was influenced by the co-researchers who were also engaged with the funded study; however, the choice of PhD question and focus for this study was my own. The sense-making phase of data analysis, as outlined in the Methodology Chapter, was supported by a process of "consultation" (Cornwall, 1996), with critical friends in relation to the validation of the findings of the study. I viewed this as consultation, as due to time constraints, I sought the opinion of critical friends and retained control of the process of data analysis. However, feedback from critical friends, suggested that this validation was more than mere consultation and had instead provided an opportunity for them to share their knowledge, contested the term "plasticity of assumptions" and had increased their own awareness of assumptions. Based on Cornwall (1996) this would suggest that "co-learning" was therefore the mode of participation, rather than "consultation". This difference in perception of the mode of participation particularly highlights the problem of evaluating the degree to which a study has been participatory based solely on a researcher perspective. It was only by engaging with critical friends that my assumption that I had merely consulted with critical friends was actually challenged. This would suggest that any evaluation of the degree to which a study has been participatory would, in the future, be more appropriately undertaken in collaboration between researchers, participants and in this instance, critical friends.

Participants responded positively to the participatory process not only when in homogenous focus groups, but particularly when service users and staff were in dialogue together in the facilitated mixed focus groups and at the Big Conversation Day. These discussions challenged the traditional hierarchies of the relationship between service users and staff and in doing so, also

challenged hierarchies of knowledge that can be evident in the generation of knowledge in research studies in general. As outlined in the literature review, most research in neurological rehabilitation still privileges professional knowledge over that of the service user, and most research studies still seek service user and professional views separately. Importantly, these mixed focus groups not only created opportunities for assumptions to be disrupted as participants engaged with one another's very different perspectives, but they also improved the validity of the study through the generation of shared understanding and new insights about personally held assumptions.

4.3   Evaluating the choice of methods

Homogenous and mixed groups were effective in facilitating critical conversations through which assumptions were recognised. Bringing together different perspectives provided the opportunity for them to be discussed and contested. Importantly as Lather (1986) argues, approaches which do not merely seek agreement work to increase the validity of the data. Crucially, these methods did not merely encourage participants to describe what was happening in their lives, but instead acted to disturb tacit knowledge, bringing assumptions to the fore. The combination of visual methods and critical dialogue between participants who held different perspectives was particularly powerful in facilitating recognition of assumptions and their impact on inclusion. Photography, in particular, provided a focus for discussion that was provocative and facilitated an expansion of participants' thoughts beyond what they previously knew about their assumptions in relation to neurological rehabilitation and inclusion.

4.4   Evaluating the catalytic validity: the extent to which the study has generated action and change

As articulated in the methodology, the purpose of this participatory study was to create a collaborative space, which facilitated participant self-reflection in order to increase their understanding of their own situation and or practices

(Kemmis and McTaggart, 2005). The findings of the research indicate that self-reflection and personal change did take place throughout the course of the study and this is particularly evident in the Findings Chapter, section 5.3. This emphasis on personal change is different from traditional definitions of action research, which emphasises a cyclical problem solving approach through which practical outcomes are generated with the aim of producing wider social or service change (Waterman et al. 2001). This distinction is important in evaluating the catalytic validity of this study, which has not aimed directly for wider social change, but instead has focused on the development of the self-understanding of individuals. Indeed this is the very same methodological muddle I found myself in, which I will discuss further in section 4.6 of this chapter.

Critical friends, including fellow researchers, supervisors and family have all inquired with me to dig deep into understanding the complexity of assumptions and what this means for neurological rehabilitation practice and experiences of inclusion. It is the reflections of Ruth (pseudonym), who was a participant in the funded research and this study and Christine a researcher on the funded research and this study, that are the main focus of this section relating to the catalytic validity of the study. This group of critical friends also included my supervisors, family and close friends, so in this sense we have all been enquirers into assumptions as we have engaged in critical discussion together. Many of these critical friends clearly articulate ripples of personal change in relation to their awareness of how assumptions influence their thinking and their relationships with others. Christine and Ruth reflect on this learning, providing evidence for the catalytic validity of this study.

Christine highlighted that she had come to recognise how readily the assumptions she held could be made with insufficient thought. As a consequence, she states that she found herself:

"Engaging with people with greater hesitancy and taking much more care before forming an opinion" (E-mail correspondence 7.10.16).

Ruth stated:

During the course of our many discussions...I've been challenged to re-evaluate my assumptions and have become aware that I still do have quite fixed assumptions of others…...but you have also enabled me to be able to dismantle them – and to 'let the light in' and to see that sometimes it is best to enter in to an interaction, a clinic appointment or a meeting with a Health-Care Professional with a blank-page! To try to ensure that we can work together and come to a conclusion and a decision that is acceptable to everyone concerned" Reflective Diary 26.11.2016.

The catalytic influence of this study therefore goes beyond those who were directly involved in the study, and reached those whose lives have been connected closely with my own musings and learning about assumptions and their influence. This influence has its roots in critical dialogue not merely as a one off event, but as a discipline in itself, requiring an ongoing commitment to noticing, questioning, evaluating and exploring assumptions as a focus for thinking and dialogue. As Christine and Ruth illustrated, it was only with increased awareness of assumptions that the risks and impact associated with holding certain assumptions were more fully recognised.

4.5   Evaluating empathic validity: the potential of the study to generate greater empathy between people.

Dadds (2008) suggests that the value of empathetic validity is to "transform the emotional dispositions of people towards each other" (p. 279). Whilst this was evident in the homogenous mapping and focus groups, it was particularly notable when service users and staff came together in dialogue. It is unusual in neurological rehabilitation research to bring the views of

service users and staff together. However, in this study the extent of the reciprocated empathy was testament to the deep engagement with one another's perspectives. Service users for example, gained greater appreciation of the experiences of people who lived with other neurological conditions and also noted that *"staff are people and have feelings too"* (BCD-SU-Qe). The generation of empathy and deeper understanding of the perspective of other people acted to challenge taken for granted perspectives, thereby bringing assumptions to the fore for reconsideration in light of this new understanding.

Whilst the design of the study contributed considerably to the empathic validity of this study, Koch and Kralik (2006) also note that the facilitator plays an important role in creating a "context that is conducive to rich interaction" (p. 58). Questions from the facilitator, which probed beyond the descriptions of an experience or event enabled participants to engage in a deeper analysis of their situation. This questioning process generated dialogue between the participants and the facilitator, enabling people to critically analyse their own experience. Koch and Kralick (2006) and Wadsworth (2006) highlight the important role facilitators hold in supporting participants to interpret and make meaning from their experience. Indeed, I found that this required not only that participants dig deep and engage in the "swampy lowlands" (Schon, 1983, p. 42) and complexity of their experience and practice, but it required the facilitator to acknowledge that complexity and co-inquire alongside participants. This not only enabled individuals who told their story, to gain a deeper understanding of their situation, but also provided the opportunity for other participants and myself as a facilitator to develop new emotional understanding of participant experiences.

Understanding myself, and my influence on the enquiry processes is seen as key to the skills of a facilitator (Wadsworth, 2006). The following two examples illustrate the importance of my critical reflexivity to learn from my experience whilst conducting the study and gain insights into my practice as a facilitator.

4.6. Critical reflections on establishing face validity and a methodological muddle

The Assumptions Workshop at the Big Conversation Day provided the space for participants to engage with the early analysis of the data and understand some of the early themes generated from data. The aim of the workshop was twofold, firstly to check with participants that the themes I had generated were meaningful and secondly to produce a plan for how the assumptions themes might be implemented into practice. I had intended to achieve this within two hours. From my perspective at the time, I gained confirmation that the early themes, which were presented as assumptions statements (Appendix 4), had resonance with the service users and staff who attended the Assumptions Workshop. Additionally, the workshop generated an action plan to address these themes in practice and participants reported that they had enjoyed the event and valued the opportunity to talk to people who held different perspectives. I deemed the workshop to be a success from my perspective.

In relation to the first aim, following the event, I reflected on Lather's (1986) articulation of face validity of the findings. She argues that this requires not merely the "re-cycling" (p. 67) of themes back through participants, but also that there should be opportunity to for the themes to be debated in relation to whether they are true or not. Based on this premise, I subsequently questioned whether my attempts to check the early findings with participants, had indeed been merely an act of confirmation rather than validation. There were two specific issues that led me to consider this:

1) The key assumptions generated from the data were not presented with examples from the data; therefore, whilst participants could comment on the assumptions in relation to the meaning they held for their lives, they were not able to comment on my interpretation of the data itself. This therefore missed the point of establishing the face validity of the findings specifically in relation to the data.

2) McTaggart (1998, p. 224) argues that validity in participatory research requires that "*difference is recognised, expressed and understood*". My search for confirmation of the findings, led me to be blind to ensuring that differences in viewpoint were highlighted for exploration. However, reading through the transcript after the event, there were times when differences of opinion was expressed, but as a facilitator I had not attended to these during the course of the workshop. Opportunities for developing the face validity of the findings were therefore missed. My concern was, therefore, that I had merely persuaded participants to agree with the early interpretation of the data rather than ensure - as highlighted by the ICPHR (2013) -that participants were facilitated to own the research process. In hindsight, I would suggest that in this situation I had remained in control of the extent to which participants were able influence and shape the enquiry into these early findings. In light of this, data analysis has been reflected in Table 10 under the heading "consultation". However, participant experience of the workshop also suggested that it generated the opportunity for learning together, i.e. "co-learning".

I found it challenging, as someone committed to working in a participatory way, to recognise my tendency to seek certainty in novel situations and particularly the need to "get things right" in relation to my perception of the "right" interpretation of data, thereby assuming the stance of expert. My initial response was to try to quash this tendency, however, Wadsworth (2006) notes the importance of facilitators holding a mirror up to themselves in order to recognise and accept their "own inner diversity" and in so doing more readily accept the diversity of others (p. 328). This appreciative approach to facilitation encourages me to not dismiss such personal tensions, but work towards a greater valuing of ambiguity in myself and in the interactions between people in the processes I am involved in facilitating.

The second aim of the workshop had been to generate specific actions for practice in relation to the key assumptions identified by participants. At the time of conducting this workshop, I was in somewhat of a methodological

muddle. In hindsight, I was unclear how the workshop related to the aims and objectives of my study and I held the assumption that in order to bring about change in neurological rehabilitation practice, my study needed to recommend findings and outputs that were tangible, easily defined and could be readily implemented through service improvement programmes. Based on my health care experience, this is what I believed practitioners and service users found to be of most value to practice. Whilst these tangible outputs for practice were certainly interesting and included for example the development of a service user passport that would go with service users whichever neurological rehabilitation service they needed to use (Appendix 13). I have made the decision to exclude the actions generated from the Assumptions Workshop in the findings of this study. I am however, confident that what has ultimately been articulated instead is something much deeper and more fundamental to neurological rehabilitation.

4.7   Critical reflections on facilitation dilemmas: living the tension between ethics in action and the delivery of a method.

Maximising the participation of all participants (ICPHR, 2013) implies that it is important to create an inclusive space whereby participants and researchers are able to come together and have an equal opportunity to share their perspectives with one another. Indeed, an inclusive approach is one of the guiding ethical principles within participatory research (Centre for Social Justice and Community Action, 2012). Inclusive research requires that people who are traditionally sidelined or ignored in research are heard (Nind, 2008) and treated with respect (Walmsley and Johnson, 2003). The guidelines from the Centre for Social Justice and Community Action (2012) additionally suggests that an inclusive research process should challenge discriminatory practice and ensure that meetings are accessible, meeting the needs of the diversity of participants.

The following example explores how my assumptions about ethical conduct within participatory research were challenged by my concurrently held assumptions about the method of delivering this particular mixed focus group. My reflections recognise the important role the facilitator plays in determining a space for interaction that is based on trust, dignity and respect (ICPHR, 2013) between participants and the researcher. I will first outline the scenario and subsequently present my critical reflections.

The mixed focus group highlighted in this example was run in Phase 3 of the study and had been planned to ensure a balance between the different participant groups. However, at the last minute, there was an unexpected imbalance of numbers between service users and staff, 1:5 respectively. As the single service user arrived they were greeted from their transport and given the choice to take part or not. The service user chose to continue as planned despite the imbalance in the group. As participants introduced themselves to one another, she introduced herself by name and as a service user. However, after a short period of time the service user began to contribute to the discussion from her knowledge and experience as a member of staff in another NHS facility, rather than as a service user. This continued to the end of the focus group. Her transport to return home arrived on time, so there was no opportunity to talk to her prior to her departure.

My overarching dilemma was how best inclusive ethical principles could be supported during the facilitation of this focus group. What worried me here was that the service user would feel overwhelmed and intimidated by the number of staff in the focus group, such that she did not feel able to share her perspective or at worst felt so unsafe that it caused her emotional distress. What unsettled me was the risk of perpetuating traditional power hierarchies between staff and service users and raised my attention as to how my role as facilitator might ensure her voice was heard and she was positively supported to engage in dialogue (ICPHR, 2013). My concerns were augmented further by the knowledge that in Phase 2 of the study, this service user had asked that her interview was not recorded as she had felt uncomfortable with this and did not wish to hear herself. This left me feeling

very uncertain about how comfortable she would feel taking part in a focus group that was digitally recorded.

My dilemma of how to conduct the focus group in an inclusive way was informed by a number of assumptions. These were held with different strengths during the pre-focus group phase when the service user arrived, during the facilitation of the early stages of the focus group, and during the facilitation of the middle to late stages of the focus group. My assumptions fell into two broad categories, the first related to upholding ethical principles that were inclusive and did not inflict harm. The second category focussed on the timely and purposeful delivery of the focus group, which in this case aimed to bring staff and service users together in dialogue. My assumptions and reasoning related to these two categories were as follows:

Do no harm: the hierarchy and power imbalance within the group could be anxiety provoking for the service user.

Give voice to the marginalised: as a facilitator I needed to create space for the service user to have a voice

Autonomy and respect: everyone had the capability to make autonomous choices and these needed to be respected.

Support critical dialogue: critical dialogue is most productive when different kinds of knowledge and experience are brought together in particular the knowledge of service users and staff.

Successful delivery of the method according to its purposes: the study needed to be delivered according to the purposes and procedures related to that particular method, which included the facilitation of critical dialogue.

These assumptions about ethics and the delivery of the research were interwoven and each held different weightings at any one time, influencing

my reasoning and decision about how best to facilitate the group. The following three diagrams and associated text illustrate the competing weighting of assumptions during three different phases of mixed focus group facilitation. The weighting is represented by the thicknesses of the arrows in relation to each other.
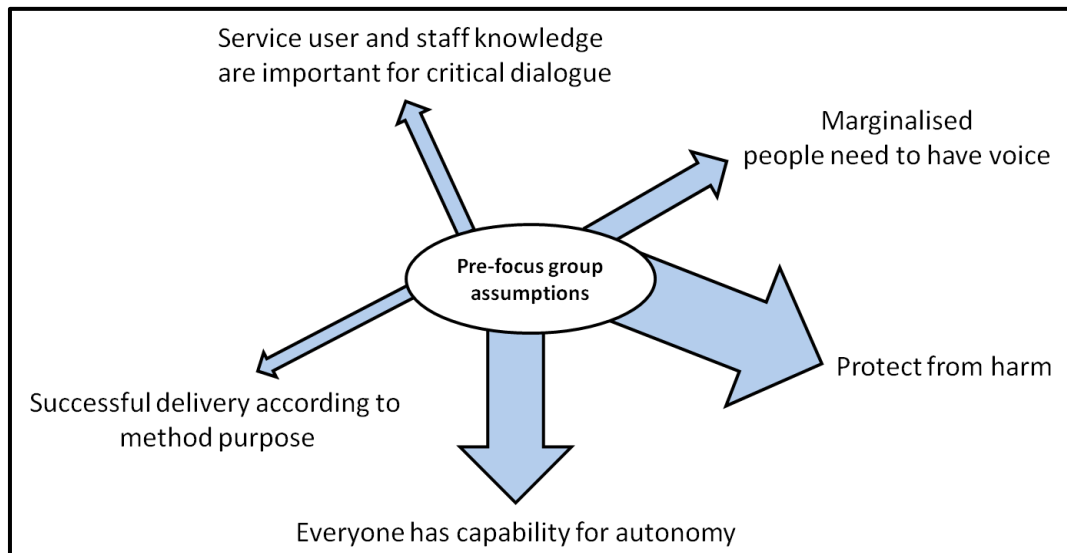
Figure 11. Weighting of personal assumptions immediately prior to the focus group.

Awareness of the imbalance in numbers between service users and staff led to initial assumptions that drew from ethical principles of protection from harm (beneficence) and respect personal autonomy (Sim, 1998). These assumptions were most dominant and assumptions relating to the purpose and delivery of the focus group were low as identified above in Figure 11.

As the focus group started, my attention moved to focus on the delivery of my perception of a successful focus group. My assumption was that in order for this to happen, there needed to be space for the marginalised voice of the service user to be heard in order for critical dialogue to take place. This assumption also held within it, the assumption that members of staff would not also feel marginalised within the focus group. This was certainly not my impression at the time, but serves to highlight how a focus on traditionally marginalised individuals could have created an inattention to staff members

147

also feeling on the fringes of the group. The change in arrow width between Figure 11 and Figure 12 illustrates the shift in the strength of my assumptions from a pre-occupation with the ethics of protecting from harm to the ethics of creating the space for voice. However, at the same time, there are heavily weighted assumptions about the need to deliver the focus group and an assumption that data illuminating assumptions would primarily be generated through critical dialogue involving service user and staff knowledge (Figure 12).
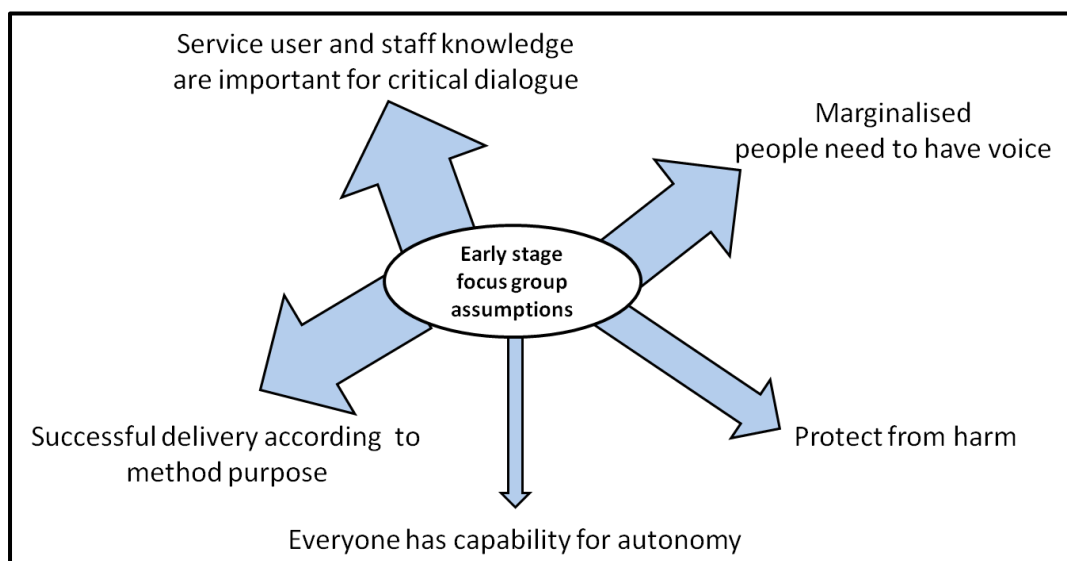
Figure 12. Weighting of personal assumptions in the early stages of the focus group

A shift in the weighting of my assumptions between ethical values and procedural delivery of the focus group took place as the service user shared her knowledge and experience as a member of staff rather than as a service user. From my perspective, it was an unexpected stance by the service user. I had anticipated silence, but not this shift in identity. This jolted me to take greater note of the situation, challenging my assumptions about whether the technical delivery of the project was more important than the ethics of inclusion. Whilst this internal mental discussion may have only lasted for a moment, it was significant in leading me to ultimately question how I could best facilitate an inclusive process for the remainder of the focus group.

Questions such as "does anyone have a different perspective to bring to that" left the door open for the service user to share her perspective based on this identity. However, my assumption that the success of the focus group relied on bringing service user and staff knowledge and experience together in dialogue had been strongly challenged and its' weighting became considerably less (Figure 13). Subsequently, I strongly held the assumption that everyone had the capability to act autonomously and choose how they took part.
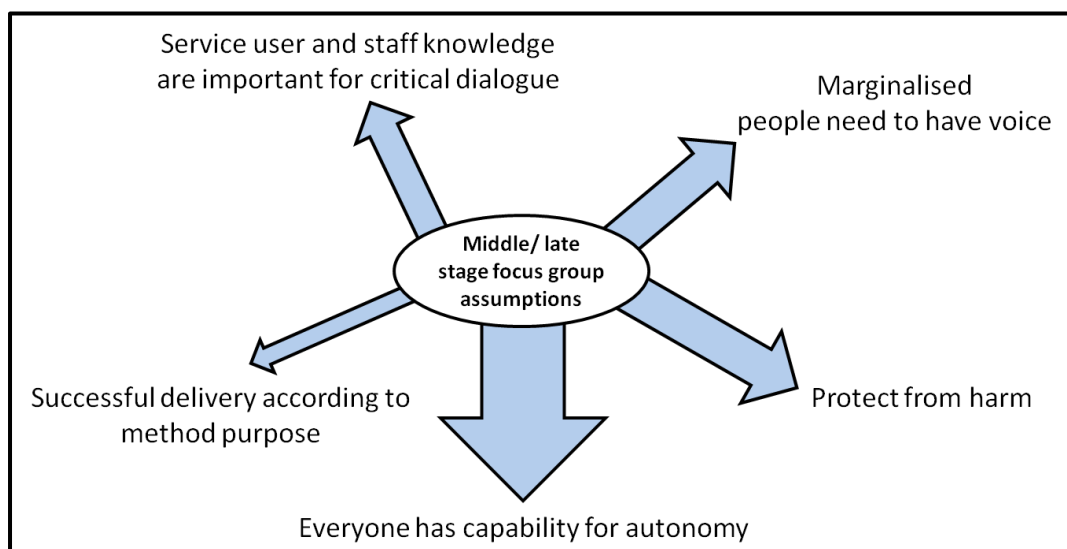
Figure 13. Weighting of personal assumptions in the middle to late stages of the focus group

This experience highlighted the problematic nature of the composition of focus groups. Indeed, it is well recognised that power asymmetry in focus groups can affect the openness of participants (Berghold and Thomas, 2012; McTaggart, 1998). Symbolic interactionism also indicates that our social selves which are defined in interaction are directly related to the group of people whose opinion is thought to matter (Charon, 2010), in this situation the views of staff members. However, as in this example, sometimes the most well planned research processes are thwarted by unexpected events, requiring on the spot flexibility and responsiveness from the researcher in order to facilitate interaction between participants. I would argue that such

flexibility requires an awareness of and alertness to personally held assumptions and the tension that can be created as Ideal World assumptions are challenged by the experience of the real world situation.

Particular tensions in assumptions in this example were between the technical management and delivery of the focus group and embedding the ethical values of inclusion. Assumptions about what a successfully delivered focus group looked like were particularly problematic as they were rigidly held until my assumptions were jolted into considering a different perspective. In this instance, it was the unexpected stance of the service user which required me to ensure that there was space for her self-determination, This evaluation of my assumptions, in the midst of the action of the focus group, required me to be comfortable with ambiguity. In addition, be responsive to the diversity of the group and respect autonomy, as required by inclusive ethical principles. By holding heavily weighted assumptions about how research "should be" technically delivered and anticipating how people will play out their role and participation in the research, I had categorised participants, thereby limiting my openness to diverse ranges of knowledge. Whilst it would have been difficult to plan for the unexpected, it was how the unexpected was responded to and subsequently explored that was important. In this situation exploring these tensions with the group in my view, would not have respected the position the service user had adopted.

4.8   Summary

Overall, the study design did reflect participatory values, which aimed to not merely involve participants in the research process, but actively facilitate a process of critical dialogue between service users, staff and researchers, leading to the illumination of assumptions. However, basing a study on a set of espoused values was not sufficient in itself to ensure that a study was of high quality. Every attempt was made to support participatory values within this study, and where this was not possible for pragmatic reasons; alternative approaches particularly to data analysis were sought, supported by the use

of theory. The importance of my own critical reflexivity as researcher and facilitator of individual and group interactions has been demonstrated to be central to the generation of the quality of both data and the findings. This evaluation has clearly demonstrated that the facilitation of participatory research was crucial to the quality of the study, such that it could not merely be reduced to set of skills or the delivery of a method. Instead, it required a relational approach within the research process that demanded a critical reflection on the inter-layered assumptions of ensuring ethical research practice and technical research delivery. This complex interplay required thought and action in the moment in order to respond flexibly to places of tension and also after the event in order to understand more fully the dynamics of the situation. The facilitation of the Assumptions Workshop and the mixed focus group presented in this chapter, were certainly far from exemplary. However, they offer learning to other participatory researchers in relation firstly ensuring clarity about the purpose and theory behind the delivery of any research method. Secondly, attending to tensions in focus groups either internally or overtly, as these are the very places where learning and understanding are generated.

Chapter 5: Findings

5.1   Overview of the chapter

This chapter will present the findings of the study; these are structured around three fundamental sections: 1) Complexity of assumptions; 2) Connectivity between assumptions about neurological rehabilitation and inclusion; 3) Changing assumptions about neurological rehabilitation and inclusion. A short précis and mind map of the main themes and sub-themes will be presented at the beginning of each section. These will then be expanded upon and related to the data so that the findings of this study are grounded in the authenticity of participants' examples and verbatim quotations. The key to the source of the data from which quotations are taken can be found in Appendix 14.

5.2   Complexity of assumptions

There were five key themes and sub-themes generated from the data that contributed to an understanding of assumptions. These are their nature, type, order, how they are formed and their strength as illustrated in Figure 14. Understanding the complexity of assumptions provides the foundation from which to recognise their importance to neurological rehabilitation practice and their influence on experiences of inclusion. These findings are presented in a structured format due to the constraints of the two dimensional writing process. However, it is hoped that what will be conveyed is their complex and multi-layered nature, as they are shown tacitly to influence both thinking and action.
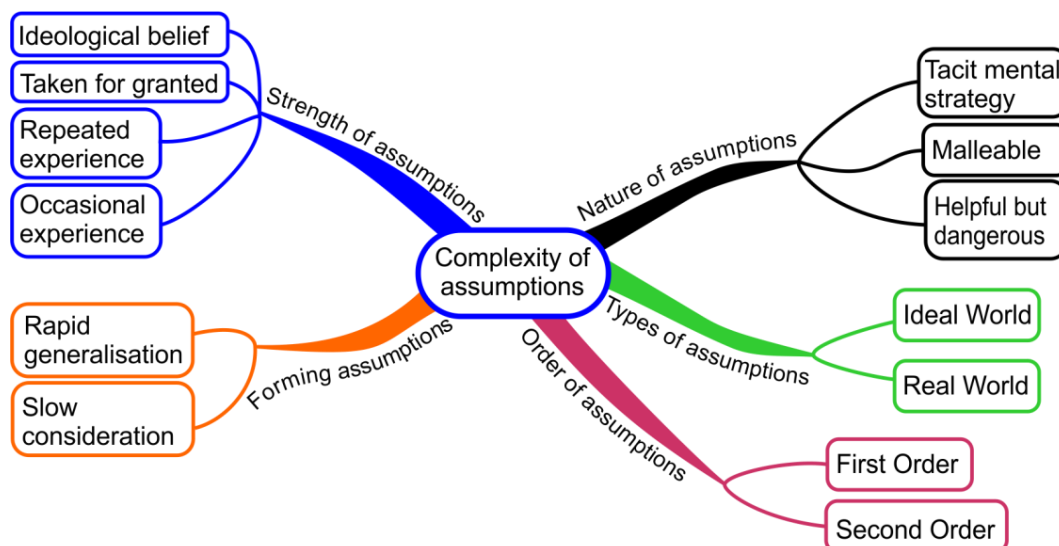
Figure 14. Mind map: Complexity of assumptions - themes and sub-themes generated from the data.

5.2.1 Nature of assumptions

There were three key findings about the nature of assumptions relevant to this study. These were 1) Assumptions as a tacit mental strategy for making sense of situations; 2) Assumptions as malleable; 3) Assumptions as helpful but dangerous.

1. Assumptions are a type of tacit mental strategy that helped participants make sense of and process the complexity of the world around them. They supported participants to recognise patterns of interaction, action and events, creating order in their internal world by enabling an understanding of what was most likely to happen in a situation. Additionally, they formed the basis for actions and interactions in practice and the wider community.

2. Assumptions are malleable and often do not represent a situation accurately or from all angles. Therefore, participants required an awareness of the influence they might be having on their worldview, thinking, actions and interactions. This awareness then held the possibility that in context, assumptions could be developed or changed. However, this was not an easy process as assumptions

were not always recognised as merely provisional and were often strongly held.

3. Increasing awareness of assumptions required an understanding of their nature, their type, order, form and strength. On the surface assumptions appeared simple and certain, enabling actions to be predicted. However, they were identified as highly complex, inter-layered, prone to misuse and could lead to misinterpretation.

Assumptions as a tacit mental strategy for making sense of situations

Using assumptions as part of the mechanism for dealing with the world around them, allowed participants to set up schemata or generalisable mental patterns about particular situations and act accordingly. Whilst holding these schemata, could be useful and beneficial in many circumstances, they were not always helpful and could lead to misunderstanding, miscommunication and consequently, to feelings of exclusion.

For example, a disabled access sign was displayed and the assumption was held that it was accessible to all disabled people regardless of impairment. However, this was not always the case, and whilst many buildings and environments were accessible to wheelchair users they were not accessible for example for people with a visual or memory impairment or even wheelchair users. Practitioner Jenny illustrated this point:

> *"I think a lot of the photographs have shown that it's other people assuming that things will be able to be accessed ... I think it's just the idea of physical access to somewhere being something that we all take for granted and when you look at a lot of these images it's just not, is it?" (S2-F-P)*

Jenny's example identified that the underlying schematic nature of assumptions could be based on many years of experience and reinforcement through cultural beliefs and/or practices that were often taken for granted. They provided what were perceived as a set of unseen foundations for

making sense of the world and acted as a tacit starting point for participants understanding their lives and the perspectives of other people. It was apparent that these schematic assumptions risked becoming places of certainty, suggesting that such assumptions tended to be strongly held. This was illustrated by service user Ruth's comments about society's perceptions of people on benefits as reported the media:

> *"I've just read [in the newspaper] today about that assumption of… That people who are claiming benefits are all spongers."* *(SU32-F-I theme validation)*

Such reasoning by the media would appear to be dualistic, where one person was presented as "right" and the other person was "wrong". Ruth indicated that the polarity of such positioning led people who were perceived as wrong or not fitting in to a group or situation to be seen as outsiders and they were therefore excluded. Consequently, this led to the formation of stereotypes about disabled people who were then cast into a specific role in society, which was often negative. It seemed that the complexity of the meaning of such situations could be readily lost, particularly when assumptions were expressed as a certainty. This appeared to risk taken for granted interpretations of the world becoming rigid and myopic. However, the value of assumptions seemed to be that they not only provided a schema and set of mental patterns that acted as a framework for making sense of situations, but importantly, they were also malleable and able to change.

The assumptions participants held indicated *how* the world was viewed, rather than merely *what* was seen, thereby assumptions acted as the interpretive lens through which action and interaction were informed. As practitioner Sue reasoned, if she was listening to people, then she was holding the assumption that she did not know all the answers.

> *"I suppose by listening you're… Well I suppose you're assuming you don't know all the answers and you're valuing other people's opinions and hoping that, you know, together we… We might be able to achieve more, I suppose". (S18-F-FG)*

Her assumption created a different schematic order from the previous examples, which highlighted the way that assumptions can label and categorise people. Instead, Sue's assumption framed the situation as complex and importantly recognised the ambiguity of personal interpretation. Her assumption acted as a tacit mental strategy, which created space for a recognition of perspectives other than her own. From Sue's perspective, this assumption played a critical role in supporting a positive interaction between herself and service users.

Malleability of assumptions

Participants indicated that assumptions were indeed malleable. This was illustrated by Jenny in the previous section who recognised that her own assumptions had changed in response to new information about disabled access. It was also suggested that other people's assumptions were malleable and could be influenced. When this position was adopted, it was suggested that a challenge to existing assumptions was required in order to bring about this change, a point illustrated by staff member Penny:

> *"it's about really thinking hard about how inclusive we are here*
> *And we're sort of taking things to the next level and challenging*
> *some of the assumptions that may be around." (S11-F-Map)*

Whilst the malleability of assumptions was clearly indicated, this did not necessarily mean that their development or change actually took place. Where the sense of meaning attached to a situation was strongly held, the assumption became more resistant to change. Service user Robert provided an example of the influence of embedded cultural practices on the strength with which assumptions are held.

> *"Well that's another cultural thing, isn't it? There is the thing that's*
> *always said about British people – we don't complain about*
> *anything. And I think it is true." (SU40-M-MFG)*

In this example, the assumption of "not complaining" was widely viewed as a condition of the British people. Service users and staff taking part in this

study indicated that even when more than one person was unhappy with a service and people were aware that there were others who were experiencing the same problems, there was still a reluctance to complain. Participants found their lack of complaining about services in the NHS rather peculiar and even somewhat out of character. Whilst there was awareness of the illogical nature of "not complaining", service users and staff suggested that it was the dominance of their emotions of fear and vulnerability, that impacted on their choice not to complain. It would seem therefore that the negative emotion associated with the assumption of not complaining, gave it a strength that kept it firmly fixed in place.

This section has identified that assumptions are by their nature malleable; however, they may not always need to change or be open to change. Further detail of the conditions that can influence change in assumptions can be found in section 5.4 of this chapter.

Assumptions as helpful but dangerous

Participants indicated that their assumptions formed the basis for thinking and action and were particularly helpful in categorising what was processed through the senses, bringing organisation and order to patterns of thought. Such compartmentalising of information allowed participants to simplify complex information and hold assumptions, about for example other people, who they were, what they might be interested, in and what they might do in a given situation. As service user Steve stated, holding assumptions is common to everyone: ,

> *"...it's human nature. That person was a bus driver or that person was a surgeon or that person was a… Whatever they used to do, you make an assumption, don't you?" (SU16-M-Assumptions workshop)*

This ability to classify people, situations and objects was viewed as an important mental process without which, the amount of information to be processed would be overwhelming. In this sense, assumptions were viewed as inherently helpful, providing rules by which sense could be made of the

world. However, whilst it would appear that it was impossible to live without holding assumptions, as practitioner Fran identified assumptions themselves could also be risky and prone to error:

> *"once you've built up a relationship, there's that risk that you make assumptions. And you've got to be so careful that you're not making an assumption and that just because somebody has presented this way the last time that you saw them, that the issues are still the same."*
>
> *(S6-F-MFG)*

Such assumptions were built on past experience and the belief that the patterns of behaviour on which assumptions were based will repeat themselves in both the present and the future. This example illustrated that basing the present purely on the past was both a risky and unhelpful strategy that did not allow for any change in circumstance. It would seem that holding such assumptions without acknowledging their limitations, could lead to misunderstanding and the exclusion of other perspectives. These perspectives held the potential to inform and provide another way of seeing a situation. In clinical practice, this level of awareness of the fallibility of assumptions was crucial for decision-making. It enabled a space to be created for enquiry with service users in which an issue or situation could be explored and assumptions validated or modified. Without an awareness of the fallibility of assumptions, changes in clinical or social conditions were missed; service users did not feel listened to or if they did try and make their voice heard they were often labelled as "*troublesome*" (SU32-F-P; S4-F-Map).

Differences in assumptions between service users and staff also held the potential to lead to dissatisfaction and risky situations. Such situations could often sneak up quickly and unannounced, surprising those who were involved. In this example, the practitioner anticipated that the status quo would continue as usual:

> *"So I think I'm like, "This is the path we've agreed and we're trundling along and we're going on this." And then something*

changes. And if you've not checked that, then you suddenly find that… That client is going off that way, and I'm going off this way..." (S3-F-MFG)

Service users and staff identified that they could quickly find themselves in polarised positions with different expectations about the process of rehabilitation and its outcomes. The danger lay not in seeing assumptions for what they actually were, that is malleable, tenuous and open to change, but instead, viewing them as concrete, certain and providing the basis from which future plans could be developed with guaranteed confidence. However, as this example illustrates, checking back with everyone that they were all working from the same set of assumptions was essential to effective neurological rehabilitation. Failing to do this risked misunderstanding, poor communication and at worst withdrawal from treatment or a complaint being made. Such situations suggested that there was the risk of wasted time and effort if there was no communication between service users and practitioners about one another's assumptions.

5.2.2 Types of assumptions

There would seem to be two main types of assumption, Ideal World and Real World. Ideal World assumptions reflected the schema relating to "the best" of what should or could happen in a situation. Real World assumptions reflected schema relating to what would, or was most likely to happen. Real World assumptions generally appeared to be informed by the repeated experience of the practical issues or problems that were anticipated in everyday life. These assumptions presented as the starting point for thinking and acting and, therefore, impacted upon how both neurological rehabilitation and inclusion were constructed and practised.

Ideal World Assumptions

Participant experiences suggested that whilst Ideal World assumptions were tacitly held, they were often overtly expressed when experiences of neurological rehabilitation practice or everyday life that were hoped for, were not matched in reality. These Ideal World assumptions informed inclusion by

identifying what was perceived to be the gold standard of practice. This was particularly the case when service users had lived with their condition for a number of years, and had a clear idea about how practitioners and service users could best work together in an inclusive way. This was illustrated by service user Ruth who had lived with multiple sclerosis for over fifteen years.

> *"I think quite possibly… I think it would have helped had he said… Had he said, or had he asked me...*
>
> *Interviewer: What would you have wanted him to ask?*
>
> *Is there anything else? How are you getting on? I'm aware of there's been provision of… Are they still working? Is there anything else that we can do or talk about?" (SU32-F-P)*

Her experience suggested that when Ideal World assumptions were framed as possibilities of things that *could* happen, they were generally hopeful but nevertheless also tentative. It would appear that it was because they were not rigidly held that there was the potential for different perspectives to influence them. This openness indicated that new understandings could be reached as service users and staff communicated with one another through dialogue and interaction. This provided an opportunity for a shared construction of meaning of the situation reflecting the perspectives of all parties concerned.

Ideal World assumptions could also be deterministically framed as something that *should* happen and therefore risked being moralistic in nature, creating expectations that might not be attainable. Such assumptions were held by both service users and staff who often held clear ideas about how neurological rehabilitation should be delivered or experienced. Where this happened there was the risk that negative judgements about people or services were held. For example, during an interaction between a shopkeeper and a service user, the shopkeeper was perceived by the accompanying practitioner to be acting in a way that was disrespectful to the service user. From the practitioners perspective this was not how one should behave and consequently he labelled them as:

"ignorant...not deliberately ignorant, but ignorant..." (S7-M-MFG).

Such labelling suggests that moral judgement is being conferred on the other person and risks becoming a metaphorical stick to beat them with. It could also be argued that taking such a stance misses the potential to engage in constructive dialogue with the shopkeeper. Had this occurred, an opportunity may have been created to explore what it means to be included and how service users who visited the shop in the future feel more included.

Ideal World assumptions would not appear to acknowledge the realities of everyday life and could therefore be criticised for not recognising the challenges of exclusion experienced by both service users and staff. However, as Ruth's experience (p.160) has already highlighted, without assuming that an ideal world of inclusion is actually possible, practice would run the risk of being stuck in a world of mediocre principles based at best on patchy experiences of inclusion.

Real World Assumptions

Participants indicated that Real World assumptions were based on their lived experience and were held about what was most likely to happen in a situation, at a particular point in time and within a given a set of circumstances. Such assumptions were held in situations that were viewed as a fact of life, for example the step outside a shop, an unwelcoming receptionist at a doctor's surgery or clinic. In the following example in which service user John reflected on the reliability of a theatre's booking system, Real World assumptions were employed particularly when immoveable challenges or barriers were anticipated. As a consequence, some form of intentional interaction was required in order to manage the situation successfully.

> *"you can't assume that you can get in, you know you have to check, you can't just turn up you have to make sure you booked the accessible seat at the theatre or whatever it might be." (SU50-M-I)*

John (SU50) had lived as a disabled person for many years, but had recently acquired a neurological impairment. He held the Real World assumption that the systems in place to provide disabled access could not be relied upon and therefore he had to intervene in order to address this potential barrier. It was this intervention that made his inclusion at that location more certain. Pre-planning prior to events was commonly used by service users who had experienced exclusion from events, meetings, public transport or buildings on a number of previous occasions. Taking action based on Real World assumptions was seen to facilitate inclusion, avoid disappointments and enabled a smooth run.

5.2.3   Order of Assumptions

Analysis of the experiences of participants indicated that when holding assumptions, there were two levels of interpretation that were made by one person in relation to other people, objects or concepts within a specific situation.   These are presented as two orders of assumption and have been termed First Order and Second Order.

First Order Assumptions

First Order assumptions were the direct assumptions that person A was holding about B, where B was another person, an object, service or a concept. They appeared to have one layer of interpretation, from A to B. For example, practitioner Sue (A) held the First Order assumption that there were certain situations (B) that she was unable to influence.

> *"...it's just something that you have to sort of accept that there will be things that you have no power and influence over, you just have to pass the information on and get on with it." (S18-F-FG)*

First Order assumptions held meaning that could be subjective as in the example above, and therefore could hold an emotive interpretation in relation to how someone felt about their inclusion in that situation. First Order assumptions were also held where the meaning was more objective and the focus was predominately on objects. In such situations, the impact on

162

inclusion was dependent upon whether the object was directly interpreted as a barrier or facilitator to inclusion. For example, A held the assumption that B, the hilly cobbled street, was a barrier to inclusion and, therefore, acted in accordance with that assumption.

Second Order Assumptions

Second Order assumptions would seem to be more complex. They were indirect assumptions, where person A assumed that person B was holding assumptions about him or her. This also suggests that in turn person A was holding assumptions about what B's assumptions were. Whilst this does appear to be complex and messy, such deep interpretation of one another's perceived thought patterns was evident in the accounts of both service users and staff. Take for example Steve who is talking about some of the reactions he gets from people in relation to his memory problems because of his head injury.

> *"They just look at you and think you're some sort of idiot." (SU16-M-Map)*

Steve's example illustrates that there are two layers of interpretation present in Second Order assumptions. Steve was assuming that someone thought he was an idiot, but he did not actually know that, he was just assuming that he knew what the other person was thinking. Such assumptions about other people's assumptions may or may not be accurate, but they did involve an element of one person feeling that they could read the mind of the other. They were also evident when person A felt that they knew just what B was feeling and therefore knew just how to include them. Alternatively, as in Steve's example, Second Order assumptions could lead to people labelling themselves negatively. Such assumptions would appear to be founded on past experience and were often laden with meaning, highly emotive and deeply embedded in the way that service users and staff related to one another. Their emotive nature was due to the fact that they were assumptions that somebody else was making about "me" and therefore were highly personal.   It would appear that due to the multiple layers of

interpretation, and the potentially high emotive content involved, Second Order assumptions were at a particularly high risk of misinterpreting the situation and, therefore, could unintentionally lead to the exclusion of oneself as well as others.

5.2.4 Forming assumptions

The findings indicated that assumptions were formed through two different processes, rapid generalisation and slow consideration. The former provided a quick approach to assessing a situation, whereas the latter was more evaluative and drew on the perspectives of others.

Rapid Generalisation

Rapid Generalisation involved the rapid formation of an assumption based on a limited amount of knowledge or information. It was a process that appeared to require little active or deliberate thought, but was used to quickly simplify complex information. The speed of the process would appear to have provided little space for the development of any awareness or time for reflection on the impact of the assumption that was being formed. Service user Sophie illustrated the impact of someone else's assumption on her feelings of inclusion that appear to be formed through Rapid Generalisation.

> *"I get the impression, very much, when I walk into the Job Centre they just see… They are for your physical disability. They see the chair before they see the person. And it's wrong. And I'm very much a statistic, and a number and a figure." (SU3-F-Map)*

Sophie was holding a Second Order assumption about the assumptions of the person in the Job Centre. Her account was interesting, as it highlighted not only the problematic nature of someone else potentially rapidly generalising about her personal capabilities, but in turn, she was also making a rapid generalisation about the people at the Job Centre. Whilst we do not have the perspective of the Job Centre staff, it seemed that the combination of Second Order assumptions and the formation of assumptions through a process of Rapid Generalisation was a toxic mix. In such situations, feelings

of exclusion predominated through interpretations of being seen as an object rather than as a person.

Slow Consideration

Juxtaposed to Rapid Generalisation was the process of Slow Consideration, where time was taken to form an assumption. Participants suggested that this was a deliberative process that drew on a breadth of past experience and current evidence that might inform a situation, preventing conclusions from being formed too quickly. This process appeared to lead to service user Ruth feeling included by a member of staff at her local swimming pool when she first went to look around

> *"...she said they would put a hoist out if I wanted to use it and I could go along whenever I wanted... [What] made her a goody [was] that she didn't immediately assume that because I was in a wheelchair I would only ever be able to cope with that one special [disabled swimming] session on a Monday afternoon." (SU32-F-P)*

Slowing down the process of forming assumptions had the impact for Ruth of being seen as a person who wanted to swim rather than someone who would slot into the swimming timetable based on their physical presentation. In this situation, Ruth's Ideal World assumptions of what good inclusion looked like and felt like resonated with her actual experience of being treated first and foremost as a person. Ruth's account indicated that it was the other person's slow consideration of the situation, which contributed to her feeling valued and included, rather than being immediately labelled as disabled.

5.2.5 Strength of assumptions

The strength with which assumptions are held has implications for how readily they are able to change. This includes whether they are ideological dominant beliefs, taken for granted, and whether an assumption is based on repeated or occasional experience. Many of these have been alluded to in the preceding sections, but are briefly presented here.

Ideological dominant beliefs are often influenced by social or organisational culture in which someone sees something as correct or true, even when there is evidence to the contrary. For example, the way in which disabled people are negatively presented by some sections of the media as outlined by Ruth on p.155. Such ideologically dominant beliefs are not strictly classed as assumptions as they are not easily influenced by new information or a different perspective. They have been included here as this stance was identified by participants as problematic to experiences of inclusion.

Assumptions based on what is taken for granted, suggest that a relationship or situation will always present in the same way and is accepted or relied upon without thought or question. For example, disabled access to local facilities as outlined by Jenny on p. 154. Such assumptions can be strongly held, but can also be influenced by a different perspective or experience.

Repeated experience of relationships, roles, organisational systems and environments, can lead to an assumption that future contact with similar situations will present in a similar manner. Thus, the assumption is based on a repeated experience. This is illustrated by Fran p.158. These assumptions may be initially strongly held, but can be influenced by additional information and assumptions being evaluated and reformed.

Assumptions based on occasional experience indicate that a situation may have happened once or twice; however, a pattern of expectation may not yet have been formed. Assumptions may be readily influenced by additional information leading to assumptions being re-evaluated.

5.2.6 Summary

In summarising this section on the complexity of assumptions, Figure 15 illustrates both the key characteristic of assumptions identified in the data and their interconnectedness. The rigid framework that is presented belies the complexity of assumptions that inform relationships and interactions within neurological rehabilitation. In everyday life, it is difficult to distil and separate the individual characteristics, as they are inherently fluid. However,

the figure provides a useful framework from which to recognise and understand the complexity of assumptions influencing the practice context.
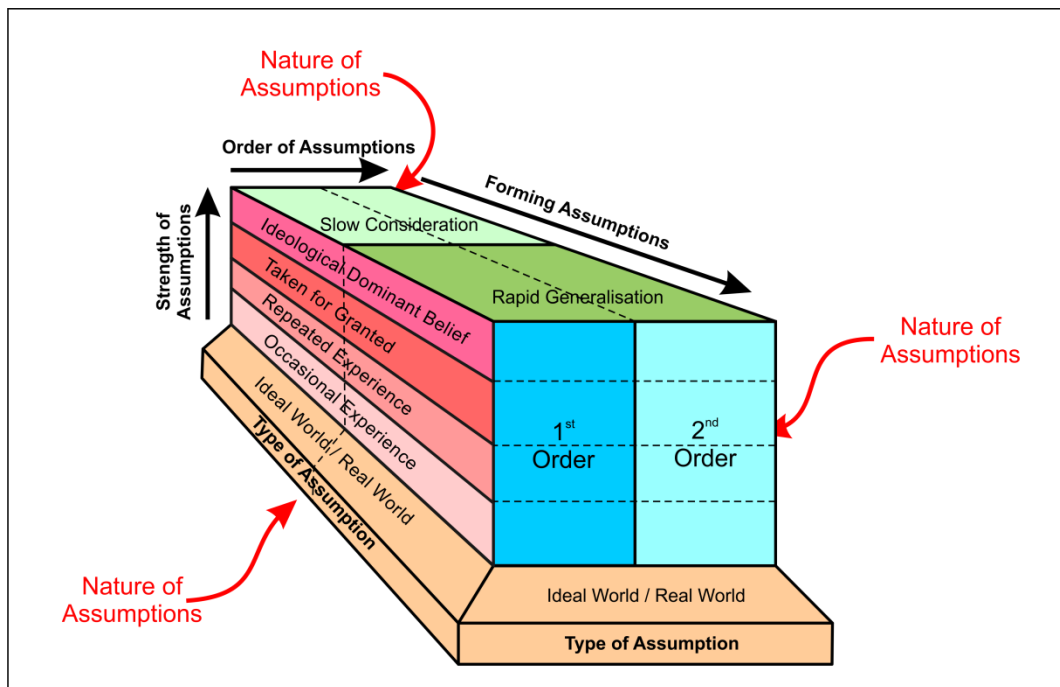
Figure 15. Framework of key characteristics of assumptions influencing inclusion in neurological rehabilitation.

The findings indicate that each of the key characteristics of assumptions presented above (Figure 15) can influence experiences of inclusion in different ways. The relationship between these characteristics and inclusion is not straightforward due to the complex, fluid and inter-connected characteristics of assumptions. Drawing on the findings in section 5.2 and looking ahead to section 5.3, Table 11 summarises the influence the characteristics of assumptions can have on inclusion.

Table 11. Characteristics of assumptions and their influence on inclusion.

	Assumption characteristic	Influence on inclusion
Type of assumption	**Ideal World assumption**	Generates possibilities of what inclusive practice could looks like. Risks being moralistic, therefore excluding others with different perspectives.
	Real World assumption	Prediction of problems that might exclude, leading to a) generation of solutions and action leading to inclusion or b) acceptance of the problem, passivity and exclusion.
Strength of assumption	**Ideological dominant belief**	Can facilitate inclusion if linked with an Ideal World assumption that inclusion is constructed between people. Resistant to change and can risk excluding someone holding a different perspective.
	Taken for granted	Can lead to exclusion due to lack of awareness of impact of unquestioned practice. Inclusion may be illusory if not viewed as something that needs to be worked for.
	Repeated experience	Inclusion not seen as needing to be worked for and positive experiences of inclusion become an expectation. Established expectations reduce the need to question and understand the perspectives of others.
	Occasional experience	Inclusion is possible as a uncertainty can lead to people working together. Uncertainty can also lead to defensiveness, clear role delineation and exclusion.
Formation of assumption	**Rapid generalisation**	Risks leading to exclusion through the objectification and categorisation of people and situations based on insufficient evidence
	Slow consideration	Curiosity and exploration can recognise diversity, lead to understanding of different perspectives and therefore be inclusive. Critical reflexivity about ones relationship to others can actively support inclusion as worked for together
Order of assumption	**First order**	Anticipates what might be important to the inclusion of someone else. Risks being inaccurate if not checked out with that person.
	Second order	Risks exclusion due to the double layer of interpretation, can lead to labelling oneself as different from a dominant group. Assumptions often difficult to check out due to perceived power asymmetry.

Having explored the complexity of assumptions influencing inclusion in neurological rehabilitation, the following section will investigate the connections between the particular assumptions participants hold about neurological rehabilitation and their influence on inclusion.

5.3   Connectivity between assumptions about neurological rehabilitation and inclusion

This section draws out five key themes that illuminate the assumptions participants held about neurological rehabilitation practice and unpacks them in considerable detail. These themes and their sub-themes are presented in Figure 16. The influence of these assumptions on experiences of inclusion are identified throughout and summarised in Figure 17 on p.200. The section begins by presenting the assumptions held about inclusion, this is followed by an exposition into assumptions held about role, knowledge, power and empathy in neurological rehabilitation.
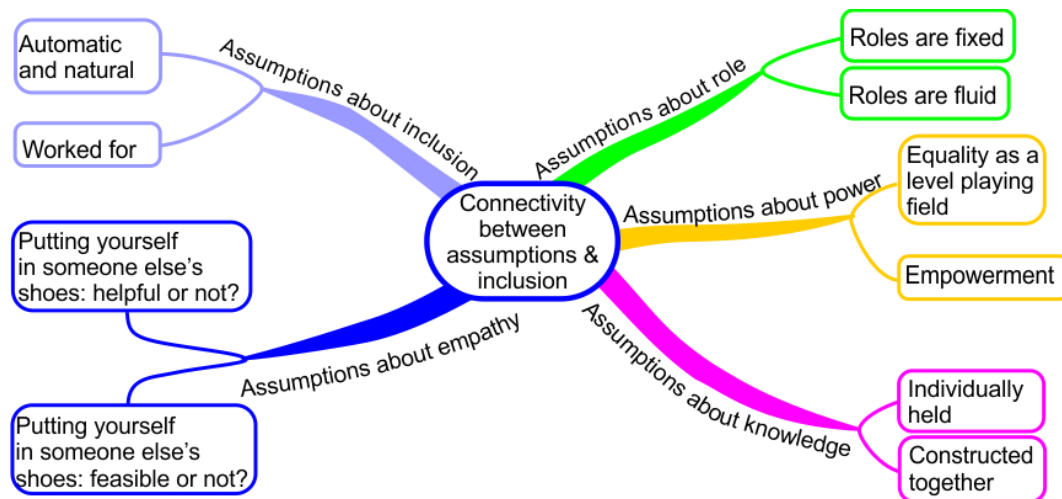
Figure 16. Mind map: Connectivity between assumptions about neurological rehabilitation and inclusion – themes and sub-themes from the data.

5.3.1   Assumptions about inclusion

The assumptions that were held about inclusion itself determined how it was viewed and practiced. Participants' assumptions that inclusion was an

experience that was readily available to all, where no barriers were encountered, has been named "automatic and natural". The assumption that inclusion was part of a process of interaction, characterised by a commitment to dialogue and work together towards a shared goal of understanding one another's perspective, has been named inclusion that is "worked for".

Automatic and Natural

A small number of participants held the Ideal World assumption that inclusion should be an automatic and natural process and that one's own and other people's inclusion was something that should be able to be taken for granted. This finding would seem to present inclusion as a moral good or right that should be experienced by all. It was held on the basis that everyone had the right to be a member and be active in a social group or community.

> *"if you've got a disability or a mental health problem, then that doesn't make any difference. So you shouldn't be looked at as different and not be included because you're a little bit different. So it should be a sort of, automatic pilot that you are included as opposed to excluded."*
>
> *(S11-F-Map)*

Experiencing inclusion as automatic and natural pre-supposed that there were no barriers either attitudinal or environmental excluding people from participation. Indeed, John's personal experience would suggest that his inclusion in a work context was also automatic. He stated:

> *"you know people understand that they have to ensure that meetings are in accessible rooms and so forth."* *(SU50-M-I)*

John was able to hold this assumption with a sense of certainty because he had repeated experience of having been to that specific location previously and as a regular member of the group his requirements was already known. However, such automatic inclusion required that other people had an awareness of the barriers to John's inclusion in order to ensure the environment was accessible for him. Accommodating John's diversity

170

required active thought from those people setting up the meeting, indicating that inclusion could not necessarily be guaranteed without some form of conscious intervention. Therefore, it is suggested that the assumption that inclusion is automatic and natural, could only ever be tentatively held in situations which require human intervention. Where there was the possibility that someone would forget to set out the room or they might interpret a situation incorrectly, there was always the risk that inclusion may no longer be experienced as automatic. This would seem to suggest that it is highly contestable that inclusion could ever be assumed to be automatic and natural.

Worked For

Participants predominately held the assumption that inclusion was not something that could be taken for granted as automatic and natural, but instead had to be worked for, requiring effort from everyone involved in the situation. The findings suggested that this effort was related to how people worked together in both interaction and also planning for an inclusive environment.

One of the metaphors used by participants to illustrate this assumption that inclusion is worked for was that of teams collaborating together. The idea of pulling together, working together and having a shared purpose were frequently referred to by participants, confirming the assumption that inclusion is worked for though an interactive process. This was illustrated by service user Gemma:

> *"I think you feel worthwhile because you are, as we keep saying, we are putting back in. And you feel as though you're important and you're part of the team. And you work together." (SU38-F-Map)*

This Real World assumption was based on Gemma's experience of what had actually happened in her involvement with neurological rehabilitation services. It was an assumption that was based on the *process* of people

working together, indicating that inclusion itself was realised through a fluid and responsive interaction between people.

Holding the assumption that inclusion was worked for by all parties, created the opportunity for everyone to participate and engage in dialogue about the issue or situation. It was an assumption that led to active collaboration and at times required emotional investment that made the process hard work. No one had a passive role, as practitioner Kathy illustrated through her interaction with a service user:

> *"Just trying to listen properly and reflect back by not repeating what they'd said...it was a revelation to me. But I don't know if I could keep it up, because of that emotional cost." (S4-F Map)*

Kathy's experience validates the assumption that inclusion was something that was worked for, suggesting that inclusion was not something that could be readily adopted as a skill or technique. Instead, it relied on the interaction and the development of understanding between one human being and another. In that sense, it was impossible to hold the assumption that inclusion would always be experienced. It relied on the fostering of a relationship between people and as such the fallible nature of human beings was something that constantly influenced this.

5.3.2 Assumptions about role

Service users and staff assumed a role in neurological rehabilitation based on their assumptions about what they thought they should be doing in relation to the actions of another person and or the situation at any given point in time. Within this complex process of interpretation and interaction there were two important assumptions held by service users and staff which influenced experiences of inclusion. Firstly, roles are fixed, therefore clearly defining the boundaries of action and interaction.   Secondly, roles are fluid and can be enacted based on personal preference, and negotiated in relation to the interaction and the context. The strength with which these two assumptions were held was also influenced by professional and

172

organisational guidelines that dictated the standards and ethics of practice. Such rules of practice contributed to conditions that positively or negatively influenced experiences of inclusion.

Roles are fixed

Participants assumptions about role indicated that they had established schema for their own role as either a member of staff or service user, suggesting that they relied on a stable pattern of behaviour in a given situation and context. Being able to anticipate what they should be doing or what someone else might do in a given situation brought a sense of certainty and even a sense of comfort in knowing what to expect. For example, this staff member reflected on the importance of knowing the expectations of her role:

> *"...you understand what your role is in something – why you're there. How you can contribute...It's being comfortable within, you know, an environment." (S11-F-Map)*

Participants suggested that assumptions about roles relied on historical perceptions, for example of doctor and service user, these tended to be rigid and fixed as they often related to the assumption that practitioners were the expert.   Service users typically acted in relation to this role by demonstrating deference. In such situations, service users had a tendency to be passive and at times were reluctant to initiate responsibility for their own health and well being. This is illustrated by service user Amy in relation to her observations of other service users.

> *"a lot of people will go and they say "Well I don't know. You're the expert, you tell me." Well that's the wrong attitude." (P7-Assumptions workshop)*

Whilst this is an assumption that Amy did not personally agree with, it highlights the long standing assumption service users often hold of health practitioners, who act in accordance with their expert role, telling service users what is best in relation to their health and treatment. Where such assumptions about the fixed nature of role are strongly held, some service

173

users indicated that they felt comfortable in a relationship they understood and were familiar with. There was no evidence from the data that service users, who held the assumption that practitioners should tell them what is best, actually do feel included in their treatment. However, Amy's comment above does suggest that when assumptions are held that practitioner and service user roles are fixed, behaviour can risk becoming habituated. As a consequence, this may reinforce practitioners adopting the role of the expert, thereby encouraging the service user to be a passive recipient of care and treatment.

Whilst it was apparent that some service users did make an active choice to positively accept the assumption that roles were fixed, many service users in this study found themselves reluctantly being coerced into adopting this position. This was particularly the case when practitioners held the assumption that they were the expert, not merely on clinical issues but also on aspects relating to a service user's life. This was viewed as an imposition by some service users, leaving them feeling excluded and a non participant in discussions about their care and even their own future. Service user Hannah illustrated this from her experience at a neurological rehabilitation out-patient clinic. Hannah was a young woman who was coming to terms with recent neurological surgery. Her assumptions were Second Order as she is holding the assumption that the practitioners are assuming that they are the experts in her care and, therefore, assume that they knew what was in her best interests.

> *"I have had a lot of all the doctors saying, "You need your independence. You need to get back to Uni. And you need to do this." And, actually, part of me, I've just wanted to say, "No, just leave me alone"."*
> *(SU28-F-P)*

Practitioners acting according to what are perceived to be the best interests of the service user may appear to be highly laudable. However, this required practitioners to assume the role of expert and when this occurred, it would appear that the service user merely became an object of practitioner attention, rather than being an active participant in decision making. In

174

Hannah's situation, where the practitioner had a fixed view of their role, this influenced Hannah's ability to articulate what was important to her during the consultation. Hannah's discomfort with her interaction with the practitioner was not expressed at the time of the consultation and therefore it would certainly seem that the practitioner's assumption that they knew what was best for Hannah was not disrupted. Instead, Hannah remained acquiescent during the consultation but away from the clinic setting rebelled against the advice of the practitioners:

> *"I found it a bit difficult every time I went back and they were saying, "Well, have you started Uni? Have you got in touch?" ... lots has changed. I think I've just got a different path for my future than what it was before... the wheelchair and everything has helped me think "No, this is the life I want"." (SU28-F-P)*

Hannah's experience illustrates that the influence on service users of assuming that roles are fixed and therefore unable to be negotiated, suggesting that this stance can readily lead to feelings of exclusion and silent dissatisfaction for the service user. The cause of such dissatisfaction often mystified practitioners, particularly when they genuinely felt that they were doing their best for service users. This was evident in neurological rehabilitation at the point when service users wished to be discharged from the inpatient rehabilitation facility to home. Practitioner Rachael talked about what can happen, and she began by speaking as though she was one of the members of her clinical team:

> *"If you [service user] stayed here, I could get you on your feet. I could get you doing this. Why don't you want me [practitioner] to do that? They [the practitioner] feel it's personal – sometimes a personal – thing on them. The patient just wants to go home and will get on with it. And walk around the house, grabbing on to the furniture or crawl up the stairs – they'll find their own way, and sometimes that's difficult for the professional to accept." (S22-F-FG)*

The dilemma for the practitioner was seemingly created because they assumed the role of expert. As a consequence, they appeared to personalised opposition to their expertise and found it difficult to engage with

other perspectives. This difficulty in seeing beyond their own role as the expert led to defensiveness and inclusion as something that was worked for between themselves and the service user, became very difficult if not impossible to attain. In this example, it would appear that the service user did not accept the fixed nature of the practitioner's role as an expert, but instead, was determined to do what was important and mattered to them. A tension was therefore created between what the practitioner assumed would happen and what actually took place. This example suggests that there is a need for an awareness from practitioners to move beyond a sense of certainty in their own expertise. Instead, it highlights the requirement to embrace role not as fixed, but as a more fluid concept that enables them to respond more flexibly to the priorities of the service user and the presenting situation.

Codes of conduct, organisational policies and procedures were viewed as creating the rules that NHS staff and employees of other community based organisations were required to adhere to. These also contributed to staff viewing their role as fixed. It would seem that holding a role that required the implementation of such procedures, could also lead to staff seeing themselves as "right", therefore by default, other people had to be "wrong". This once more positioned staff in the role of expert, leaving little room for dialogue involving other perspectives. This is illustrated by this service user in relation to an experience at a community venue:

"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 …that was a lovely service, they were providing a safe place for me to be put..." (SU32-F-P)

Organisational policies and procedures were influential in determining the role that these staff adopted, in which the enactment of role was based on a performance in line with pre-determined criteria. If they had failed to meet the criteria, their ability to undertake their job role may have been questioned. NHS Organisational policies and procedures were viewed as problematic by service users and staff, who felt as though they were

becoming '*slaves to the system' (S4-F-Map).* A sense of resignation and sometimes despair was felt from both service users and staff when they found themselves battling with a system that was unable to respond to diversity. As a consequence, they often felt hampered by the systems that were meant to support practice, but rendered them unable to create the conditions required to work together to construct an inclusive experience.

Roles are fluid

Whilst assumptions of role as fixed were evident from both service user and staff experience, it was not a position that all participants subscribed to. Assumptions about role indicated that whilst there were schemata outlining their broad function and responsibilities, the enactment of role also reflected personal preference, was open to negotiation through interaction with others and was responsive to the specific context and situation. Assumptions were therefore also held that roles were fluid and through human choice and action it was possible to extend the boundaries of traditional perceptions of role in order to interact and practice in a more inclusive way. This conception of role, also supports the assumption that inclusion could be worked for in the relationship and interactions between people. However, it would also appear to be debatable whether the assumption that roles are fluid always led to inclusion that is worked for together, or whether there were times when it merely led to one person being in a position to define what inclusion meant for the other. These two aspects of assumptions of role being fluid will be explored further in the following examples.

Practitioner Kathy recognised her duty of care to the service user, but on this occasion paid attention to the needs of the carer illustrating the assumption that role can be fluid and responsive to the situation.

> "*the outcome of one consultation was, [that] 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.*" (S4-F-Map)

177

Kathy held a Real World assumption based on her repeated experience of practice, that a response to the needs of the carer at that moment in time required her role to be flexible. Making a deliberate choice, she actively listened to the carer, ensuring they felt understood and included in the interaction. She later discovered that this was a turning point for the carer, preventing them from leaving their partner and even taking their own life. The dialogical process between Kathy and the carer, required them to engage constructively, in order to ensure a beneficial outcome at the end of the session. Kathy has been required to step outside of the traditional boundaries of her traditional clinical role, in order to ensure that the carer's needs were met.

The freedom to act outside the assumptions of role as a fixed concept was congruent with the responsibility of being an autonomous practitioner. However, this was held in constant tension with the bureaucratic requirements of professional bodies and employing organisations. This was illustrated in Kathy's further reflection on her time with the carer. She adds:

> *"But it's hard to do that [actively listen], isn't it? It's hard because there's not… What can I write in the patient's notes?" (S4-F-Map)*

Practitioner decision making does indeed need to recognise the broad parameters of role in order to ensure that practice is undertaken competently. However, practitioners were particularly concerned that there were times when the parameters were so tightly defined by the task itself and the measurement of performance, that the human element was neglected. Deviance from performance requirements was expressed as a dilemma for practitioners, who were constantly balancing the competing agendas of the presenting needs of service user and their families, with the bureaucratic requirements of national and local policy. In Kathy's example, her professional values and principles outweighed any rigid adherence to bureaucratic processes; however, other practitioners additionally highlight the challenges of accounting for their time and practicing in accordance with government targets and financial constraints.

Recognising the need for human to human connection was more apparent when the assumption was held that roles were fluid, could respond to the situation and developed in and through interaction. In these situations, both staff and service users held the assumption that they needed to take on the role of facilitator and actively influence the situation. Examples included clinical decision making processes and drawing alongside someone at a time of distress. Participants identified that these situations required them to see beyond the usual assumptions held about their role and its associated behaviours.

For example, practitioner Steph stepped beyond her usual role as a treating therapist. In holding the assumption that she could also act as a facilitator, she actively sought to support service users to ensure that they felt included in the treatment environment:

> "'… a big part of being in the gym is being part of the banter and part of what's happening. But people only can be a part of that to a greater or lesser extent, depending on their ability to understand and / or respond....So then it's the therapist's role to come back to that and bring the person in... As a therapist I would say it's how receptive we are to facilitating it [inclusion] to happen." (S3-F-FG)

Steph held the assumption that it was important for practitioners to facilitate service users, who may appear to be on the margins of a group, to join in with the group's activities. It would certainly appear that stepping outside the traditional practitioner role, being more fluid and adopting the role of a facilitator was well intentioned. It held the potential to encourage the contribution and strengths of service users with a wide range of impairments. On the surface this positively supported inclusion as it was perceived that everyone was now able to take part in the gym banter. On the other hand, if the assumption is held that inclusion is worked for through an interactive and dialogical process, then the argument that adopting the role of facilitator enables inclusion is more questionable. In such situations, inclusion is merely defined by the dominant party; it is not based on personal choice but on the assumption that conformity to the behaviour of the majority is expected. In Steph's example, it was possible that the service user may not

have actually wanted to join in the banter in the gym. Instead, this was Steph's interpretation of the situation based on her own experience. This is an example of a First Order assumption in which Steph holds an assumption about what she thinks would be best for the service user.

Whilst staff and practitioners in particular, may hold the assumption that their own role was fluid, they still ran the risk of defining the service user role as fixed. In doing so, the assumption was often unwittingly held that all service users needed to be helped. The impact of such categorisation in the past was described by service user Ruth:

> *"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."* (SU32-F-P)

Ruth's account did not necessarily imply that stepping beyond the historical boundaries of role and adopting the role of facilitator was always unhelpful. As in Kathy's example, without facilitation, there was the risk that service users or staff who were perceived as being on the margins of a dominant group, would remain so. However, it would certainly seem that where the assumption was held that one person could facilitate the inclusion of another, this needed to be handled with caution and dialogue was required between all parties as to the best interests of everyone concerned.

5.3.3 Assumptions about knowledge

Assumptions held about who holds knowledge that might inform a specific issue, the validity of each person's knowledge and the way knowledge was constructed, were central to service user and staff interaction and relationships. There were two key assumptions that participants held about knowledge that affected experiences of inclusion: 1) Knowledge is individually held. 2) Knowledge is constructed together. Whilst these two assumptions are presented separately they were not mutually exclusive. They interwove, could be held simultaneously by the same person and were acted upon in response to a specific context and situation. Issues of

authority, expertise and deference were seen to play out in the interaction between people in relation to assumptions about knowledge.

Knowledge is individually held

The assumption that knowledge is individually held automatically separates one set of knowledge from that of another, creating boundaries between "what I know" and "what you know". Such boundaries held the potential to create a divisiveness that held one person's knowledge as more valuable and credible than the other, potentially leading to the inclusion or exclusion of one, over and above the other.

Both service users and staff recognised the value each other's personally held knowledge. For service users "his/ [her] knowledge" was the technical knowledge of the practitioner and "my knowledge" was the service users own experiential knowledge. The value of practitioner specialist neurological rehabilitation knowledge was not disputed and was clearly respected and appreciated by all service users. However, it was evident that the experiential knowledge of both service users and staff was not always valued by practitioners or managers. At times, their experiential knowledge was neither paid attention to nor utilised effectively in order to have a positive influence on practice. This was illustrated by service user John's experience:

> *"I think their failure really to consider...what my needs were...there was rigidity of we don't this, we do do that, you shouldn't do this, you should do that which didn't really reflect the complexity of my lived experience." (SU50-M-I)*

Ideal World assumptions that were manifest in such an approach and set out who "should" do what, were problematic for John, as they had a tendency to dictate whose knowledge was most important. It was evident that where practitioners appeared to hold such assumptions, they were perceived as having knowledge that was superior to the service user and by default devalued the knowledge of the service user. Such assumptions did not create space for the inclusion of experiential knowledge, which reflected the lived experience, messiness and complexity of service user lives. Instead,

they supported a procedural approach to neurological rehabilitation that followed an expected pathway of service delivery. As a consequence, once discharged and at a physical distance from the perceived expertise of practitioners, service users were seen to disregard advice and abandon equipment that had been prescribed to help them with their daily life. John's reflection on his situation led him to conclude that more often than not, service users who were dealt with by practitioners in a technical manner ended up like himself "*doing their own thing*" (*SU50-M-I*) on discharge from services.

Practitioner technical knowledge and service user experiential knowledge held different priorities at different times in the neurological rehabilitation process. In the early phase of neurological rehabilitation, the assumption was generally held by practitioners that service users appreciated the clarity and order that practitioner knowledge could bring to novel and unfamiliar situations. Consequently, such knowledge took precedence as illustrated by staff member Steph:

> *"...when somebody first comes in I have to appreciate they're an individual in their own right and their life is personal to them and what they want to achieve. But also at that time I have the knowledge, the professional knowledge of what I'm seeing and what I've seen before. And the expectations that are realistic for the future." (S3-F-MFG)*

Creating a sense of certainty and direction was seen by the practitioner as reassuring. However, at a time of vulnerability for the service user, it also reduced the possibility of addressing the issues that might be problematic or even scary, as illustrated previously by John. The assumption held by practitioners that they "know what is best" appeared to have been made with the best intentions. However, such assumptions held on behalf of the service user, did not appear to take account of their personal views. This apparent lack of dialogue and interaction, based on the assumption that knowledge is individually held, created a power imbalance, positioning the practitioner as holding *the* expert knowledge. Whilst this may be unintentional, it would imply that service user experiential knowledge was not

credible and was of little value at that point in time. As a consequence service users would appear to risk being unwittingly excluded during the early phases of neurological rehabilitation.

Service users were not alone in feeling that their personal experiential knowledge could be distanced and disregarded by others. At times staff expressed distress when they felt that management held the assumption that their knowledge and experience was not of sufficient value to be considered:

> *"They're not listening to me – but are they discounting…? Do they not think I've got that experience and knowledge and think, you know, that I'm not worth the job I'm doing in that sense and that my opinion is worth nothing?" (S9-F-Map)*

The assumption that knowledge was both separately held and should remain firmly within the boundaries of the membership of a particular group of people or role was a source of exclusion for both service users and staff, and at times elicited raw emotion. Such an assumption merely separated and divided one from the other, creating a hierarchy of knowledge, where the dominant party determined the kind of knowledge that was valuable and therefore whose knowledge was listened to. Given this assumption, even when membership of a group was proffered and nominal inclusion was granted, having a voice and being able to influence was not necessarily guaranteed. Practitioner Kathy illustrates this point.

> *"I'd be included physically, but not included in any of the…And if I had to keep making an effort and butting in to try to get a conversation, I'd pretty soon give up." (S4-F-Map)*

Those people whose knowledge did not fit the criteria set out by the person or people perceived to hold the highest authority often found themselves marginalised. On the surface, this may appear to be a personal choice not to speak or withdraw from the group. However, this example illustrates that assumptions held about knowledge can play an important role in whether someone feels included or not.

Knowledge is constructed together

Knowledge that was constructed together required a commitment by all parties in generating new knowledge and understanding. Service users and staff both held the assumption that knowledge generated together impacted positively on feelings of inclusion. There was recognition that the genesis of such knowledge began as individually held technical and or experiential knowledge. However, through a process of generative communication and dialogue, new knowledge could be created. Where the assumption was held by both practitioners and service users that this approach to clinical interaction would be taken, new understandings of both the neurological condition and what it meant to live with that condition were generated. This was illustrated by service user Ruth:

> *"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-F-I theme verification)*

The assumption of constructing knowledge together was held as a Real World assumption in that Ruth and her consultant had worked this way in the past and their intention was to continue to do so in the future. Their construction of knowledge was a two way educative process, where each valued the knowledge of the other. It went beyond a mere exchange of information where knowledge remained individually held, to both parties actively generating new knowledge together in a middle ground between them.

As service user Melanie importantly highlights, constructing knowledge in this middle ground also enabled individual knowledge to be contested, considered and one another's assumptions validated in order to find the best way forward for treatment. Ensuring that practice was effective was therefore, not merely agreeing with one another, but importantly ensuring that there was a critical discussion that reflected one another's experience at the level of assumptions.

> *"...if I think he's given me too much botox and he's caused unwanted side effects, I'll tell him that ...he won't just do that, you know, on my say-so. If he agrees then he will do that...He does give me plenty of opportunity to have a lot of say...but obviously he uses his expertise as well to advise me."*
> *(SU31-F-Map)*

Inhabiting this middle ground held the potential to remove the boundaries and borders created by traditional assumptions about the dominant role and power of practitioners and the deferential position of service users. It was a space that could consider the complexities of lived experience identified previously by John, because social order conventions that sought to separate the knowledge of service users and practitioners had been disrupted. For some participants, it was an uncomfortable and uncertain space, as it went against the grain of long held assumptions that the practitioner would use their knowledge to "tell" the service user what to do.

Practitioners found when they did act based on their assumption that practice was most effective when knowledge was constructed together between service users and staff, this could leave them at odds with organisational systems and processes. This was not just in clinically orientated interaction as already identified by Kathy on pp. 177-178, but also in the development of services. For example, staff member Rachael worked together with service users, drawing on their knowledge, to develop a patient information sheet that met the needs of people using neurological rehabilitation services. However, she found herself at variance with organisational priorities and decision-making,

> *"there's an edict come down from the Trust about patient information, everything has got to be generic now...so, of course, ours [information sheet] doesn't fit... Everything that our service users want, you can't have... I've just got to come to terms with, this is something that I don't like, I don't agree with, but we have no choice whatsoever." (S22-F-FG)*

Rachael's experience illustrates the dissonance between the espoused values and principles of staff, who seek to work together with service users to generate accessible information, and an organisational tick box approach

that seemed to prioritise the interests of an outward facing corporate style. These tensions illustrate the difficulties that can occur when the Ideal World assumptions of staff and service users, who are, for example, committed to constructing knowledge together, find themselves at odds with the Ideal World assumptions of corporate functionality. It would seem in this example, that corporate priorities were not related to the values of *how* people engaged together to produce a product. Instead, what was required was the mere production of a product that met key criteria. Mismatches of Ideal World and Real World assumptions were viewed by participants as places of personal emotional cost, disappointment, disillusionment and wasted time and effort. It would seem that such experiences could create considerable angst as to how best to proceed, raising questions as to whether to challenge or acquiesce to organisational processes and standards. In this example, as in many others in this study, such decisions were made based on the perceived openness of those people in a dominant position to engage in creating "middle ground knowledge". Where such a dialogical process was not deemed possible, inclusion did not appear to be realised.

The assumption that knowledge could be constructed together would seem to only be possible if both parties had a level of awareness about the limitations of their own knowledge and recognised its fallibility. "Not knowing all the answers" was identified by practitioner Sue as an important assumption in order that a shared construction of knowledge might be realised. In a moment of heightened awareness, Sue recognised the importance of this assumption in order to ensure that service users felt listened to and therefore included.

> "*by listening you're… Well I suppose you're assuming you don't know all the answers and you're valuing other people's opinions and hoping that, you know, together we… We might be able to achieve more, I suppose. Which may be the value that you place on the people that you listen to...*" (S18-F-FG)[3]

---

[3] This quotation has been used previously as a tacit mental strategy for making sense out of situation. Whilst it is recognised that it is not usual practice to use a quotation more than once in qualitative research, it was felt to be acceptable in this instance, in order to reflect the important issues that it raised.

Sue's example suggests that recognising what was not known was of great importance for creating a dialogical space in which new understanding could be generated between service users and staff. Ambiguity and uncertainty therefore seemed to be the basis for interaction in which such understanding and learning from one another could be realised. The importance of "not knowing all the answers" emphasised the point that there was no longer a need for someone to be an expert. As service user Ruth stated:

> *"I think I sensed that when I did come to [the rehabilitation centre] that there were no experts around...and there was a lot then to be learned both ways, it become a two way street." (SU32-F-P)*

Service users indicated, that loosening the grip on being "the expert" in neurological rehabilitation did not mean negating the specialist technical or experiential knowledge that was individually held. Instead, it reflected the need for an awareness of the impact of adopting a position of authority within the interaction. Holding the assumption of "not knowing the answers" created the possibility for affirming the technical and experiential knowledge of both the service user and the practitioner. In such situations it appeared that mutual learning, understanding and reciprocity became the focus for engagement rather than a mere exchange of factual information.

5.3.4   Assumptions about power

Critical to any interaction in neurological rehabilitation practice were assumptions held by service users and staff about power, particularly those which reflected issues of equality and empowerment. Power was a subtext in the accounts of participants that was seldom overtly acknowledged. However, assumptions held about power played a significant role in how people positioned themselves in relation to one other, determining who had a voice and who was or felt silenced. This positioning played a key role in determining the nature and processes of interaction, ultimately impacting on both the process and outcomes of neurological rehabilitation and experiences of inclusion. Power was expressed and experienced through both relationships and organisational processes; it was not a fixed entity, but

constantly moved between people as an interaction evolved and situations changed. Participants expressed two key assumptions about power, these were in relation to 1) equality as a "level playing field" and 2) empowerment; both affected how inclusion was viewed and practiced.

Equality as a "level playing field"

The assumption of a "level playing field" was held in relation to the equality that was hoped for in relationships between service users and staff and or disabled people in relation to the rest of society. Service users in particular expressed that they should be recognised, respected and valued as a human being on equal terms with others, rather than being labelled as a wheelchair or a diagnosis. However, the realisation of a level playing field was a contested issue.

Service users viewed the Ideal World assumption of a "level playing field" as a fallacy, suggesting that the construction of positions of privilege and deference in practice made for a playing field that was uneven and at times even combative. Whilst its realisation could be tantalisingly close for some, service users suggested that it remained difficult if not impossible to attain.

This juxtaposition between the Ideal World assumption of the "level playing field" as a principle of good practice and the Real World assumption that was unlikely to be attained was illustrated by service user Sophie:

> *"It can never be considered equal because, at the end of the day,*
> *I am in a minority and many of the people here probably do find*
> *themselves in a minority. And everyday sometimes feels like a*
> *constant battle for it to be a level playing field." (SU3-F-MFG)*

Her comments indicate that disabled people were perceived as a minority group, who were subordinate to those in the non-disabled dominant majority, thereby suggesting a lack of equality in society. An "uneven playing field" in society was manifest in the lack of opportunity for disabled people to have the same choices as non-disabled people. For example, service user Ruth described the lack of choice to be able to sit with friends at a concert;

instead, she was segregated and "corralled" together with other disabled people. Merely being present at a venue, was not classed by Ruth as being on a "level playing field" with other ticket holders, as the opportunity to participate fully based on her personal preference was not realised. In this example, the playing field gave the illusion of being level because everyone could take part. However, it was the dominant party, in this case the venue managers who dictated the policy, thereby "setting the tone" for the *quality* of the disabled person's experience. If taking part on the manager's terms was not acceptable, then there was no choice, participation was not a possibility and exclusion was experienced. In this example, the dissenting voice of the service user, which sought to raise awareness of inequality, was no match for the authoritative stance of managers who followed bureaucratic rules aimed at mitigating risk. In such situations generalised assumptions appeared to be made about disabled people being a "hazard" to be managed, an object to be dealt with, which therefore took no account of diversity or made any adjustments to accommodate personal choice. Inclusion in this example was perceived by the managers as automatic as taking part in the activity was permitted. However, it was not an approach to inclusion that held any personal value to the service user and the inclusive access presented by management was therefore rendered meaningless.

Practitioners often appeared to unwittingly play a role in creating an "uneven playing field", privileging their own position over that of service users, particularly those service users who were viewed as challenging. Where generalised assumptions were made that service users were too difficult to engage with, the opportunity for them to have a constructive voice in their care or services was reduced or at worst lost. For example Barbara who had been working in the neurological rehabilitation service for many years, stated:

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

189

Barbara's comparison between people who were easy to communicate with and those who were not, weighed one person up against another and judgements were formed based on her personal internal criteria. These tacit mental measurements unintentionally created a comparison between who was "better or worse", "easier or more difficult". Such binaries risked leading to decisions being made about who was classed as "in" and who was "out". In this example, it was the privileged practitioner who set the rules of interaction, determining the tone of the relationship from the outset. From a pragmatic perspective, Barbara's Real World assumption that some service users were more challenging than others appeared very reasonable. However, where this was not countered with the Ideal World assumption that a "level playing field" could also be worked for, it was evident that some service user voices were not heard, nor their capabilities utilised and nurtured. Such lack of recognition of the positive contribution of service users creates an "uneven playing field" limiting the opportunity for people to fully participate in their neurological rehabilitation. This hidden privileging of one person over the other often went unnoticed in the accounts of practitioners, suggesting that such an approach was taken for granted and strongly embedded in their established personal and practice based assumptions.

Even when the ideal world of a "level playing field" between staff and service users was almost experienced, it was viewed as a tentative place. It was one where service users could never be fully certain that the playing field would be level and they would truly be in a place of equality with staff or other people in society. It was described as: a *"sort of level playing field" (SU32-F-P)* which held the potential for a *"fairly equal relationship"* (*SU50-M-I).* This lack of confidence in attaining the ultimate goal of being equal with others suggested that inclusion through the ideal of a "level playing field" could only ever be an assumption that was lightly held by service users.

Such Ideal World assumptions of a "level playing field" were tempered by real world issues and problems, be these a physical step or a dismissive

attitude, indicating that equality in practice was difficult if not impossible to achieve. This suggests that the assumption that the ideal of equality was sufficient in itself to address the imbalance of power was therefore a flawed assumption. Service user accounts support this, clearly identifying that at the very least, attempts needed to be made to raise awareness that inequality was present and a considered response to the inherent "uneven playing field" was needed. However, it would also seem that just because a "level playing field" was not felt to be possible, this did not mean that equality was not a principle that should not be worked for. Service users clearly identified the importance of the opportunity for everyone to realise their capabilities and have their choice respected, thereby ensuring that diversity was recognised. In holding a "level playing field" as an aspiration, this also acknowledged that humanity was most likely to fall short. These findings suggest that if inclusion through a "level playing field" was to be realised, the assumption could not be held that it would happen naturally. Instead, it would require an active choice by all parties to battle against the natural human tendencies of comparison and categorisation, to work for the recognition of a plurality of views and experiences.

Empowerment

Empowerment was a term used by both service users and staff and was seen as important for practice. However, no clear definition was evident and the assumptions held about power, that underpinned empowerment, were markedly different. There were two key assumptions that were held about empowerment, 1) it is created through an educative interaction. In this context, learning together was the central principle, although the initiation of the process may be taken by one person. 2) It is 'gift' that is bestowed on another person. Where it was viewed as an educative interaction this held the potential for inclusion to be worked for together, where viewed as a gift, the risk of exclusion was evident. These two aspects of empowerment will be discussed in the following sections.

Service users held the assumption that education is the cornerstone of empowerment, experienced through an interactive and dialogical process which generated understanding between service users and practitioners or members of the public. It was not a one way education process where practitioners gifted their knowledge to service users, thereby maintaining their position of privilege as benefactor.   It was instead a process that required people to work and learn together as identified by service user Ruth.

> *"What, then, do you do to lift people's awareness beyond the glance, beyond the look, beyond the thing of, "Oh yes, you can't walk" or "You can't do this." So therefore you're different, to think "Well, okay, if I'm in a position to enable – if I'm in a position to empower, then how do I do that with you?"" (SU32-F-theme verification)*

Ruth's account illustrated that there were two key assumptions that were made about empowerment through an educative interaction. The first was the importance of the dominant party's awareness that a service user was a person who had the capability to contribute and engage in interaction with other people. In this example, Ruth made the First Order assumption that it was *her* role and responsibility to engage with others in order to raise awareness of her strengths and abilities. The second was the importance of being asked a generative question, opening up a dialogue about how the practitioner and service user might engage together. This held the possibility for what could happen as good practice. Central to this process was the act of the practitioner questioning *"how do I do that with you?"*   Where such a generative question was not asked, there was the risk of disempowerment, as service user John comments in relation to his treatment:

> *"I like to have control I would like to have more understanding of why we are doing this now, ...it's not that I think anything has gone wrong, I mean I'm not a professional what would I know but I don't feel as if I'm empowered to understand fully..." (SU50- M-I)*

Understanding what was important to John about his neurological rehabilitation, what "having control" might mean to him, could have led to a more positive and effective rehabilitation experience in which he was actively engaged. Such feelings of disempowerment illustrated the unwitting

privileged stance practitioners can adopt when deliver treatment. It is a stance that is perceived by service users as failing to take account of personal preferences and recognise what is meaningful to them. "Doing to" the service user in this way, may not necessarily affect the technical treatment that is delivered to the service user. However, as John identified, not fully understanding how the rehabilitation process related to his ultimate prognosis and rehabilitation outcomes, prevented him from making an informed choice about his level of commitment to his exercise programme.

The use of generative questions was seen as particularly important in exploring how service users and practitioners might relate together and learn from one another in order to achieve the best possible neurological rehabilitation outcomes. This suggests that inclusion was therefore worked for through an educative dialogue. Whilst there were examples of where service users felt empowered following an educative interaction, service users generally identified this as "hoped for" way of working in practice, rather than a moralistic statement of what should be happening.

Empowerment as a gift was an assumption that was held by some practitioners who felt that empowerment could be achieved by taking power from the dominant person and giving it to someone who was less powerful. This is illustrated by Sue who stated:

> *"Well if we're empowering people or involving people to make decisions about their daily lives in this centre, then that's a skill that, you know, that they're going to keep and build on for being, you know, expert patients of the future." (S18-F-FG)*

The intention behind "empowering people" certainly appeared laudable, in this situation it was used to enable service users to make decisions about their neurological rehabilitation and thus become experts in their own care. However, it would appear this stance was informed by an asymmetry of power between service users and practitioners, with practitioners in a dominant position. Sue continued:

"Well who has the power really?" It's we're giving you the power, but, you know, it's… It's still sort of healthcare professionals having the power over the patients." (S18-F-FG)

Power in this example was viewed as something that was static, which could be passed from one person to another. The assumption was held that service users were the object of the 'gift' of power, placing them in a position of gratitude in relation to the benevolent practitioner. It was a statement that affirmed the dominant roles of practitioners and the subordinate roles of service users.

Practitioners' aims to empower others may indeed have been to enable service users to increase their involvement in decision-making. However, this would seem to be a First Order assumption, suggesting that practitioners were interpreting on behalf of service uses, what might be empowering for them. Despite practitioner attempts to be helpful, holding the assumption that it is possible to empower others would appear to reinforce the "uneven playing field", rather than lead to service user empowerment.

5.3.5 Assumptions about empathy

Empathy was viewed as the means of creating an emotional connection between people that enabled one person to imagine themselves in the position of the other. This was specifically described as "putting yourself in somebody else's shoes". There were two assumptions that were held in relation to "putting yourself in someone else's shoes" that influenced experiences of inclusion 1) whether it was helpful or not 2) whether it was feasible or not.

Whilst "putting yourself in someone else's shoes" was seen as an essential and beneficial component of the relationship between service users and staff in neurological rehabilitation practice, it was also a contested issue. At the heart of being empathetic was the requirement to hold assumptions about what the other person might be thinking and feeling. This was realised by one person generalising their experience in relation to that of another,

requiring assumptions to be held about how the other person was interpreting the situation. At best this enabled one person to make an emotional connection with the other that was valued, at worst it was viewed as presumptuous or patronising, making the very practice of being empathetic potentially problematic. Despite the imaginative act of "putting yourself in someone else's shoes" potentially leading to misinterpretation of what really matters to the other person, it was generally advocated by participants as supporting experiences of inclusion.

"Putting yourself in someone else's shoes" helpful or not?

Service users indicated that living with a neurological long-term condition could be a daily struggle. The empathy of practitioners or other service users provided support and understanding, which appeared to enable one person to draw alongside another during times of distress and uncertainty. Service users and practitioners held the Ideal World assumption that at such times, empathy was helpful and an important part of neurological rehabilitation practice. In order to show empathy to one another, they also held the First Order assumption that they knew what the other person's needs and feelings might be in that specific situation. This assumption appeared to be based on generalisations from person experience in order to attempt to identify and understand what the other person might be thinking and feeling. These interpretations then formed the basis for action.

Practitioner Ben highlighted how he "put himself in the shoes" of the service user prior to them commencing neurological rehabilitation.

> *"I like to use that knowledge of that person to be... Just to put somebody at ease. Just put yourself in someone's situation. They're going into a large area. Lots of people are working, doing different things, and they don't know anyone. I mean, I know how I would feel". (S7-M-MFG)*

It would certainly seem that Ben's intention was to ensure that neurological rehabilitation was as comfortable and supportive an experience as possible for the service user and he perceives his actions to be helpful. However,

there is no clear indication from his account suggesting that he checked the accuracy of his interpretation with the service user. There is therefore, uncertainty as to whether Ben's attempts to "put himself in the shoes" of the service user were actually helpful to the service user or not. Some service users do indeed indicate that it is valuable when staff hold the assumption that it is helpful to "step into the shoes" of another person. Service user Hannah illustrated this point from her experience at a riding stable:

> *"The woman, I think, who runs it, has worked – has done this type of work for years and she's brilliant. And there's a young girl that she's got teaching me – and she said she thought it would be nice for someone more my age. And she's lovely as well." (SU27-F-P)*

Hannah's account, suggests that it was very helpful for the riding instructor to draw on their experience of tried and tested practices, in order to anticipate Hannah's practical and emotional requirements. As a consequence, Hannah felt supported and included.

Service users held the assumption that it was helpful that they could "put themselves into the shoes" of neurological rehabilitation staff. They indicated they were aware that staff felt particularly burdened in relation to time pressures, the amount of paperwork to be completed and the challenges of dealing with people who were perceived to be "difficult". As a consequence, service users responded in a variety of ways. Some service users reported that they actively tried to emotionally draw alongside staff and others chose not to ask questions that were concerning to them because they did not wish to be an additional burden. Whilst "stepping into the shoes" of staff in this way was viewed by the service user as being helpful, it could mean that some of the important issues of concern to service users were missed. This held the potential to lead to wasted time and effort

"Putting yourself in someone else's shoes", as a way of attempting to understand another person's viewpoint, was also viewed as risky and unhelpful practice as it may not necessarily represent the true perspective of the other person. Service user Stella (SU34) and practitioner Steph (S3)

engaged in a dialogue relating to the challenges of assuming that it was both helpful and possible to "put yourself in someone else's shoes":

> S3: "I think with the group of people that I work with, one of the barriers to inclusion is making sure that you're including everybody and not just the people who are able to make their voices heard. And that's a really important issue for me…
>
> SU34: But the people making their voices heard is also helping all the people who can't speak up for themselves.
>
> S3: If those other people think the same way as you do.
>
> SU34: They probably do, but they just can't get it out.
>
> S3: Yeah, I… But, you see, I… I would agree that in some cases with some issues, that's very true. But not with every issue that I come across. And it's how do you make sure that you represent everybody who's had… You know, I'm sure that you can't generalise." (S3-F-MFG & SU34-F-MFG)

Steph's discussion with Stella, highlights the ease with which it is possible to assume that it is helpful to "put yourself in someone else's shoes", and represent them, without actually seeking their views. This would particularly seem to be the situation where people were perceived to share the same label or identity, for example, "service user". It is clear from Steph's response that she viewed generalising from one's own experience in this way as problematic. The discussion raises important issues in relation to how "putting yourself in someone else's shoes" can easily marginalise people who may have a cognitive or language impairment, because they are categorised under the generic heading of service user, rather than as people with their own voice and experience. It is an assumption that was often held with the intention of being helpful. However, instead, such an approach would, seem to risk situating service users, for example, as passive objects, rather than as people who can be engaged in decisions about their care and neurological rehabilitation. Whilst this approach was not problematic for everyone, it would seem that representing others in this way risks silently "doing to" the person rather than talking with them about their personal needs or requirements. In such situations, there was the risk of coercion and

the opportunity for collaboration in shaping the process and outcomes of neurological rehabilitation was lost.

"Putting yourself in someone else's shoes" – feasible or not?

Service users particularly expressed a desire for practitioners to be able to put themselves in their shoes.   It was held as an Ideal World assumption and brought hope to many service users that practitioners might just be able to get a glimpse of what it felt like to live with a neurological long-term condition. Holding such an assumption suggested that if it was possible for practitioners to understand this more fully, then, support and treatment might be more effective. However, there was also the realisation that this depth of understanding would actually require an embodied exchange. This was highlighted by Gemma:

> *"And I've even said to my consultant, "If we could swap heads, you would know what it's like to be head injured"...they don't really deep down understand." (SU38-F-Map)*

Gemma's account identified the frustration that could be felt by service users when they hoped for deep level of understanding from practitioners, in order to receive the best possible treatment. Both service users and practitioners recognised that whilst it may be desirable, it was very difficult or even impossible to "put yourself in someone else's shoes", because no two people shared the same view of the world. Service user Sophie expressed this very eruditely:

> *"With the best will in the world, they [practitioners] can't have an appreciation of what it's like for someone else because they're not within their frame of reference." (SU3-F-FG)*

Sophie suggested that it was a fallacy for practitioners in particular to assume that it was feasible to "put themselves in service user shoes" and experience what they were experiencing. This would suggest that "stepping into service user shoes" is merely an imaginative construction that risks being built solely on personal memories, rather than on an understanding of what the meaning of the situation is for that service user. The finding that

"putting yourself in someone else's shoes" was not feasible appeared to strongly counter the assumption that it was an action that it was helpful.

In neurological rehabilitation practice both practitioners and service users wanted to be helpful towards one another. They identified that at times holding assumptions about what they perceived to be helpful to another person did appear to work well. However, getting to the heart of what really mattered to people was not deemed to be possible without asking questions and engaging in dialogue. Attempts to be inclusive or act on behalf of others by "putting yourself in someone else's shoes" seemed to require holding assumptions based merely on one's own personal experience. If such assumptions remained unexplored, then there was the risk that they might not meet the needs of the other person, lead to inappropriate representation, coercion and well-meaning paternalism, all of which could contribute to ineffective practice. The findings suggest that an awareness of the risk of the fallibility of such assumptions holds the potential to firstly bring, wider engagement with people who either do not have a voice or are the focus of "help". Secondly, an honesty to practice that recognises that it is not possible to "step into the shoes" of someone else and therefore time and space are required to explore the meaning of situations for the individual, rather than them being "helped" by the interpretation and misappropriated goodwill of someone else.

5.3.6 Summary

The findings outlined in the section 5.3 have identified and illustrated the connection between the assumptions service users and staff hold about neurological rehabilitation and their influence on inclusion. Many assumptions were helpful in facilitating experiences of inclusion, whilst others risked inclusion being realised. These risks and facilitators are not an either or, as assumptions can readily move between one position and another in response to the presenting situation. Figure 17 summarises the key points.
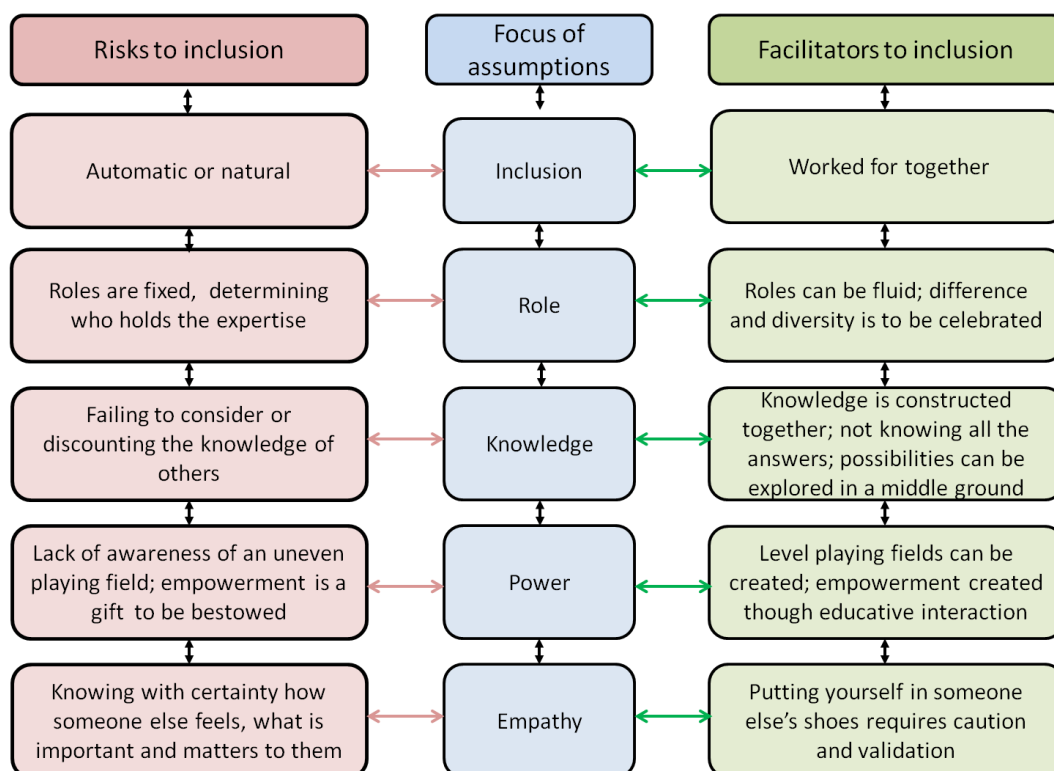
Figure 17. Assumptions that act as risks and facilitators to inclusion.

This simplified summary of the potential risks and facilitators to inclusion does not do justice to the complexity of the influence of assumptions about neurological rehabilitation on inclusion. However, the figure does provide a helpful overview through which is can be clearly seen that assumptions which are founded on relationship, interaction and socially constructing knowledge and understanding together, support the facilitation of inclusion. The final section of the Findings Chapter will investigate the conditions that support a change in assumptions about neurological rehabilitation and inclusion.

5.4   Changing assumptions about neurological rehabilitation and inclusion

My third research objective was to explore the conditions that enabled changes in assumptions to take place. The malleable nature of assumptions has already been established in section 5.2.1, identifying that it is this aspect

of their nature that enables them to be adapted and changed. The findings identified that the process through which assumptions changed was not specifically influenced by one person actively setting out to change the assumptions of the other person. Instead, it was the interaction and dialogue between people that was important and it was this that precipitated an increase in personal awareness of taken for granted assumptions and mindsets. It was in the light of this heightened awareness, that assumptions about both neurological rehabilitation and the meaning of inclusion for service users and disabled people were expanded and changed. There were three themes identified as important conditions in changing assumptions 1) Cognitive awareness; 2) Emotional connection; 3) Slow critical reflexivity. For clarity, these are presented in Figure 18 below. Two specific examples from the data will be drawn upon to illustrate these conditions under which changes in assumptions occurred.
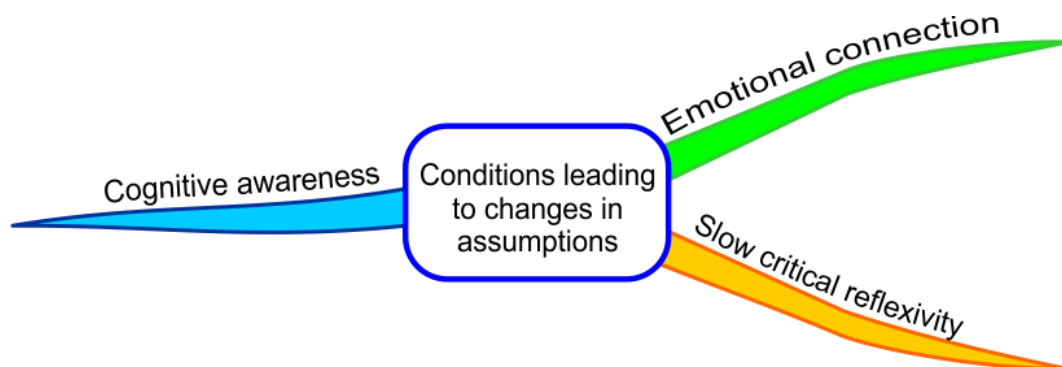
Figure 18. Mind map: Conditions leading to changes in assumptions.

5.4.1 Cognitive awareness

Expressing an awareness of personally held assumptions was only occasionally evident in the accounts of participants. Where this awareness was present it appeared to be created by a dissonance between what had been anticipated and what was actually experienced or observed. A disturbance in taken for granted ways of thinking about a situation, appeared to generate a pause, which in Jenny's example, caused her to actively stop,

think and evaluate what she was seeing. It would seem that this was a rational and logical process.

> *"I think one of the advantages of having the camera was it made you really stop and think about it a bit more rather than just registering it on a superficial level..." (S2-F-P)*

Jenny's experience indicates that engaging with a different view of the world was central to increasing her cognitive awareness of personally held assumptions. Without this different perspective, it was quite possible that her established frames of reference, about neurological rehabilitation practice and inclusion, would have remained the same and her assumptions would have been unchallenged. Jenny highlights the importance of slowing down her thinking, by disrupting her initial rapid generalisation of situations. The consequence of this, for Jenny, was to rationally reconsider her existing assumptions in a slow manner. For example, the challenges of accessing buildings as a disabled person had not occurred to Jenny previously. She had made the assumption that this was straight forward. However, the more she looked through the lens of the camera, the more aware she became that inclusion was not something that could be relied upon in shops or public places. Her emerging cognitive awareness enabled her to see differently, reconstructed her understanding of situations and as a consequence her existing assumptions were expanded and modified. The importance of Slow Consideration to the formation of assumptions has been highlighted previously in section 5.2.4 p.165.

Disturbances in cognitive awareness may take place, as in Jenny's example, but this did not necessarily mean that changes in assumptions necessarily followed. The example used in Section 5.3.5 p.197 in the dialogue between Stella and Kathy illustrated that despite Kathy challenging Stella's assumption that "standing in someone else's shoes" was helpful, Stella did not pause and reconsider her assumption more slowly. Instead, she continued within her existing frame of thinking and appeared to be intransigent to a different point of view. It would seem therefore that where there was a strong sense of certainty in being "right" or there was a familiarity

with a particular way of thinking or acting, this influenced the willingness or reluctance to explore different perspectives. Such assumptions may be formed by ideological dominant beliefs, or what is taken for granted. For people with cognitive impairment, such mental flexibility can be difficult or sometimes impossible to attain. This raises the question of the degree to which changes in assumptions are possible for people with some cognitive impairment, though it is beyond the scope of this study to speculate, aside from raising the issue as a question to be mindful of in any future work.

5.4.2 Emotional connection

Whilst the rational thinking process was important in considering the case for changing assumptions, it was identified that rationality may not be sufficient in itself to appreciate the full meaning of a situation. Instead, participants indicated that this required the creation of an emotional connection between people, through which the fears, risks, costs or benefits of the situation might be weighed up and understood. Subsequently, it was on that basis, that assumptions could be clarified and modified as appropriate.

The use of provocative symbols was particularly noted for their ability to disturb and disrupt assumptions, heightening cognitive awareness and creating emotional connection between people. This disturbance in existing assumptions was essential to stimulate an awareness that the situation may not be as it at first seemed. However, it appeared that establishing an emotional connection was also important in facilitating the development of new understanding, which might lead to an expansion of existing assumptions.   For example, service user Ruth took a photograph of the swimming pool hoist and created a provocative symbol by naming her photograph the "Ducking Stool" (Figure 19). In her account of her photography, she stated:

'it's like a witch's stool really, you know the (laughs) once you're lowered in if you don't drown then they'll burn you at the stake when they get you out, it's horrible and the other cruel thing is that you have no way of knowing how hot or cold or warm the water is until you're chest high..." (SU32-F-P)

Figure 19. The Ducking Stool.

The symbolism within the language used to describe the photograph, did not represent an inclusive experience, but rather one of punishment for Ruth, who saw herself as an object of torture rather than a swimmer. However, it would seem that it was Ruth's storytelling in relation to the photograph that highlighted the true symbolic meaning of the pool hoist. Without this, the potential to create emotional connectivity with other people was limited; it merely remained a picture of a pool hoist. Her use of a provocative caption and the story associated with it enabled an emotional connection to be made with other people, leading to well established assumptions being challenged and changed. This is evidenced by a staff member Beth at the Big Conversation Day who recorded her reflections on her reflective questionnaire following her encounter with Ruth.

"This piece of equipment [pool hoist] was something that I viewed as being "inclusive" and "promoting Access" to community leisure

facilities, but from the caption on the photograph it was viewed as "anything but" by the person who took the photo... 'She made me realise that it wasn't just a piece of equipment that was important, but how it made her feel to use it." (S:g-BCD-Q)

The human emotional experience particularly spoke to Beth, and led to a change in her assumptions about her neurological rehabilitation practice and what actually made practice inclusive. She realised that what mattered most was not merely being able to take part, but the quality of the emotional experience that accompanied Ruth's participation. Beth's initial rational interpretation of the picture merely facilitated a generalised assumption from her existing mental framework. Whereas, the dissonance created by the emotional engagement with Ruth, led to an awareness of the limitation of her existing assumptions. This emotional engagement with someone who held a very different perspective to her own opened up the space for the generation of new understanding. Other examples also illustrated the importance of understanding what actually mattered to people about inclusion, and identified that emotional engagement with their perspective that got beneath the superficial presentation of the situation was central to any subsequent change in assumptions. Whilst the importance of emotional engagement with people did not preclude rational dialogue, it certainly appeared to lead to a deeper understanding and awareness, not only of service user perspectives, but also of personally held assumptions. It would seem that making an emotional connection was therefore paramount to *"dismantling people's comfort zones"* (SU32-F-P) in order that assumptions were both challenged and changed in relation to both neurological rehabilitation and inclusion.

5 4.3 Slow critical reflexivity

Where assumptions of service users and staff changed, there was also evidence that they had engaged in a critical questioning process that went beyond what was happening in the immediate situation. For example, both Jenny and Beth considered how their new understanding, about neurological rehabilitation and inclusion, might be applied to their daily neurological

rehabilitation practice. This critical self-questioning focused not only on personally held practice values, but also on the priorities and principles of neurological rehabilitation. As service user Ruth noted, when assumptions were disturbed a *"ripple effect" SU32-F-P-HA* was created. However, it would seem that a disturbance was not sufficient in itself to bring about change in assumptions. Instead, a slow critically reflexive consideration of personally held assumptions about knowledge and power was also required in order to support a process through which assumptions might be modified and or expanded.

Based on her experience of taking photographs of a shopping centre and talking to people who used it, staff member Jenny found herself questioning and weighing up the value of neurological rehabilitation in relation to what she now understood about experiences of inclusion.

> *"I just think we could work as hard as we like here to get people as well as the mobility they can have in their chairs but if there is nowhere for them to use them where they can't enjoy themselves then it's a bit pointless really isn't it?" (S2-F-P)*

Jenny's slow consideration appeared to be triggered by the juxtaposition between her original Ideal World assumption, that shopping centres are inclusive for everyone, and her emerging Real World assumption that this is not actually the case. The tension and feelings of uncertainty this appeared to create, provided a platform from which Jenny subsequently evaluated the very meaning and purpose of her practice in neurological rehabilitation. Looking at the situation through a very different perspective, enabled Jenny to enquire into her practice and raised questions about the effectiveness of neurological rehabilitation intervention.

Both Jenny and Beth actively engaged with service users who had different perspectives to their own and found that as a consequence, their comfort zones and familiar, established patterns of practice were disturbed, raising questions about their practice. In applying the lessons learned from her

changing assumptions about inclusion, Beth paid attention to her own actions and how they needed to develop and change in the future:

> *"Trying to ensure I am inclusive in my practice and open to being challenged." (S-BCD-Qg)*

It would appear for Beth that part of the ripple effect which took place following a change in her assumptions was a heightened awareness of how her personal behaviour also needed to alter in accordance with her new thinking. In relation to inclusion, this required her to actively welcome the perspectives of others and move to a position where she openly welcomed the learning that could be generated through the challenging perspectives of service users. In such situations, inclusion would therefore be worked for together rather than determined by the ideas and assumptions of one person.

Jenny also continued the momentum from her own learning by considering how others could share her experience of the juxtaposition between Ideal World assumptions about inclusion and the lived reality of inclusion for service users.

> *"Just to make them [students] think and to make them think and 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 the effort in to make sure that it works." (S2-F-P)*

Jenny's slow critical reflexivity enabled her to move her thinking about her changed assumptions beyond the effectiveness of her clinical interaction to the education of future generations of practitioners. Her comment recognised both the value of exposing students to the concept of inclusion, but also acknowledged the importance of challenging assumptions through engaging with the perspectives and experiences of service users. Jenny particularly noted the importance of "*working it out in practice*", highlighting the importance of slow critical reflexivity in order to ensure that an inclusive approach to practice worked for everyone concerned. This would ensure

that inclusion in practice was not merely consigned to the rhetoric of aspirational principles.

It would therefore appear that assumptions were modified and changed when there was a disturbance in taken for granted ways of thinking. This disturbance had the effect of raising cognitive awareness that the situation was different to what had been expected and therefore required attention. Creating an emotional connection between service users and staff enabled assumptions to be disrupted further, different perspectives to be explored and new knowledge and understanding to be developed. Taking time to slowly consider the experiences and viewpoints of others and critically explore them in relation to both personal and professional practice was seen to lead to changes in assumptions and consideration of the effectiveness of practice.

The three processes presented above do indeed hold the potential to transform thinking, behaviour and ultimately practice. However, it should also be noted, that whilst these themes were perceived as the essential building blocks to assumptions being modified, the change process was also influenced by many of the issues that have already been raised in this findings chapter. For example, the strength with which assumptions are held, how knowledge and expertise is perceived, how level the playing field is and whether there is an openness to learn from one another. Capturing the complexity of this change process is not straight forward, but it is hoped that taken as a whole, this chapter has contributed to an understanding of the conditions that facilitate a change in assumptions,

5.5   Summary

This chapter has identified the complex interpretive nature of assumptions and demonstrated their fundamental influence on service user–practitioner relationships, neurological rehabilitation practice and experiences of inclusion. I have endeavoured to present the findings in a way that acknowledged the fluidity of assumptions, reflecting on how they are formed

and constructed through interaction. At the same time, it has been important to recognise how assumptions can also be held rigidly, readily limiting and constraining collaboration between people and ultimately leading to feelings of exclusion and ineffective practice. The participatory methodology adopted in this study created the space for participants to go beyond the mere story of their experience, and instead provided the opportunity for participants and researchers to delve beneath the surface and generate a deeper critical understanding of neurological rehabilitation practice and inclusion. The next chapter will consider and discuss the implications of these findings.

Chapter 6 Discussion

This chapter critically reflects upon the findings presented in Chapter Five. The discussion addresses how an inattention to assumptions in neurological rehabilitation practice can lead to ineffective practice and the production of service user and practitioner wasted time and effort. Re-conceptualising practice in this way challenges the adoption of client centred practice and other core principles of practice upon which neurological rehabilitation is currently founded. I argue that assumptions can only be challenged effectively by using a questioning approach through which the relational space between service users and practitioners is crafted, and suggest that a critical relational ontology is the most appropriate means to realise this. It is recognised that a critical relational ontology is not an easy option for service users and practitioners alike, as it challenges long-standing accepted approaches to practice. Taking the findings from this study forward is, therefore, of prime importance in relation to practice, education and research. The final section will outline the strengths and limitations of the study.

6.1 Inattention to assumptions can lead to ineffective practice

Reliance on assumptions to categorise and simplify what is seen and heard often means that the true complexity of service user experience, their personal situation and practice contexts can be overlooked. This overreliance on and inattention to assumptions and the influence they have on people, relationships and how situations are interpreted, can lead to ineffective interventions. The study has revealed situations where service users were often aware that practitioners were working in ways that were ineffective for them. However, service users felt unable to question or challenge practitioners, as their assumptions were founded on understandings of their role as a compliant receiver of neurological

rehabilitation. Practitioners, on the other hand, often lacked awareness that their practice was ineffective and instead assumed that they were delivering the required intervention to facilitate the service user's rehabilitation. It would seem, therefore, that a lack of attention to assumptions and an inability to create a space where they can be addressed, can act to perpetuate ineffective practice, leaving a messy trail of misunderstandings and angst that could ultimately lead to wasted time and effort on the part of both service users and practitioners, alike.

Assumptions that viewed service users or staff as merely a number or object, rather than a person, particularly acted to marginalise, exclude and in some situations strip people of their worth, value and agency. Consequently, the opportunity for their knowledge and experience to contribute to a shared learning experience, clinical decision-making or service development was overlooked. Such assumptions, often unintentionally held by staff about service users, not only wasted the untapped potential of the capabilities of service users, but also led to wasted time and effort on the part of the practitioner. This was particularly evident when practitioners acted out of the best of intentions, but assumed that they alone knew what was best for the service user. Pursuing unilateral modes of thought based on clinical evidence, practice protocols and their own experience, privileges their practitioner knowledge and perspectives over that of the service user. As illustrated in the findings, where service user preferences were ignored, this not only led to a breakdown in communication, but also to inappropriate provision of equipment, unwanted assessments, complaints and, as a consequence, wasted time and effort.

Practitioners making professional decisions based on the assumption that they know best is a point of controversy in health care practice, raising the issue of whose knowledge counts (Hammell, 2006). Hierarchies of evidence in medicine traditionally privilege experimental approaches (Carpenter, 2004). However, this seldom considers what is important and matters to service users. This has the likely consequence that the focus of research

efforts is on issues that academics and practitioners feel are important but which have little overlap with service users' priorities: Research based on such hierarchies risks remaining separate, detached from and uninformed by service user experience and knowledge, leading ultimately to studies of little or no clinical relevance.

Disability theorists have consistently argued that assumptions held by practitioners who view service users as an object of intervention, privilege practitioner knowledge over that of the service user, thereby marginalising the service user (Oliver, 2003; Davis, 2004). Oliver (2003) and Hammell (2006) argue that such a stance can lead to service users simply complying with professional practice norms, resulting in their disengagement from their health care. The main focus of disability theorists has been to highlight oppression in health care practice. However, unlike this study, these authors have not gone on to articulate the impact of this oppression on the effectiveness of practice in neurological rehabilitation services and consequent wasted time and effort.

The intention of this study is to raise awareness of the impact that the inattention to assumptions can have on individuals, relationships, outcomes of neurological rehabilitation and the use of resources in practice. Indeed, this study provides support for the suggestion by Shakespeare (2005), Shakespeare, Iezonni and Groce (2009) and Hammell (2006) that practitioners act out of ignorance in relation to the impact of their assumptions and calls for an increased awareness and attention to them. However, it is apparent from the findings, that the influence of assumptions goes beyond their effect on the individual, to the level of the service and, by implication, wider health services. Cook et al. (2011) clearly identified that where people are excluded from practice, wasted effort and resources are evident, however, they do not specifically link their work to assumptions.

Building on the work of Cook et al. (2011) this study clearly sets out the necessity for practitioners and service users to recognise the critical role

assumptions play in influencing their thinking, action and behaviour. This is consistent with the critical thinking literature (Paul, 1993; Paul and Elder, 2006). However, it is the emotional response associated with assumptions that was also identified by Nussbaum, (2001) that appears to lead service users, in particular, to feel unable to speak out about their experiences of ineffective practice. The framework of the key characteristics of assumptions presented in the Findings Chapter on p.167 provides a way of critically engaging with assumptions that recognises their place in both rational thought and emotional interpretation. It is suggested that the term framework should be used loosely in order to recognise the complexity of assumptions and the way that their formation and use interweave. However, it is proposed that its value will be in raising the awareness of practitioners, in particular, of the way in which tacitly held assumptions hold the power to influence experiences of inclusion, and both the process and the outcomes of neurological rehabilitation.

Currently health care services are operating under the strain of austerity measures and the requirement to save money and streamline services. This study has identified ineffective practice. This is linked to inattention to the assumptions of both service users and practitioners, leading to thinking that has not been validated and a lack of critical dialogue within interactions, which can readily lead to service users feeling excluded from their care. Paying attention to assumptions holds the potential to not only get to the heart of what matters to service users in the context of their lives, but would also recognise the complexity of the practice context within which services are delivered. Particularly against the backdrop of tightening health budgets, therefore, it would, seem that paying attention to and addressing assumptions would make an important contribution to the prevention of wasted human and financial resources in health care.

6.2 Recognising assumptions: from client centred practice to a critical relational practice

Client centred practice is the accepted approach advocated by NHS long-term conditions policy (e.g. DH, 2005a), professions and services within neurological rehabilitation. Whilst this approach does emphasise the value and worth of individuals, it is recognised theoretically as being underpinned by individualism which, in fact, separates the individual from the practitioner, the context of practice and wider society (Hocking, 2012). By doing so, the relational element of practice is not considered, practice remains uncritical, and assumptions held by service users and staff that influence the situation tend to go unrecognised. Reconceptualising practice is, therefore, required in order that staff and service users can recognise and scrutinise their assumptions in the context of practice.

Assumptions about neurological rehabilitation practice reside in the comfort zones and taken-for-granted ways of thinking about service user and staff roles, the relationship between them and service provision. However, because assumptions are naturally tacit, recognising them requires a specific intention to disturb these established thoughts, bringing them to the surface and enabling exploration through dialogue. Placing the relationship between the service user and the staff member at the very core of practice actively brings together their two very different perspectives, creating the potential for this disturbance in assumptions to take place. However, even within the context of the relationship, without an intention to address assumptions many of the disturbances in thinking will be passed by and opportunities to gain a deeper understanding of the complexity of not only service users' situations, but also of the context of practice will remain hidden, not understood and, therefore, go unaddressed. This study identifies that assumptions about roles, power, knowledge and empathy particularly influence service user experiences of inclusion in neurological rehabilitation, contributing to ineffective rehabilitation and a waste of health care resources. Based on the findings of this study I argue strongly that recognising assumptions, their influence on people, practice and inclusion requires a new approach to

neurological rehabilitation practice. I suggest that a critical relational approach to practice, in which the different perspectives of the service user and staff member come together to disturb and challenge assumptions about neurological rehabilitation practice could make a critical difference not only to inclusion of service users in neurological rehabilitation, but to the effectiveness of neurological rehabilitation services.

If assumptions are going to be recognised, explored and challenged in practice, service users and staff need to recognise how their assumptions can influence one another, their relationship, the process of rehabilitation and its potential outcomes. As identified in this study, this process starts with a focus on both the relationship and assumptions, that does not view the service user and staff member as operating in isolation from each other, but sees them as interdependent, each influencing, challenging or reinforcing the assumptions and thinking of the other.

Importantly, for assumptions to be recognised, it is not sufficient to put service users and staff in the same room together and expect that assumptions will be recognised merely through the sharing of different perspectives. Indeed, as indicated in the Findings Chapter, assumptions held by practitioners that their knowledge accurately reflects a service user's situation can thwart and undermine any potential influence this service user might have on such reasoning. Practitioners readily and often unwittingly create a relationship in practice, which suggests to the service user that their perspective is invalid, because their viewpoint is not asked for and taken into account. Such situations reflect a practice that is neither relational nor critical and merely perpetuates existing assumptions about the power asymmetries in the relationship, which privilege practitioner knowledge.

Instead, as illustrated by staff members Steph and Jenny (pp. 201 -207), the bringing together of different perspectives whilst important, is merely the precursor to recognising assumptions. The key here is that the relationship is used to disturb, question and explore together assumptions about one

another's role, relationship and neurological rehabilitation practice. The recognition of such assumptions, therefore, requires practice to be underpinned by a social constructivist critical relational ontology that moves beyond seeking to merely understand the other person's perspectives and situation. Instead, its primary intention is to place a critical exploration of assumptions at the centre of the relationship through which the critical questioning and examination of all perspectives is used to investigate how things might be done to best facilitate service users in their desired direction of travel. Knowledge, therefore, is, co-created in the middle ground between the service user and the staff member. Importantly, there is an intention to pay attention to assumptions, be curious about them together and check out each other's understanding. This takes the relationship beyond a mere silent interpretation of meaning between people, or a service user sharing their narrative with the staff, but instead requires a focus on critical dialogue. This is not about winning an argument and does not necessarily aim for consensus. Instead, it seeks to get underneath any superficial understanding of a situation and dig deeper to get to the heart of what really matters to people.

A critical relational ontology at the core of practice could provide the ontological basis for a deeper level of understanding which gets beneath the surface level narrative or acquiescent smile or nod of the head in faux agreement. It would "legitimise" and encourage an awareness and critique of assumptions held by service users and staff. Such a joint unpicking and exploration of assumptions by service users and staff could thus enable a more complete understanding and valuing not only of service users by staff, but also by service users of staff. In this new ontology it is not the service user alone who is in the centre, but the relationship and understanding is developed jointly between service user and staff. This would be the basis for an approach to neurological rehabilitation, which informs all its principles and processes, and based on the findings from this study it is evident that it is likely to lead to more effective interventions.

A relational approach rather than a client centred approach to neurological rehabilitation practice has been a growing focus of attention in recent years (Bowen, Yates and Palmer, 2010; Kayes et al. 2015). However, these authors' failure to introduce a critical element to their work leaves assumptions predominantly unaddressed. Kayes et al. (2015) argue that the relationship between the service user and the practitioner should be a ""core" component of practice". They suggest that "practitioner ways of working" (p.254) influence rehabilitation outcomes and, therefore, should be seen as a "legitimate intervention" (p.259) in its own right, that requires practitioners to reflect and make visible their assumptions. However, there appears to be an inconsistency in this argument in that an intervention is based on the assumption that one person "does to" another, creating a situation which once more separates the practitioner from the service user and where practitioners would appear to have power over service users. Kayes et al. (2015) do recognise the importance and influence of practitioner assumptions on the relationship; however, they merely advocate the use of reflective tools which would appear to lack the reference to critical theory necessary to purposefully examine assumptions (Brookfield, 2009). In contrast, as I have argued previously, it is the interactive process of the relationship itself that presents the opportunity to critically reflect on assumptions, rather than practitioners merely reflecting in isolation, thereby reinforcing their unilateral perspective.

Critical theorist Habermas (1984, 1987, 2008) identifies the importance of relationships in fostering dialogue that can enable assumptions to be tested out and scrutinised. This "ideal speech situation" requires that everyone who can make a relevant contribution is included; everyone has the same opportunity to speak; participants must mean what they say and raising issues and critiques must be unconstrained (Habermas, 2008, pp. 49-50). This "ideal speech situation" was found to be a rare occurrence in this study, due to the perceived impossibility of creating a level playing field and the hard work required from service users and staff to co-create an inclusive experience. Indeed, the literature also highlights that "ideal speech

situations" are atypical in health care (Greenhalgh, Robb and Scrambler, 2006; Walseth and Schei, 2009; Gillespie et al., 2014). However, I would suggest that it is in these mis-matches of assumptions between what is perceived to be an ideal situation and yet the expectation that the real world will be very different, that the potential for a critical dialogue in practice exists. This will be explored further in section 5.3 working with assumptions in practice.

Participatory health research shares the critical relational stance proposed by this study, their principles highlight the importance of multiple realities in creating meaning, emphasises the creation of knowledge through critical dialogue and seeks to promote participant critical reflexivity (ICPHR, 2013). These principles emphasise the value and importance of bringing together different perspectives such that assumptions can be contested and explored. Using a participatory research approach, Cook et al. (2011) place particular emphasis on a critical relational approach to practice, arguing that inclusion can be realised through the creation of communicative spaces between service users and staff. The ontological and epistemological congruence between Cook et al.'s (2011) research and this study is unsurprising given the interconnectivity between the two projects. However, the importance of a focus on assumptions and clearly situating this study as philosophically different from client centred practice, brings a new challenge to neurological rehabilitation services that has not been articulated by Cook et al. (2011).

The contribution to knowledge of this study is not only in raising awareness of the impact of assumptions on inclusion in neurological rehabilitation practice, but also in theoretically reframing practice so that assumptions have less opportunity to remain hidden, but instead can be questioned and explored together. Challenging issues have been raised about how current understandings of client centred practice perpetuate the power asymmetry between service users and practitioners and how a critical relational approach might be realised in practice. The following section of the

discussion outlines how this might be achieved in neurological rehabilitation *practice.*

6.3 Working with assumptions in practice: recognising and holding tension and acknowledging the challenge

Places of tension are commonplace in neurological rehabilitation practice. They mark where an assumption has been disrupted, indicate a mismatch of assumptions between service users and staff and highlight where an assumption held about what should happen is not experienced in reality. Such tension can bring into sharp relief what service users and staff take for granted, for example about the way they expect to relate to one another, who they perceive has expert knowledge and the way professional and organisational requirements influence relationships and practices in neurological rehabilitation. Examples include when service users are very keen to return home but based on previous experience, practitioners feel there is more to be gained by them remaining as an in-patient or feel that an early discharge is too risky. A place of tension is often difficult, unsettling and can create defensiveness in both service users and staff. As a consequence, service users can readily be labelled as difficult or a problem, and similarly staff can be perceived as unhelpful or negative.

Creating and holding these tensions up to scrutiny and enquiry would seem to provide the key to working with assumptions in practice. Due to the tacit nature of assumptions, participants in this study indicated that this requires conscious and deliberative work that starts with what appears to be a simple question "How do I do this with you?". This question, highlighted by service user Ruth (p.192), importantly disturbs assumptions from the outset, immediately challenging historical pre-conceived notions of service user and staff roles and ways of relating to one another. Openly holding the tension for shared enquiry and exploration provides the opportunity for service users and practitioners to craft and co-construct the relational space together. Importantly, this places critical co-inquiry into assumptions about both the relationship and issues of concern to all parties at the core of practice,

enabling understanding to be questioned, deconstructed and reconstructed in a way that positively supports the service user and the practitioner to work together. "How do I do this with you?" is a question that can shape the space for interaction and recognises the variance in perspectives that can occur across generations and cultures.

McPherson, Kayes, Weatherall, (2009) also see the importance of practitioners asking questions about their practice suggesting they ask "what am I doing" (p.300) that might influence the process of goal setting. Such questioning is valuable in developing an understanding of how practitioners contribute to the power asymmetry between themselves and service users (Bright et al. 2012). However, it stops short of requiring practitioners to engage with service users in order to explore "how do I do this with you"? The question "how do I do this with you?" goes deeper than a mere verbal exchange about how service users and staff might work together. Instead, it requires attention to the hidden unspoken tensions that exist where assumptions about the relationship between service users and staff and the delivery of neurological rehabilitation are not questioned. These unrecognised tensions pervade practice influencing whether a service user feels marginalised, disempowered or included and able to participate in neurological rehabilitation and wider society. They exist between, for example, assumptions that the playing field is level and yet it is experienced as uneven (Sophie, p.188); between the importance of making an emotional connection and yet understanding that putting yourself in someone else's shoes can be unhelpful or even impossible (Sophie, p.198; Gemma, p.198); between an educational approach to be delivered by practitioners to service users, yet a two-way interactive learning process is hoped for by service users (John, pp.181 and 192); between being the expert and yet also recognising the importance of not knowing the answers (Sue, p.186). The way that these different assumptions play out in practice creates the interactive space between service users and practitioners. Working with these tensions in practice does not return us to the question so "how do I do this with you?", but instead asks "how do we do this together?" I suggest

that asking this question moves beyond mere practitioner critical reflexivity and instead holds open a space for a shared service user-practitioner critical relational inquiry that addresses issues of shared concern and those seen and unseen places of tension.

6.4 Critical relational practice and the principles of neurological rehabilitation

The tensions identified above, do not sit easily with the principles of neurological rehabilitation outlined in the Introduction on p.7. which include, client centred practice, service user education, problem solving issues of disability, goal setting and service user and practitioner responsibilities in the rehabilitation process. A critique of client centred practice has been offered in section 6.2. Whilst it is beyond the scope of this study to discuss in detail why and in which way all of these principles are challenged, it is important to note that similar to client centred practice, the principles of neurological rehabilitation would appear to be founded on assumptions of individualism. For example, their focus on the service user as the sole recipient of education (Wade and deJong, 2000; Barnes, 2003a) provides no scope for recognising that learning is a mutual process and it is equally important that service users can educate practitioners about their experience of living with their health condition. Living with a brain injury, for example, is recognised for its impact on personal identity, life roles, relationships and community life (Stewart, 2014). However, without a two-way educational process, practitioners will fail to grasp the struggles service users encounter on a day to day basis and can, therefore, only base their practice on assumptions of what living with a long term neurological condition might mean.

Barnes (2003a) does recognise that the relationship between service users and practitioners is important and not one where rehabilitation is done *to* service users, arguing that rehabilitation should instead be done *by* service users, thereby supporting service users to take responsibility for their own rehabilitation. However, from a critical relational perspective, this fails to recognise firstly, how the interaction between the practitioner and the service

user shapes the process and effectiveness of neurological rehabilitation, and secondly, pays limited attention to the tension created by the uneven nature of the field of practice and the way it is skewed towards the privileging of practitioner knowledge and expertise over that of the service user. Barnes' (2003a) principles were considered highly progressive in their time. However, with the benefit of a different ontological lens, they seem somewhat naive and show limited recognition of the way historical ideologies of role and expertise continue to inform the assumptions of both practitioners and service users. Examples from this study have already illustrated how the unwitting assertion of knowledge and expertise by practitioners can determine an unwanted direction of travel for rehabilitation and unwanted assessment and intervention. In order to achieve neurological rehabilitation practice that is not as Barnes (2003a) suggests "done to" service users by practitioners (p.iv3), I suggest that the current principles need to be re-framed using a critical relational ontology. This would recognise the importance of not merely the interactions between service users and staff that can be seen, but also hidden deeper interaction influenced by assumptions that are based on history, tradition, personal and professional cultures and organisational contexts.

6.5   Taking the findings of this study forward

It is a significant challenge for any health care system to change its ontology in quite such a radical way. On the other hand, a strong argument has been made as to why this needs to be radical in order that practice becomes more effective, and that current ontological approaches to practice do not provide an adequate basis for addressing these assumptions. However, as identified, this is problematic in terms of implementing such an approach: firstly, because it goes against the grain of a stable practice environment which prefers certainty to disruption and secondly, people are uncomfortable with change. Some practitioners will suggest that it takes more time, others that the system does not allow this to happen due to the domination of systems, standards and protocols. Indeed, Habermas (1987) refers to this as the colonisation of the "lifeworld" (of service users and staff) by the system. Where such colonisation takes place, the relational element of practice is

often lost, attempts to challenge assumptions thwarted and opportunities to learn from these tensions are missed. However, it has been strongly argued that if practitioners adopt a critical relational approach to practice and assumptions are actively being addressed as part of an ongoing iterative approach enabling service users and practitioners to work together to get to the heart of what really matters to people, then neurological rehabilitation is more likely to be effective, and getting it right first time becomes commonplace.   By working together in this way, the systems that serve to colonise the lifeworlds can be exposed and challenged and tackled together. I suggest that delays in conversations about why people are not engaging and what would help them to engage better merely prolong time spent in neurological rehabilitation that is unhelpful and ineffective.

A strong argument has been made for the need for change in neurological rehabilitation practice. This requires a fundamental ontological and epistemological shift in thinking not only within practice, but also within pre-registration practitioner education, continuing professional development (CPD) and supervision of all staff. This claim may appear unrealistic in the context of current performance and efficiency drivers in the NHS. However, a social constructivist stance towards change argues that all parties associated with the organisational or professional culture are in a position to influence its cultural direction (Scott et al. 2003).

Adopting this position as I take this study forward, I firstly recognise the importance of taking the findings back into the practice context for validation by service users and staff currently engaged with neurological rehabilitation services. Secondly, I particularly recognise the importance of working with other academics, practitioners and service users locally, nationally and internationally who are also committed to generating criticality in practice, education and research. The collaborative approach central to this study will, therefore, be mirrored in the construction of future work. This will form four key work streams around dissemination, future research, practitioner based learning and enquiry and pre-registration professional education programmes.

Work stream 1: Dissemination of the study's findings

Validation of the findings of the study with service users and staff in practice context where the study was undertaken will enable me to explore my own assumption that this study is relevant and of importance to service users and staff currently using and working in neurological rehabilitation practice. Presenting the findings in an accessible way will be essential to support critical dialogue from everyone who wants to take part. Feedback will help to shape subsequent practice development and research work within the service and wider neurological rehabilitation practice.

Given the radical nature of the findings of this study, dissemination through publishing and conference presentations is viewed as a priority in stimulating and contributing to critical debate in the field. Journal articles will be targeted predominantly at rehabilitation practitioners and professionals working in different clinical specialities. Managers will also be targeted, but mainly through non-peer reviewed journals such as the Health Service Journal. Without this publishing credibility any plans to develop CPD programmes or pursue further research opportunities that build on this work are most likely to stall at the first hurdle. These traditional avenues of dissemination will publicly situate my study in the wider body of academic knowledge and contribute to critical discussion. Social media provide new avenues for communicating research, and despite my hesitancy with social media, being active on for example Twitter would provide opportunities to share my work beyond the bounds of academic journals.

Draft titles of papers outlined for publication currently include a mixture of findings and methodological orientated papers for example: "How do we do this together?": working with assumptions through a critical relational approach in neurological rehabilitation

Work stream 2: Future research

Future research to pilot the implementation of these findings into practice requires collaboration with a service delivering for example community based neurological rehabilitation services. NHS Research Capability Funding provides an ideal funding stream to support this process and provides a sound basis from which to apply for NHS Research for Patient Benefit (RfPB) funding at a future date. An RfPB bid could draw on the methodological approach of McPherson, Kayes and Weatherall, (2009) who used a small randomised control trial (RCT) to explore a new way of working between service users and staff in goal setting in neurological rehabilitation.   RCTs remain a preferred source of evidence in the development of policy and practice guidelines (Greenhalgh, Howick and Maskrey, 2014). Therefore, adopting such an approach is likely to be important in order to embed change into practice. Alternative methodologies that support a cost-benefit analysis will also be explored in order to further investigate the finding from this study that an inattention to assumptions can ultimately lead to wasted time and resources in practice.

The literature review indicated that there is little empirical research relating to assumptions. Opportunities for future investigation are suggested in relation to undertaking a concept analysis of "assumptions", enabling a comprehensive examination of the characteristics of the concept (Walker and Avant, 1995; Cronin, Ryan and Coughlan, 2010). Investigation is suggested into understanding how assumptions are formed by people with cognitive impairment, how this links to current understandings within neuroscience and the impact this might have on experiences of inclusion. Further research might also explore gendered ways of understanding how assumptions are formed and cultural and ethnic influences on the formation of assumptions which influence inclusion. Additionally, our understandings of inclusion have changed over recent years; it would be interesting to explore the history of inclusion and the role of assumptions in influencing its development and the influence this has had on health care systems and policy.

Work stream 3: Practitioner based learning and inquiry

Expanding the minds of staff to inquire into their assumptions and the impact they have on their practice and relationships with others requires an engagement with different human and theoretical perspectives. Education, CPD and supervision all provide opportunities to explore personal practice, as a receptionist, manager or practitioner through a different lens. Small first person action research studies provide an ideal framework through which to investigate and improve personal practice, particularly for practitioners and managers. The focus of inquiry is individual, however; stimulated by the findings of this study the following questions indicate an example of possible areas for study:

- How do we work together to create a space where we can challenge one another's thinking and assumptions?
- How do we work towards creating an even playing field in, for example, assessment or goal setting?

McNiff (2010) argues that first person action research has particular value in generating critical reflexivity. This suggests that using this approach to support professional development would contribute to the explication of personally held assumptions. A series of first person action research projects would not only hold the potential to change personal practice, but would contribute to a culture of criticality in practice through which a wider appreciation of assumptions and their impact on relationships with service users is recognised. Undertaking a meta-analysis of a series of projects exploring similar themes would also contribute to a developing picture about the barriers and facilitators to implementing the findings of this study into practice.

Creative methodologies used in this study had the impact of disturbing staff assumptions, in particular, and this has provided the inspiration for the idea of creating the opportunity for staff to learn about this critical relational

approach to practice using techniques from Augusto Boal's Theatre of the Oppressed. This approach based on the work of Freire (1970) challenges understandings of oppression and explores solutions in a participatory way. This holds the potential to enable staff to be reflexive about their relationship with service users. Early discussion has already taken place with an academic working in this field with a view to considering how the critical relational approach presented in this study might be explored by staff as a part of their learning and development. A programme of evaluation would be essential to capture the impact of the learning in practice.

Work stream 4: Education: professional pre- registration programmes

Critical debate is of primary importance in pre-registration professional programmes. I propose that the ontological shift in practice proposed by this research can be facilitated by students' exploration of the theory and assumptions that underpin accepted models and approaches to practice and by sensitising them to the implications for neurological rehabilitation practice of this study. Interest in this study has already been expressed by physiotherapy educationalists in Luxembourg. Additionally, creating critical dialogue between students and service users in relation to mental health and physiotherapy has drawn on knowledge developed about disrupting and challenging assumptions from this study, the findings from the National Institute for Health Research (NIHR) Inclusion study and an NIHR emancipatory action research mental health study. This work is being evaluated and is already being proposed as CPD for practitioners. The impact narrative of this study in relation to other work that aims to disrupt traditional ways of thinking and learning is already being articulated in teaching and potentially in practice.

Building future research collaborations

Research collaborations are immensely important in moving the findings of this study forward. Disruption of thinking has been identified as an important

theme by academic colleagues at Northumbria University who are working closely with the NHS Trust that was the host for this project. This study will contribute to their work, providing a deeper understanding of assumptions and their impact on practice when they are not disturbed and validated. The Trust's commitment to explore the idea of disruption as part of their work on culture change provides an excellent platform for continuing to develop and consider the findings of this study. It situates my work within a broader body of knowledge through which changes in both practice and research can be explored. Wider national and international collaborations will be actively explored and fostered, with clinical, professional and academic colleagues who share an interest in disrupting taken for granted assumptions about practice and research.

6.6   Strengths and limitations of the study

The strength of this participatory action research study was in creating spaces for critical dialogue between all participants who shared a commitment to understanding and changing their practice in relation to inclusion. Facilitating critical dialogue was of central importance enabling assumptions to move from being held tacitly to becoming visible and explicit when exposed to different perspectives (Brookfield, 1990). Photography, in particular, offered quite literally a different lens through which to view concepts, objects and experiences. The limitation of being unable to take photographs of people due to ethical governance, was instead a strength of the study, requiring participants to give greater consideration to how inclusion might be captured.

There were also distinct pragmatic advantages of having been a member of staff in the service when it came to the practical tasks of booking rooms for focus groups, knowing who to contact to support the sampling process and recruitment to the study. Having previously worked as a member of staff at the neurological rehabilitation centre, I knew many staff and service users who took part in the study. This had

particular benefits in that some staff, in particular, felt able to be more open than they had anticipated.

From a PhD perspective, there were also distinct advantages of undertaking this study as part of a larger funded piece of research. In particular, it meant that sampling, recruitment, ethical approval and the majority of data generation were undertaken as part of a larger research team. During my early deliberations about my study focus and question, this team provided welcome and ready-made support and encouragement.

The main limitations of the study are threefold. Firstly, the study was not designed to create an opportunity to validate participants' assumptions on an individual basis following the first phase of data generation (Phase 2 of this study). This would have provided first-hand feedback from participants whether my interpretation of their assumptions had resonance with them and contributed to the face validity of the study.

Secondly, it was a strength that the study was designed to be inclusive of all participants who were able to give consent to take part. However, it also became apparent that there were only a small number of service user participants who had a cognitive impairment. This was disappointing given the effort that had gone into recruiting service users to the study and the inclusive study design; however, it is difficult to know what could have been done differently. Many service users who were just starting their neurological rehabilitation were not well enough to take part, and other service users with behavioural impairment were screened by staff for their ability to consent. However, by placing posters around the neurological rehabilitation centre and talking to staff and service user groups, every opportunity was given to those who wanted to take part to do so.

Finally, the study was not designed to return to the practice setting in order to explore the influence of any increased awareness of assumptions on service user and staff approaches to neurological rehabilitation and inclusion. Understanding the challenges to enacting this new found awareness about

how assumptions influence inclusion would have been part of engaging in another cycle of participatory action research which would have been more organisationally focussed. This was outside the scope of this study. However, as outlined previously, following the completion of my PhD, it is my intention to take these findings back to the practice areas that gave their experience and time in contributing to this study.

6.7 Summary

This discussion has presented the argument for a fundamental paradigm shift in neurological rehabilitation, calling on service users and staff to re-frame practice in line with a critical relational ontology. This new conceptualisation moves away from existing individualistic approaches to practice. Instead, it requires service users and staff to work together through critical dialogue to dig beneath surface narratives and explore the assumptions that form the basis for their thinking and action. The findings of this study have relevance to a broad range of academic and practice programmes, and proposals for taking the study forward following the completion of this thesis have been outlined. In the interests of transparency, the limitations of this study have been articulated. The final chapter will bring together the threads of this thesis and articulate its contribution to knowledge.

Chapter 7 Conclusion

In undertaking this research, my aim was to investigate and unpack the assumptions held by service users and staff about neurological rehabilitation. I was curious to know why assumptions were so influential, whether there were particular assumptions that staff and service users held about practice that particularly influenced experiences of inclusion and what conditions led to a change in such assumptions.   I recognised that there was a lack of research specifically focussed on investigating assumptions and their link to both neurological rehabilitation and inclusion; indeed, this is the first study to investigate this research topic. In pulling together the threads of this study, the conclusion begins by identifying my contribution to knowledge, provides an indication of implications of this study for practice, education and research; reflects briefly upon my own learning and closes with a concluding remark.

7.1   Identifying the nature of assumptions: the contribution of a new framework

Overall, this study strengthens the suggestion of other authors (Paul, 1993; Brookfield, 1995) idea that assumptions are tacitly held and have a powerful influence on thinking and action. However, this study goes further in that it offers a framework (p. 159) for exploring assumptions in a new way, acknowledging that they cannot readily be reduced to a simplistic linear form, but instead are complex, multi-faceted and strongly influenced by multiple layers of interpretation. Importantly, this work acknowledges the context of human interactions, relationships and the complexities of practice in neurological rehabilitation. It recognises the influence of both cognition and emotion in informing how assumptions are formed, interpreted and experienced. This framework provides a new lens through which assumptions can be critically reflected upon and understood in greater depth,

231

enabling their relevance and importance to neurological rehabilitation and inclusion to be recognised and explored.

7.2   Conditions that lead to changes in assumptions

This study provides valuable insights into the conditions contributing to change in assumptions, recognising that it is a complex process which goes beyond a mere rational cognitive thought through which an assumption is deemed valid or not and moves into the realms of human emotion. Examples where a change in assumptions took place identify that disturbance is required in order for assumptions to become explicit. This study also recognises the importance of critical dialogue and critical reflexivity in order that assumptions can be scrutinised and subsequently modified. These findings are supported by literature using critical theory (Habermas, 1984; Walseth and Shei, 2011) and participatory approaches (Cook, 2004a; ICPHR, 2013). Importantly, this study notes the importance of emotion in stimulating a disturbance in assumptions, but equally identifies that emotion has a role in creating fears and anxieties that constrain people from speaking out. What appears to be more important is not necessarily that assumptions change, but that there is an opportunity to recognise, consider and understand personally held assumptions and their influence on interactions and practice.

This requires holding open for enquiry these places of disturbance and tension created by the differences in assumptions between one person and another. Practitioner preference for unilaterally generated technical solutions and a sense of certainty based upon what is familiar all conspire to prevent this from happening. However, examples illustrate that an openness to learn from one another and a commitment to critical reflexivity positively contributes to expanding thinking and understanding of oneself and others.

7.3   A new ontology for neurological rehabilitation practice

As fully explored in my findings, people did hold assumptions about role, knowledge, power and empathy. Failure to recognise assumptions can have a profound effect, readily, invisibly and insidiously leading to alienation of service users, ineffective practice and wasted time and effort. Whilst

assumptions held by service-users and staff in relation to neurological rehabilitation are important, what emerged as having even more importance is the need for service users and staff to work together through a process of co-enquiry to develop an awareness of their assumptions and their influence on relationships and neurological rehabilitation practice, including inclusion.

My deep engagement with this topic has led me to realise that it is not possible to address assumptions (and their influence on inclusion in neurological rehabilitation) within the existing principles of neurological rehabilitation that take an individualistic approach - for example client-centred practice and practitioner-led education programmes. I propose instead that a critical relational ontology is required to allow the facilitation of greater awareness of oneself in relation to others, the generation of a shared understanding of practice issues and the delving beneath surface rhetoric to establish what is important to whom and why. This new ontology is likely to provoke considerable debate within neurological rehabilitation, questioning existing taken-for-granted assumptions about how neurological rehabilitation is practised. This study builds on the provocations of Hammell (2006), who used the literature to contest the assumptions underpinning rehabilitation, and takes her argument an important step further by suggesting the ontological re-framing of neurological rehabilitation practice itself.

7.4   Implications for practice, education and research

The outcomes of this study demands that those engaged in neurological rehabilitation pay attention to and engage in a critical exploration of assumptions, because assumptions are at the heart of service user staff relationships and neurological rehabilitation more broadly. The critical relational ontology proposed in this study provides the theoretical foundation from which assumptions can be addressed, posing challenges to existing constructions of practice. The implementation of this new ontology has the potential to positively disrupt the status quo in neurological rehabilitation and has the scope to make neurological rehabilitation practice more effective for service users and more inclusive and rewarding for everyone involved. The

233

critical relational ontology needs to be examined using a health economy approach, to provide evidence to service managers and policy makers of its value and centrality to neurological rehabilitation practice.

Pre-registration and post registration practitioner education is currently founded on bio-psycho-social and or client centred models of neurological rehabilitation practice. The critical relational ontology proposed in this study introduces a new ontology for neurological rehabilitation that will generate essential critical discussion and debate within undergraduate and postgraduate curricula. It not only offers a new lens through which to view practice, but also requires students to critically investigate their own assumptions and question how these might impact upon practice. Its importance lies in generating change in the way that neurological rehabilitation is understood, considered and practised. For neurological rehabilitation to develop in its effectiveness, this new ontological approach needs to be embedded in both education and practice.

There is considerable scope for a participatory research approach to be used more widely in neurological rehabilitation. It has been shown in this study, to be of great value in generating a deeper understanding of the issues that are at the heart of the research question, challenging pre-conceived perceptions of practice and creating opportunities for deep personal learning. Bringing service users and staff together in research may not currently be common practice. However, this study clearly indicates that bringing service users and staff together in critical dialogue, not only generates personal change through the participatory process, but importantly generates insights that have the potential to change the practice, delivery and outcomes of neurological rehabilitation.

7.5   Personal learning – some final thoughts

My attempts to describe my personal learning through the process of this PhD cannot do justice to the depth of thinking and grappling with the confused, messy and uncertain spaces that undertaking this study has

created. My assumptions that there is a right answer (whatever that is) that needs to be presented and a right methodological process that needs to be followed have been challenged throughout my engagement with this PhD process. I have battled with concerns over my interpretation of the data and been disturbed by delivering a participatory approach that does not fully reflect its core principles. However, I have recognised that it is in actively questioning these uncertain and uncomfortable spaces that new understanding eventually emerges.

This new understanding has been supported by way-markers which have emerged through the fog of the PhD process and, once recognised, have provided welcome signposting for the rest of the journey. Some of my learning and way-markers have been articulated during the course of this thesis, and of particular note are the way-markers of dilemma highlighted in the data analysis section of Chapter Three. Verbalising thought with critical friends is the additional important process that has supported me through the writing of this thesis. The following reflection on my experience of writing this thesis is personal, but I hope it has some resonance with PhD students and application to the academy in general.

It took time to recognise that my preferred and most effective approach to writing was to verbalise with others in order to clarify my thought, prior to starting the writing process. This is counter to the usual assumption about the production of academic writing, which requires the student to write first and the supervisor to comment. As a practitioner, I was used to writing reports, but seldom had my work scrutinised, it was functional and did the job it was required to do. Developing an academic writing style was challenging, and despite writing copious reflections for myself, I struggled to for some time to form them into structured work to be reviewed. I identified strongly with Evans (2013) who views writing as relational, suggesting that we are surrounded by the "ghosts" (p.40) of shame and failure from our past which can silence and constrain writing. Whilst at the outset I was only aware of some of my "ghosts", I had no first-hand experience of their impact on writing. It was my engagement with the creative writing process that enabled

me to understand something of their pervading influence. The cinquain below was written relatively early in my PhD journey and expressed where I wanted to be in terms of my writing and progress with my PhD. It highlights my shackled state at that moment in time:

Unfettered, expressive patterns, vocal colour,
Dormant potential awakened, creating energy, possibility and hope.
Unveiled tacit landscapes - sharp relief
(Reflective diary: 17.7.2011)

Talking with critical friends about assumptions and methodological conundrums and digitally recording those conversations enabled me to sift the wheat from the chaff of my own thought processes. This regular analysis of my own thought processes enabled me to get to the essence of what I wanted to say, giving me greater confidence to articulate my argument and ultimately to write. It is a process that is still helpful, particularly when "the mist comes down" and I feel I am losing my way. It raises general issues for PhD students firstly about ensuring that personal ways of learning and writing are explored and supported through the PhD process. I tried many avenues before coming up with this process. Secondly, it raises questions about how students manage their own assumptions about what it means to be a "successful" PhD student and how those assumptions are held open for scrutiny with their supervisor. It could be argued that this is an opportunity for an "ideal speech" situation (Habermas, 1984, 2008). However, from a personal perspective emotions can be very strong, over-riding the need or desire for rationality. Despite a good relationship with supervisors, there was just too much at stake in the early days of the PhD process to risk having that honest conversation espoused by Habermas (1984, 2008). It is difficult to know what would have helped, as sometimes, personal ghosts are not readily exorcised. However, I have found it important over time to move from a struggling with writing narrative to construct one that is more positive. This is partly about knowing, understanding and believing the argument I am conveying, but also about finding the techniques and support that can act as those practical way-markers along the way. This remains a positive work in

progress as I step into the new challenges of taking this study into the public sphere. My thoughts are reflected in the haiku below:

Tangerine Voice
Tangy vibrancy wakes
Unquestioned time honoured thought.
Courage, faith, now sing...
(Reflective diary 30.05.2017)

My PhD journey has required me to be aware of and scrutinise my own assumptions and, therefore, I recognise how challenging and yet transformational a process this can be. Based on this experience, I firmly believe that the findings of this research hold the potential to change the way that neurological rehabilitation is both practiced and, therefore, experienced. Whilst sharing these findings will go against the grain of much current accepted practice wisdom, these findings and the methodology that supports them are important. However, until assumptions are challenged, the status quo will remain.

7.6   Concluding thoughts

Participatory research is recognised for its messiness (Cook, 2009) in which the outcome of the study is not known at the outset (ICPHR, 2013). In this study, this messiness was compounded by the complexity of investigating assumptions, which by their very nature are difficult to identify, prone to misinterpretation and, when disturbed, can lead to misunderstanding and defensiveness. On the surface, this suggests the potential for research disaster. However, what has emerged from this study is far more profound than I could ever have imagined at the start, in relation to both my own learning and the findings. What has emerged from this study moves beyond the mere identification of assumptions in neurological rehabilitation and their influence on experiences of inclusion, to instead provoke deep questions about the underpinning ontology of neurological rehabilitation.

I hope that at the end of this PhD process I have created a platform for further critical discussion about assumptions in neurological rehabilitation. In creating a space for the re-framing of practice with enquiry into assumptions at the core, I hope that those assumptions, which go undetected and yet alienate and marginalise service users, can be surfaced, explored and worked with, in order that practice might be both inclusive and effective.

Appendices

Appendix 1: Executive Summary "Towards Inclusive Living"

Northumberland, Tyne and Wear NHS Trust

northumbria UNIVERSITY

Inclusion?

Towards Inclusive Living: A Case Study of the Impact of Inclusive Practice in Neuro-Rehabilitation/Neuro- Psychiatry Services
Department of Health Policy Research Programme
LTNC
Reference Number 530010

Dr Tina Cook and Ms Helen Atkin
Northumbria University

Ms Lindsay Carter (deceased), Mr Paul Mitchell and Mr Phil Moore
Service Users

Mrs Eunice Bell
Carer/Family Member
Walkergate Park Regional Neuro-Rehabilitation/Neuro-Psychiatry Services

Mr Mick Bond, Ms Christine Hutchinson and Mr Alistair White
Voluntary Service Representatives

Dr Margaret Piggott and Dr Barbara Wilson
DeNDRoN

with support from

Dr Jane Wilcockson, Dr Deborah Goodall an Mrs Eileen Birks
Northumbria University

North East DeNDRoN
Dementias & Neurodegenerative Diseases Research Network

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.

- Whilst inclusion is individual there are some important common principles for inclusive practice that can be developed.

240

- Barriers to inclusive practice exist in both personal and organisational perceptions of effective practice, including the perception of the importance of communicative spaces. 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.

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

241

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.

Figure 1 Consensus and Development
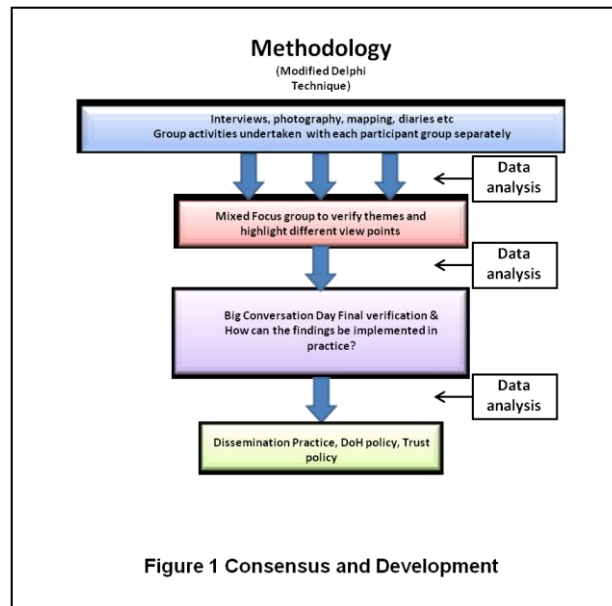
5. What was learnt from the study

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

243

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 characteristic:

- **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. 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

a) 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.

b) 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.

c) 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.

d) Inclusive approaches 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.

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

f) 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

a) 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.

b) Communication practices and processes

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

ii) The type of communication has an impact on inclusion. Consultation is not necessarily sufficient. 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.

iii) 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 more effective communication.

c) Understanding of and respect for 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.

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
1st level - researcher analysis – taken back to participants in focus groups
2nd level - researcher/participant analysis taken to heterogeneous focus groups
3rd level – researcher analysis using Nvivo as data storage and sorting/sifting mechanism
4th 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 priorities measurable actions. There is a need for a re-conceptualisation of practice and the monitoring or 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.

Appendix 2: NHS Research Ethics Service permission

NHS

National Patient Safety Agency

National Research Ethics Service

County Durham & Tees Valley 2 Research Ethics Committee
The Tatchell Centre
University Hospital of North Tees
Piperknowle Road
Stockton-on-Tees
TS19 8PE

Telephone: 01642 624164
Facsimile: 01642 624164

20 April 2009

Dr Tina Cook
Reader in Inclusive Research Methodologies: School of Community, Health and Education
Studies Research Centre
Northumbria University
CHES Coach Lane Campus East
Northumbria University
Newcastle upon Tyne
NE7 7XA

Dear Dr Cook

Full title of study: **Towards Inclusive Living: A Case Study of the impact of Inclusive Practice in Neuro-Rehabilitation/Neuro-Psychiatry Services**

REC reference number: 09/H0908/20

Thank you for your letter of 02 April 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

[Other conditions specified by the REC

The Committee requests receipt of the DVD as soon as this has been produced.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		20 February 2009
Protocol	1	15 January 2009
Investigator CV		
Application	IRAS 2.0	08 February 2009
Compensation Arrangements		09 February 2009
Peer Review		22 December 2008
Letter from Sponsor		08 January 2009
Advertisement	1	
Confirmation of indemnity arrangements in relation to harm arising from the conduct of the study.		30 March 2009
Guidance notes for researchers		
Response to Request for Further Information		02 April 2009
Letter of invitation to participant	Service users V2	26 March 2009
Letter of invitation to participant	Staff - V2	26 March 2009
Letter of invitation to participant	Voluntary Section - V2	26 March 2009
Participant Information Sheet: Service User & Carer	2	26 March 2009
Participant Information Sheet: Walkergate Park Staff	2	26 March 2009
Participant Information Sheet: Voluntary Sector	2	26 February 2009
Participant Consent Form: Service Users	2	26 March 2009
Participant Consent Form: Carers	2	26 March 2009
Participant Consent Form: Walkergate Park staff and voluntary sector	2	26 March 2009
Information about methods for service users and carers: interviews	2	26 March 2009
Information about methods for service users and carers: focus groups	2	26 March 2009
Information about methods for service users and carers: diaries	2	26 March 2009
Information about methods for service users and carers: blogs	2	26 March 2009
Information for service users and carers: photography project	2	26 March 2009
Information about methods for service users and carers: mapping	2	26 March 2009
Information about method service users and carers: Big Conversation Day	2	26 March 2009
Questionnaire: Service users	2	26 March 2009
information about methods for staff: interviews	2	26 March 2009
Information about methods for staff: focus groups	2	26 March 2009
Information about methods for staff: focus groups	2	26 March 2009
Information about methods for representatives from voluntary sector partners: interviews	2	26 March 2009
Information about methods for staff and voluntary sector partners:	2	26 March 2009

diaries		
Information about methods for staff and voluntary sector partners: blogs	2	26 March 2009
Information methods for staff and voluntary sector parnters: photography project	2	26 March 2009
Information about methods for staff and voluntary sector partners: mapping	2	26 March 2009
Information about methods for staff and voluntary sector partners: big conversation day	2	26 March 2009
Questionnaire: Client-Centred rehabilitation questionnaire	2	26 March 2009
Outline of questions & prompts for interviews and focus group: service users and carers	2	26 March 2009
Outine of questions& prompts for interviews and focus groups: trust staff and representatives from voluntary sector partners	2	26 March 2009
Demographics	2	26 March 2009
Reflection questions	2	26 March 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0908/20	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Leigh Pollard

pp **Rachel Duncan**
Chair

Email: leigh.pollard@nhs.net

Appendix 3.1: Information letter to service users

Information letter to service users

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

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.

<p style="color:red;text-align:center;font-weight:bold">INSERT PICTURES OF RESEARCHERS HERE</p>

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:
_____

_____

_____

_____254_____

_____

☎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

[   ]

Appendix 3.2: Information sheet for service users

Information sheet service user

University headed paper

Trust logo

Date

Information Sheet: Service User

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 they 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 might 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	☐

Appendix 3.3: Service user consent form

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 signatu

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_____

Appendix 3.4: Staff consent form

Consent form staff

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 3.5: Information about research methods for service users

Information about Research Methods for Service Users

University headed paper

Trust logo

Date

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

<center>**Focus groups**</center>

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 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 effects 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.

University headed paper

Trust logo

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 3.6: Assumptions workshop information sheet

Absolutely Inclusion: What about next steps?

Helen Atkin & Alistair White

Here are some of the **assumptions** about inclusion and inclusive practice that are held by participants who have taken part in the project.

What are assumptions?

These are things we **take for granted** about other people or our circumstances. They can also be things **we believe will happen** because of someone else's or our own actions. We generally don't question or think about the assumptions we make, we just accept them. If we just accept them then nothing changes.

What will happen in this workshop?

We will have the opportunity to discuss some of these assumptions, as **you may or may not agree with them**. Based on some of the assumptions, we will then think about **what needs to happen** to develop a more inclusive culture. We will talk about

and plan what people can do together to make a positive difference to peoples experiences in the future.

Appendix 4: Assumption statements for Assumption Workshop

Overarching assumptions statements and related assumptions for Assumptions Workshop

1. **Do you really understand who I am and do I really understand who you are?**

    a. If you see me as a person rather than an impairment, number or part of the system, then this will make a difference to how I feel about my life, treatment or staff role

2. **Do we understand what is important to each other?**
    a. If we value each other's voice and experience (even if one of us isn't able to speak for ourselves) and we seek to listen and understand each other, then this will make a difference to how we communicate with each other.
    b. Everybody should be given a choice about the things that are important to them

3. **Do we understand how powerful both our attitude and the environment can be in making each other feel included or excluded?**
    a. Staff and the targets and procedures of the Trust have the power; service users and relatives have no power
    b. If you label me and make assumptions about me then this has the power to determine my future. How you label me will either create new opportunities or will restrict my progress.

4. **Do we understand the importance of creating an environment where challenge and change can take place?**
    a. Everybody has a responsibility to say what is and isn't working for them either in treatment or in the wider service.
    b. If I make a complaint then I believe that this will impact on my treatment, so I don't complain
    c. People and systems are not perfect, so we need to work hard to make our voices heard

Appendix 5: Theory of Change mapping: example shown to participants

Theory of Change (Weiss, 1995) mapping example

Assumption
If I make a complaint then I believe this will impact on my treatment, so I don't complain

What do we want to aim for?
An openness to learn from each other & share knowledge & experience with each other

How will we know when we have got there?
- Asking – how is this for you?
- People sitting down & talking more

Barriers to creating change → What can we do together to break down barriers? → What part can I play?

What needs to happen to help create change? → What can we do together to help create change? → What part can I play?

Appendix 6: Reflective questionnaire

Northumberland, Tyne and Wear **NHS**

NHS Trust

northumbria
U N I V E R S I T Y
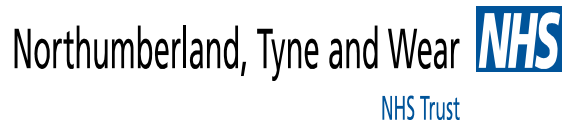
Inclusion?

Towards Inclusive Living Research
Reflection Questions

Please tick a box below and then take some time to complete the questions – thank you

I am:

A patient/ service user	
Member of staff	
Voluntary sector partner (data not used in this study)	
Carer/ family member/ supporter (data not used in this study	

1. Why do you care about inclusion?

2. What have you heard or talked about today or during the project that has:

a. Surprised you?

b. Interested you?

c. Made you think in a different way about something?

d. Puzzled you or is something that you don't understand?

3. Did you have an 'aha' moment? (That is a moment when you understood something for the first time).

If so what was this?

4. Is there something you are going to do differently as a result of participating in the project?
If so what is it?

5. What would you like Walkergate Park to do differently as a result of the project?

6. What do you think the Government needs to do to make people feel more included?

7. Is there anyone else or other groups of people who need to do anything different?

8. Anything else you would like to tell us?

Appendix 7: Example of mind mapping: developing conceptualisations of my findings themes and sub-themes

Findings: How assumptions inform inclusion and inclusive practice

Perception of social place

Concept of role
- Purpose of role
  - Reason for being
  - Reason for action
- Types of role
  - Service user/ staff Traditional
  - Non traditional/ ambiguity/ not fitting
  - Into defined role
- Categorisation
  - As an object
  - As deviant
  - Problems of categorisation

Concept of power
- Level playing field
  - Equal parts to play
  - Never be equal
  - Fairly equal
- Ways of working
  - Feeling empowered
  - Paternalistic power
  - Pulling together power
  - Done to power

Concept of inclusion
- Automatic
- Worked at
  - Include yourself
  - Including others

Concept of knowledge
- Different kinds of knowledge
  - Procedural and Technical
  - Experiential
  - Combined knowledge
  - Accessible knowledge

Concept of empathy
- Putting yourself in other peoples shoes
  - Gain understanding
  - Sharing feelings
  - Helping others
  - Knowing what's best
- Other people putting themselves in your shoes
  - Possible or impossible?

Appendix 8: Data analysis early "thinking framework"

Data Analysis early "thinking framework"

Mezirow (1990) in his work on transformational learning highlighted that we interpret the world around us through the meaning schemes and meaning perspectives.

Meaning schemes are our habitual expectations and rules for interpreting the world around us that are built on cause and effect and the conditional notion of 'if ...then'.

Meaning perspectives are 'structures of assumptions that constitutes as frame of reference for interpreting the meaning of an experience'. (Mezirow 1990)

Meaning Schemes

- Causal relationships: if...then
- Expectations about the ways things should happen & event sequences
- Expectations about appropriate behaviour

Meaning perspectives
- Schemata (a conception of what is common to all members of a class; a general or essential type or form)
- Theories (a supposition or a system of ideas intended to explain something, especially one based on general principles independent of the thing to be explained)
- Propositions (a statement or assertion that expresses a judgement or opinion)
- Beliefs (something one accepts as true or real; a firmly held opinion)
- Prototypes (a first or preliminary version of a device or vehicle from which other forms are developed)
- Goal orientation (the object of a person's ambition or effort; an aim or desired result e.g. expectation)
- Evaluation (the making of a judgement about the amount, number, or value of something)
- Ideal types
  - Role relationships

- Critique of social norms – power and influence
- Rules of thumb that inform action and present as conventional or practice wisdom
- Use of metaphor (a figure of speech in which a word or phrase is applied to an object or action to which it is not literally applicable)

(Mezirow, 1990)

Brookfield (1995) uses the term paradigmatic assumptions to capture the underlying beliefs and theories a person holds. He also suggests that there are conditional assumptions 'if this happens then this will be the consequence and assumptions based on what we believe should be happening.

Appendix 9: Early analysis using symbolic interactionism root images as a guiding framework

Situation presented in the data by SU32:

Critical incident (excerpt)

> *"One fabulous Christmas Eve when I thought I'll go to church on Christmas Eve and I was sat out in [my wheelchair] in the street for half an hour while whoever was supposed to have unlocked the door found the keys to let me in. So I wasn't happy. So I had a bit rant and a bit rave and a bit this is not right and if this was you on a Christmas Eve in [name of area] would you want to be sitting in the street. So I think I got the message across that it wasn't the most pleasant of experiences and they ….. they looked again at the access, they did give me a key which was fabulous to have a key to the door but the doors are very narrow, both doors have to be opened to get ….. so I can get in and what always, always happened was that the key to the door was fine but the other door had a padlock on the bottom and a padlock on the top and the top of the door was like ten foot high. So I could ….. I could open one door but I couldn't get in the other, so another rant and rave and a little bit more money thrown at it and they discovered that you could actually get a locking system on it which worked with an intercom ….. well not an intercom but a touchpad that they did eventually give me the numbers for, that I have remembered, so there's now a locking mechanism on it that I can release with a touchpad. All I now have to make sure is that whoever is on duty is reminded not to put the bottom lock in or to put the padlock in the door. There has been a couple of hiccups but the last 3 times that I have been I've been able to get in without ….. because the other problem is they've put an intercom on which is fabulous, ish, but when you press the intercom it goes off in the main foyer, the main foyer is usually very, very busy just before the service so nobody can hear it, when they do hear it nobody knows what it is..." SU32-F-P*

Meaning of the situation and nature of group life

Importance of church and being with likeminded people, assumption that it is important to be in interaction with others. Symbolism of the church with its traditional values in supporting and caring for one another, irony of the sheep and the shepherd metaphor and the one sheep that was outside of the fold (researcher interpretation)

Nature of objects

Structural barriers - wheelchair access to inside of church, security

the problem was that the door to the through floor lift, for security reasons, could never be unlocked. Doors as barriers rather than welcoming into a church which would traditionally welcome people.

Having to go in the back entrance – assumption- second class citizen?

Snakes and ladders - one thing is sorted and something else arises - seeing the whole and anticipating the whole -the concept of: just when you thought everything was sorted**...** links with time taken above invoking a vision of inching forward to overcome hurdles. Assumption that inclusion is a one off event.

Symbolism of the locked door – exclusion from what is important and meaningful. Having the key, opening the door but not getting in – paradox in meaning – rhetoric and the reality. Assumptions of inclusion through being given a key but the reality is very different.

Inclusion is not quite as straight forward as it seems - Complexity of creating an inclusive environment where there is multiple use and an inclusive space is not a part of the culture - (old building).

Symbolism of a welcoming church and Christian message of inclusion, however in reality, experiences of exclusion, being segregated and set apart from the flock.

Nature of social interaction

Interactions with people

Drawing attention to cause: 'Getting the message across': assumption that inclusion requires being proactive with other people

- Story telling
- Identifying what is wrong - relating it to the ethics of right and wrong
- Highlighting issues of risk re: geographical area, as a way of communicating emotion of exclusion
- Highlighting own emotions in order to make that connection with the church leadership
- Awareness raising –challenging people out of their taken for granted assumptions

Developing understanding

- Grasping the meaning of feeling different and having a different entrance
  "*it took four and a half years from the refurbishments being done at the*

church for them to really, really grasp that it was lovely having a through floor lift and ….. and it was great that I could get into the church without having to go in the back entrance"

- Asking people to put themselves in your shoes - highlighting that the difference between lived experience of getting to church and what non wheelchair users might take for granted: "*this is not right and if this was you on a Christmas Eve [name of area] would you want to be sitting in the street"*

How was SU32 perceived by others? (Some personal researcher thoughts)

- Invisible (not seen waiting outside)
- Not heard (doorbell not heard)
- Important enough to be taken seriously - credibility
- Heard
- A nuisance?? or difficult??
- Victim of an unsafe situation and failure on the part of the church
- Prisoner - *'they lock me in'* - impact of churches preoccupation with security and lack of awareness of impact of procedure on others.
- Catalyst for change?
- The source of seeing things differently?

Self and agency

Self:

- Importance and meaning of being able to 'get in' on own terms
- Desire to create change to enable personal autonomy and freedom
- Personal tenacity and patience to see change through - not giving up
- Being afforded the same freedoms and autonomy as everyone else
- Strength of feeling about situation- "*I wasn't happy"*
- Personal safety
- Not being separated ? and segregated from the rest of the congregation

Making inclusion happen – Importance of responsiveness

- Taking action – "*they looked again"*
- Continuing the dialogue - iterative process
- Exploring structural ideas for change *"they discovered that you could actually get a locking system on it which worked with an intercom ….. well not an intercom but a touchpad that they did eventually give me the numbers for, that I have remembered, so there's now a locking mechanism on it that I can release with a touchpad".*

294

- Having the money
- Shared responsibility "*All I now have to make sure is that whoever is on duty is reminded not to put the bottom lock in or to put the padlock in the door*".

- Problems of routine procedures/ assumptions and not stopping to think beyond the immediate: *"what's starting to happen is the table tennis table is getting put in ….. as always happens when there's space like an accessible loo it's ….. you usually get the Hoover and all sorts of stuff stored there because it's a space and there's storage boxes".*

- Assuaging fears about safety - recognising the importance of the anxiety of others "*because they felt that they had to keep the lift locked as well,..I mean they're all concerned about security and stuff but I have encouraged them that it's ok, I'm not going to damage it*".

What is not said (my interpretation)

- Importance of the credibility of voice leading to being listened to and a response
- Shared meanings of the importance of church

Summary thoughts

Personal beliefs about objects, procedures and structures: they can be changed, the status quo doesn't have to remain, they influence an inclusive experience, and their meaning to others is not fully understood

Personal beliefs about place in society: - right to be treated as an equal, autonomy, choice, freedom to act, having a voice, reality of this is that disabled people are excluded and not given a thought

Personal beliefs about self and agency- confidence in own person, skills, capacity and capability to create a different future, trust in the validity of own experiences.

Personal beliefs about others: fallibility, trustworthiness, have only partial knowledge of a situation, recognition of the other (humanness)

Personal beliefs about the unspoken rules of interaction: respect listening, understanding will be sought, voice will be seen as credible, together something different can be created/ done, you may misinterpret

what I am saying, Exchange of places - both visualising and emotions, common concern

Personal beliefs about the nature of engagement: getting noticed through storytelling, making connections for the listener e.g. safety issues (enabling understanding), challenge the status quo, redefining the issue through a different lens, raising awareness, iterative and recursive (keep going) responsibility for action (both parties), highlighting ethical dilemmas/ issues e.g. personal risk versus caring for the flock.

(Personal reflective diary 13.08.2010)

Appendix 10: Early analysis using Brookfield (1995) types of assumptions

"if you can raise peoples awareness to ..... I mean first and foremost that you're there and that you might want to be part of what's going on or what they're doing, you know lets all go and play together type of thing but that you're there and that you still exist really because sometimes there are so many aspects of what happens through disability that ..... that sort of 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 ..... 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 and then if there is a need to do something about it, either with their hands on physical help if that's necessary or a means by which it can happen and sometimes that's through bits of equipment and sometimes it's just through dogged determination that you're going to do it really and work a way around how you're going to do it. Erm so I think I've ..... I see ..... I see enabling probably with the use of other bits and pieces, erm but inclusion I think starting in how people view you I think." SU32-F-P

Belief/ personal philosophy	Causal assumption/ if...then or conditions under which a process can be changed	Prescriptive assumption what should be happening	Quote
You have only a partial picture of the situation	If I raise your awareness about the situation from my perspective this will make a difference as to whether I can join you in what you are doing	Being a part of a group or conversation where perspective is considered	*"if you can raise peoples awareness to ..... I mean first and foremost that you're there and that you might want to be part of what's going on or what they're doing"*
I am here and exist	If I let you know that I am here you will need to recognise and respond to me and potentially invite me to join you	Having a perspective that can contribute to group life	*"I mean first and foremost that you're there and that you might want to be part of what's going on or what they're doing"*
Seeing the	If I can get you to	Respect for	*"there are so many aspects*

person - (attitudes of others)	see me rather than my impairment it will help	the person	*of what happens through disability that ….. that sort of 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 ….. if you can get peoples attitude to think well I'm still me in the middle of all of this"*
Working together		Everyone working collaboratively	*"you know lets all go and play together type of thing"*
Choice is still a privilege	If I can't convince people to see 'me' then I won't have a choice	Right to choice	*"I would still like to be given the choice to be involved and included then ….. then that helps"*
More than accessible environments and physical help	If I have the right equipment it enables but it is only a part of 'the whole'		*"there is a need to do something about it, either with their hands on physical help if that's necessary or a means by which it can happen and sometimes that's through bits of equipment.... I see enabling probably with the use of other bits and pieces, erm but inclusion I think starting in how people view you I think."*
Belief in self and personal strengths Philosophy - if at first you dont succeed Being included isn't straight forward or easy	If I am to be included it can require personal responsibility, problem solving and dogged determination		*"and sometimes it's just through dogged determination that you're going to do it really and work a way around how you're going to do it"*
I have a	If I take		*"f you can raise people's*

298

responsibili ty to act in order to be included	responsibility and act and raise your awareness then this will make a difference as to whether I am included in what is going on		*awareness..... I mean first and foremost that you're there and that you might want to be part of what's going on or what they're doing"*

1. Assumption: You have only a partial picture of the situation
2. Assumption: If I raise your awareness about the situation from my perspective this will make a difference to whether I can join you in what you are doing
3. Assumption : I am here and real so I require recognition by you and a response from you
4. Assumption : you will probably not invite me to come and play so I will need to invite myself
5. Assumption: Playing together is better than not playing at all
6. Assumption : You see my impairment rather than see me as a person
7. Assumption: If I can get you to see me as a person rather than my impairment it will make a difference to my involvement
8. Assumption : I wont automatically be given a choice to be involved - I need to ask
9. Assumption: If I am going to be included doing something and making progress will require resilience and determination
10. Assumption : equipment enables my inclusion but it is only a part of the whole.

Appendix 11: Assumptions identified from the data

Assumptions identified from the data 1.10.10

These are the range of assumptions that were highlighted in the data; these are taken from my diary and are occasionally annotated with questions and thoughts.   Ruth highlighted in blue the assumptions that had resonance with her in relation to inclusion.   The text in black italics highlights some of the discussion Ruth and I had as we worked with the data. We looked for commonality and differences between the assumptions. .At the end of this process, we had synthesised the 100 assumptions into 30 key assumptions about inclusion. These then formed the basis for our further discussion for the subsequent development of the assumptions statements for discussion at the Big Conversation Day. Together,

Assumptions about inclusion:

It makes a difference where you start from i.e. a place of inclusion or a place of exclusion *(Does this make a difference to how people are treated?) Do people* **expect** *to be included or excluded?*

- *It is about sharing common ground – both values and activity (reciprocity)*

Its about belonging somewhere

Its based on trust *(So if it's based on trust – why is this important – so what are the implications if the trust breaks down for impact on treatment*)

Its about righting the wrong of an exclusive experience

- *The organisation or the group of people where you want to be included are more powerful than the person wanting to be included. So what does it mean for service users and carers that the staff are a powerful group and the systems of the NHS are powerful*

It is an ongoing process that needs to be constantly negotiated. *What are the implications for this on treatment?*

It assumes freedom to make choices and be autonomous both to be a part of and to leave

- *Inclusion takes courage and goes against the norms of society*

What assumptions do you have about the behaviour of others in the NHS

People will hear your voice and respond to you (*What happens if you are not able to speak or communicate?*)

- *People are fallible therefore I need to keep going to make my voice heard*

What is important to me should be important to you

I am not able to step outside the boundaries of my role as a health care worker to listen to you

In order for me to feel included people should notice and respond to me as a person

Staff: what I need to do comes first, then I will respond to you

Nature of engagement:

Takes courage

Takes time

- *To move from exclusion to inclusion I need to challenge the status quo*
- *You need to keep working at being included in something until the problem is solved*

By telling stories about my experience it makes a difference to experiences of inclusion.

What assumptions do you have about the impact of inclusion on treatment?

- *It makes a difference to how I feel about myself*

It makes a difference to the timing of treatment

It makes a difference as to whether i feel I need to complain

Current rules in practice

Professional roles may mean I may not be able to listen to what is important to you

- *Decision making is based on professional expertise*
- *Ticking boxes is important*

Fitting in with our mental health Trust initiatives is something we have to do (*So what if the Trust initiative isn't helpful?*)

Professionals control the rehabilitation journey

- *Professionals see the impairment rather than the person, this makes a difference to how involved I feel in my treatment*

Work together will make a difference to my treatment

- *I won't automatically be given a choice to be involved in my treatment, I have to ask*

SU If i take responsibility and raise your awareness that I want to be included then this makes a difference as to whether I am included in what is going on.

Being in it together – should be what the NHS should be aiming for

- *My voices and action are important to my treatment ' if my voice and actions are a part of my treatment then it will make a difference*

Drs have the power, I have no power to influence *(one persons view – who else feels like this and who doesn't and why not?)*

My lived reality is of no relevance to Doctors

Doing things together is a different way of operating for the NHS

- *If service users were seen as 'experts', staff would have a lot to learn*

A level playing field is the basis for inclusion

We are there to care for the patient

NHS isn't open to learn from patients asking difficult questions

Being difficult is wrong and leads to exclusion

From a place of exclusion, other people hold the key and power to inclusion

Segregation from something you want to be included in has a negative impact

My authentic story needs to be told

Problems can only be identified by involving the people who it concerns

Problem solving to promote inclusion can only be done inclusively

If I keep on telling people what isn't working for me it will eventually change

I can influence the thinking and actions of others

Everything is determined by health and safety

For disabled people choice in treatment is the gift of the other person – choice is a luxury

Other peoples assumptions about you are barriers to what's possible

For disabled people inclusion is conditional on what other people think is right for us

- *Disabled people don't have a right to freedom and choice – they are restricted by environments and people's attitudes*
- *People will label me and make assumptions about what is best for me*
- *Wheelchair users can be on equal terms with others*

People in power decided what should happen and who is included and by default excluded

Having the attitude of doing our best and giving choice is good enough to ensure that people are included

Disabled people are accepting of difficulties with access and being excluded

It is enough to imagine ourselves in someone else's shoes and then act ourselves.

Other people think they have included you by their standards, so that is sufficient – it is the end of the process.

I assume that I will be noticed, there will be opportunity for me to express my thoughts, I will be listened to and there will be opportunity for me to express my opinion and exchange views and I will be given feedback

- *I assume that I will be treated as a human being and not as a number*

I assume that I will have a voice so that together my best interests are at the heart of things

My opinions are not important and are not respected

- *I am expected just to fit in to the system*
- *Health care is not flexible to work together with me*

We will organise this to suit the staff and organisations needs and the service user and carer will fit in.

I know what you are thinking based on your first response

- *Involvement in the NHS is tokenistic, therefore I have to work hard to ensure it happens*

Inclusion doesn't require conscious thought until you are excluded

Inclusion is the norm

- *Exclusion is the norm* (HA question: Is this always the case? It often seems to feel that way for disabled people)
- *It is easier to be included if you have a role to play*

Including people can be easy or hard depending on the personality of the person you are seeking to include (The *outcome of this could be a lack of parity across service provision and exclusion of those who are perceived as difficult*)

Inclusion or exclusion is a selective process based on the contribution the person including you believes you can make.

If I am excluded then I get upset and become reluctant to speak (whose *responsibility is it to include people?*)

- *Patients will just fit in with the system and what is important to staff*

You will just need to wait until I am ready because I am important and in control here.

- *If you complain you get bad treatment*

If I have the label of patient then I will play that role

Goal negotiation requires effort because as professionals we like to be in control

If you are in control and communicate this to the patient then this helps people believe in you.

- *We are responsible for motivating patients to take part in treatment*

If something is financially driven then my views don't count.

If we try and understand people then they may opt into treatment

If I don't expect to be included or involved then there is no personal cost when you are not.

Inclusion is not competitive – its not about keeping a tally. (H*ow could this work in the NHS of today?*)

- *If systems and procedure dominate then the humanness of the health service is lost.*
- *Inclusion requires someone to take responsibility for it happening*

Therapists should take responsibility to facilitate patients inclusion (*comment: this could lead to variation*)

If you get your attitude wrong – then treatment gains are lost

- *Active listening and 'making time' for people is not something that is the primary concern of health professionals*
- *Health care professional time is precious – is it more precious than service user and carer time?*

Health care professionals have a specific role to fulfil in terms of patient care and stepping outside these boundaries is costly

- *NHS is driven by target and performance indicators, and role responsibilities*

Time with carers cannot be easily quantified and counted, so it needs active rationalisation in order for it to feel ok.

If we focus on the negative this leads to defensiveness, if we focus on inclusion then we are focussing on what we can do.

- *If inclusion is to be of value then there has to be a sharing of opinions*

Summary of assumptions identified through discussion with SU32 on the 7.10.10

1. It is about sharing common ground – both values and activity (reciprocity)
2. The organisation or the group of people where you want to be included are more powerful than the person wanting to be included. So what does it mean for service users and carers that the staff are a powerful group and the systems of the NHS are powerful

3. People are fallible therefore I need to keep going to make my voice heard
4. To move from exclusion to inclusion I need to challenge the status quo
5. You need to keep working at being included in something until the problem is solved
6. Decision making is based on professional expertise
7. Ticking boxes is important
8. I won't automatically be given a choice to be involved in my treatment, I have to ask
9. My voices and action are important to my treatment ' if my voice and actions are a part of my treatment then it will make a difference
10. If service users were seen as 'experts' staff would have a lot to learn
11. Disabled people don't have a right to freedom and choice – they are restricted by environments and people's attitudes
12. People will label me and make assumptions about what is best for me
13. Wheelchair users can be on equal terms with others
14. I assume that I will be treated as a human being and not as a number
15. I am expected just to fit in to the system
16. Health care is not flexible to work together with me
17. Involvement in the NHS is tokenistic, therefore I have to work hard to ensure it happens
18. Exclusion is the norm
19. It is easier to be included if you have a role to play
20. Patients will just fit in with the system and what is important to staff
21. If you complain you get bad treatment
22. We are responsible for motivating patients to take part in treatment
23. If systems and procedure dominate then the humanness of the health service is lost.
24. Inclusion requires someone to take responsibility for it happening
25. If systems and procedure dominate then the humanness of the health service is lost.
26. Inclusion requires someone to take responsibility for it happening
27. Active listening and 'making time' for people is not something that is the primary concern of health professionals
28. Health care professional time is precious – is it more precious than service user and carer time?
29. NHS is driven by target and performance indicators and role responsibilities.
30. If inclusion is to be of value then there has to be a sharing of opinions

Appendix 12: Excerpt from memo in relation to S11

> *"I think, inclusion means that you fit into the circle as opposed to being outside of it. But that's intrinsic so, for example, if you've got a disability or a mental health problem, then that doesn't make any difference" S11-F-Map*

The assumption is that to be included you need to be a part of a circle - you need to be part of a single system that is linked. This single system is diverse and embraces difference and takes on board the role of 'the other' in seeking to connect with others. Taking on board 'the other' links with Blumer (1969) and SI (Symbolic Interactionism) e.g. role taking and sees people as social beings interacting with one another.

> *"So you shouldn't be looked at as different and not be included because you're a little bit different, if you like. So it should just be, sort of, an automatic pilot that you're included as opposed to excluded"*

The assumption is that inclusion of all should be the default position as opposed to exclusion.

The metaphor of automatic pilot - suggests that we go there without thought and there is a default position that naturally takes over. However what we know is that inclusion is actually hard work, it is not a default position and whilst we espouse inclusion and embracing difference, we also are critical of difference and use difference to make ourselves feel more comfortable. Our brains work through comparison in order to make sense of the world around us.

There is the bottom up processing of starting with the raw data and using a hypothetical- deductive approach - where we have a stimulus which leads to noticing of certain features, which then leads to the combination of those features and finally making sense of the whole in recognition of the pattern.

Alternatively, we have the top down pattern recognition, which is where we start from previous knowledge and experience and then infer the rest of the

information in order to make sense of the world in which we live. van Wijck and McBean, (2012) suggest that aspects of our cognition that can influence our perception of the world include knowledge, experience, expectancy, context and motivation. Over time, these combine to create schema or a template through which we process information.

Therefore. this notion of inclusion that should be automatic pilot suggests that we have a template for inclusion that not only included our thinking and activities of the mind, but also our actions.

What we find is that our processing around inclusion is more of a network based processing as we come across areas of discomfort that make us pause in the movement towards our goals and lead us to need to problem solve.

The human on human relationship is complex as we all bring our uniqueness and difference. Whilst we have an innate desire for cooperation, we also have a suspicion of things that we do not understand. I need to look back at Young (2000) book Inclusion and democracy.

The assumption is that inclusion welcomes the notion of difference within the circle.

> *"So it takes into consideration things that perhaps aren't; considered to be mainstream. And that the majority of the population consider to be normal"*

Assumption here that the default position of people in society is what is perceived to be normal. I think that this is about how we categorise information - we look for patterns that repeat themselves and then look for differences against those patterns. By doing that in the way that we think about the world - we automatically see difference as not our default position except if we have lots of experience of working with a wide variety of people - the default position then becomes difference. The natural cognitive process

is to look for commonality in order to make sense of the world. It is the way that we analyse information; we look for themes and commonalities and then by comparing we separate out what is different, naturally either being curious about it or dismissing it as perhaps a threat or irrelevant to the situation.

Excerpt from memo 10/02/2013 11:36

Appendix 13: Assumptions Workshop: changing assumptions in practice

Group 1: Facilitator from research management team

Assumption

If we value each other's voice & experience (even if one of us isn't able to speak for ourselves) & we seek to listen & Understand each other. Then we will make difference to How we communicate with each other.

What do we want to aim for to change things so that they are the best they can be?

All barriers/assumptions removed

How will we know when we have got there? What will people be saying to each other or doing what is different? What will be happening?

| Everyone will have a neuro Passport! | No complaints!?! About not being included | Sharing of knowledge Expert patients Expert staff Expert carers |

What will be some of the barriers to creating change?

| Tradition! Discrimination Attitudes | Engagement with other services |

What can we do together to help break down some of these barriers?
Culture of NHS trust supports service user/carer involvement ensuring
That this is taken forward!

What part can I play?

Willing to commit to effect change.

What needs to happen to help create change?

| Training/awareness Staff Carer Service user | Neurological passport Working blog/diary Opportunity for family/carer/service user to comment & health professional reply | Empowering Service users! |

What can we do together to help create change?
Culture of NHS trust supports service user/carer involvement ensuring
That this is taken forward!

What part can I play?

Be willing to engage
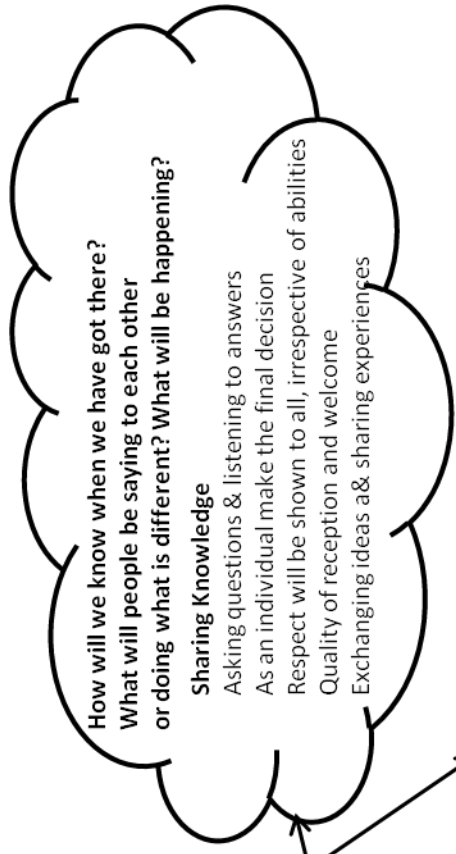
310

Group 2: Facilitator HA

Assumption

If you see me as a person rather than an impairment, no., or part of a system, then this will make a difference to how I feel about my life, treatment or staff role

What do we want to aim for to change things so that they are the best they can be?

To see the whole person, to achieve individuality and be treated with respect

How will we know when we have got there? What will people be saying to each other or doing what is different? What will be happening?

Sharing Knowledge

Asking questions & listening to answers
As an individual make the final decision
Respect will be shown to all, irrespective of abilities
Quality of reception and welcome
Exchanging ideas a& sharing experiences

What needs to happen to help create change?

Develop advocacy services – specific to neuro – LTC
Lay people volunteers train each other
Staff to recognise be trained recognising when & if people need help & on approaches for people with different abilities

What can we do together to help create change?

Communication – advocacy – volunteer to be part of the advocacy team.
As a service user treat the professional as a human being
Smile!

What will be some of the barriers to creating change?

People don't realise what they are doing
Developing advocacy – money – CRB checks – agreement from top

What can we do together to help break down some of these barriers?

Education
Confidence to challenge & speak up
Supporting/enabling staff not to feel threatened
Open enough to others experience
Respecting the professionals opinions and well as the p/t
Take more than one go – continuing staff

Teaching staff skills
Is just a part,
Not the whole

What part can I play?

What part can I play?

Smile say hello
Aim for common ground and trust

Appendix 14: Key to methods

Key to source of the data

Example: SU10-F-Map (Service user participant number 10 – Female – Mapping)

First set of letters: Participant

S – Staff

SU - Service user

Where participants were allocated a number, this will be displayed after the letter

Second set of letters: Gender

 F- Female

M - Male

Third set of letters: Method

BCD - Big Conversation Day

FG - Focus group

I - Interview

Map - Mapping

MFG - Mixed focus group

P - Photography

Q - Reflective questionnaire

Qa - Letter allocated to participant returning the Reflective questionnaire

Theme verification – theme verification interview during Phase 3 of study

References

Abberley, P. (1987) 'The Concept of Oppression and the Development of a Social Theory of Disability', *Disability, Handicap and Society*, *2*(1), pp. 5–19.

Abberley, P. (2004) 'A Critique of Professional Support and Intervention', in Swain, J., French, S., Barnes, C., and Thomas, C. (eds.), *Disabling Barriers-Enabling Environments*. 2nd edn. London: Sage Publications Limited

Adair, J. (2009). *The Art of Creative Thinking*. London: Kogan Page Limited.

Alvesson, M. and Skoldberg, K. (2010) *Reflexive methodology: New Vistas for Qualitative Research*. 2nd edn. London: Sage Publications Ltd.

Anderson, A. (2006) *The Community Builder's Approach to Theory of Change: A Practical Guide to Theory Development*. New York: The Aspen Institute.

Auger, R. W. (2004) 'What We Don't Know CAN Hurt Us: Mental Health Counsellor's Implicit Assumptions About Human Nature', *Journal of Mental Health Counselling*, *26*(1), pp. 13–24.

Atkin, H. and Carter, L. (2008) 'Who Dares Wins: Developing a critical friendship with a service user'. *College of Occupational Therapy Annual Conference*. Harrogate, July. College of Occupational Therapy

Atkin, H. and Cook, T. (2009) 'Research for Everyone; Working with service users to develop a research proposal'. *College of Occupational Therapy Annual Conference*. Brighton, July, College of Occupational Therapy.

Atkin, H., van Wijck, F. and McBean, D. (2012) 'Executive Function', in van Wijke, F and McBean, D. (eds.) *Applied Neurosciences for the Allied Health Professions*. London: Elsevier Ltd, UK, pp. 155– 164.

Atkin, H., Brandon, T., and Thomson, L. (2014) 'Is There a Pathway to Recovery Through Care Coordination? Early Findings from an emancipatory action research project'. *The Approach Journal: Care Coordination Association*, (July), pp. 13–15.

Atkinson, P. and Housley, W. (2003). *Interactionism*. London: Sage Publications Ltd.

Bailey, D. M. and Jackson, J. M. (2003) 'Qualitative Data Analysis: Challenges and Dilemmas Related to Theory and Method'. *American Journal of Occupational Therapy*, *57*(1), pp. 57–65.

Bailin, S. and Siegal, H. (2003) 'Critical Thinking', in Blake, N., Smeyers, P., Smith, R. and Standish, P. (eds.) *The Blackwell Guide to the Philosophy of Education*. Oxford: Blackwell Publishing Ltd, pp. 181–193.

Baker, J. and Zigmond, N. (1995) 'The Meaning and Practice of Inclusion for Students with Learning Disabilities: Themes and Implications from the Five Cases'. *Journal of Special Education*, *29*(2), pp. 163–180.

Banja, J. D. (2015) 'The Disability Movement's Critique of Rehabilitation's Medical Model: A Rebuttal'. *American Medical Association Journal of Ethics*, *17*(6), pp. 562–567.

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A., Moore, N., Nayling, N.,Stokoe, A., and Strachan, A. (2013) 'Everyday ethics in community-based participatory research'. *Contemporary Social Science*, *8*(3), pp. 263–277.

Barbour, R. S. (2001) 'Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?' *British Medical Journal*, *322*(7294), pp. 1115–1117.

Barnes, C. and Mercer, G. (2003) *Disability*. Cambridge: Polity Press.

Barnes, M. P. (2003a) 'Principles of neurological rehabilitation'. *Journal of Neurology, Neurosurgery, and Psychiatry*, *74 Suppl. 4,* pp. iv3-iv7.

Barnes, M. (2003b) 'Organisation of neurological rehabilitation', in Greenwood, R.J., Barnes, M.P., McMillan, T.M. and Ward, C. (eds.), *Handbook of Neurological Rehabilitation*. Hove: Psychological Press, pp. 29–40.

Barton, L. (1997) 'Inclusive education: romantic, subversive or realistic?' *International Journal of Inclusive Education*, *1*(3), pp. 231–242.

Bate, P. and Robert, G. (2006) 'Experience-based design: from redesigning the system around the patient to co-designing services with the patient'. *Quality and Safety in Health Care*, *15*(5), pp. 307–310.

Bell, K. and Salmon, A. (2012) 'Good intentions and dangerous assumptions: Research ethics committees and illicit drug use research'. *Research Ethics*, *8*(4), pp. 191–199.

Benzies, K. M. and Allen, M. N. (2001) 'Symbolic interactionism as a theoretical perspective for multiple method research'. *Journal of Advanced Nursing*, *33*(4), pp. 541–547.

Beresford, P. and Croft, S. (2001) 'Service Users' Knowledges and the Social Construction of Social Work'. *Journal of Social Work*, *1*(3), pp. 295–316.

Beresford, P. (2002) 'User Involvement in Research and Evaluation: Liberation or Regulation?' *Social Policy and Society*, *1*(2), pp. 95–105.

Berger, P.L. and Luckmann, T. (1967) *The Social Construction of Reality: A Treatise on the Sociology of Knowledge*. New York: Anchor.

Bergold, J. and Thomas, S. (2012) 'Participatory Research Methods : A Methodological Approach in Motion'. FORUM QUALITATIVE SOCIAL RESEARCH, *13*(1), Art 30.

Berman, S. I. (2001) 'Opening the closed mind : Making assumptions, jumping to conclusions'. *Et Cetera*, *58*(4), pp. 429–439.

Bigby, C. (2012) 'Social inclusion and people with intellectual disability and challenging behaviour: a systematic review'. *Journal of Intellectual and Developmental Disability*, *37*(4), pp. 360–374.

Blumer, H. (1969) *Symbolic Interactionism: Perspective and Method*. Berkley: University of California Press.

Bolger, N., Davis, A., and Rafaeli, E. (2003) 'Diary methods: Capturing life as it is lived'. *Annual Review of Psychology*, *54*, pp. 579–616.

Bolton, G. (2009) Reflective Practice. London: Sage Publications Ltd.

Boud, D., Keogh, R., and Walker, D. (2002) 'Promoting Reflection in Learning: A Model', in Edwards, R., Hanson, A. and Raggatt, P. (eds.) *Boundaries of Adult Learning*. Abingdon: Routledge, pp. 32–56

Bowe, C. M., Lahey, L., Armstrong, E., and Kegan, R. (2003) 'Questioning the "big assumptions". Part I: Addressing personal contradictions that impede professional development'. *Medical Education*, *37*(8), pp. 715–722.

Bowen, C., Yeates, G. N., and Palmer, S. (2010) *A Relational approach to rehabilitation: Thinking about relationships after brain injury.* London: Karnac Books.

Bright, F. A., Boland, P., Rutherford, S., Kayes, N., and McPherson, K. (2012) 'Implementing a client-centred approach to rehabilitation: an autoethnography'. *Disability and Rehabilitation*, *34*(12), pp. 997–1004.

British Society of Rehabilitation Medicine. (2015) Specialist neuro-rehabilitation services : providing for patients with complex rehabilitation needs. London: British Society of Rehabilitation Medicine.

Brookfield, S. (1987) *Developing Critical Thinkers*. Milton Keynes: Open University Press.

Brookfield, S. (1990) 'How Critical Reflection Triggers Transformative Learning', in Mezirow, J. and Associates. (eds.) *Fostering Critical Reflection in Adulthood: A Guide to Transformative and Emancipatory Learning*. San Fransisco: Jossey-Bass, pp.177-193

Brookfield, S. (1992) 'Uncovering Assumptions: The Key to Reflective Practice'. *The Reflective Practitioner*, *3/4*, pp. 13–18.

Brookfield, S. (1993) 'On Impostorship, Cultural Suicide, and Other Dangers: How Nurses Learn Critical Thinking'. *The Journal of Continuing Education in Nursing*, *24*(5), pp. 197–206.

Brookfield, S. (1995) *Becoming and Critically Reflective Teacher*. San Francisco: Jossey-Bass.

Brookfield, S. (1998) 'Critically Reflective Practice'. *The Journal of Continuing Education in the Health Professions*, *18*, pp. 197–205.

Brookfield, S. (2001) 'Repositioning Ideology Critique in a Critical Theory of Adult Learning'. *Adult Education Quarterly*, *52*(1), pp. 7–22.

Brookfield, S. (2005) *The Power of Critical Theory for Adult Learning and Teaching*. New Jersey: Jossey- Bass.

Brookfield, S. (2009) 'The concept of critical reflection: promises and contradictions', *European Journal of Social Work*, *12*(3), pp. 293–304.

Brookfield, S. (2012) *Teaching for Critical Thinking*. New Jersey: Jossey Bass.

Brookfield, S. (2013) 'Teaching for Critical Thinking', *International Journal of Adult Vocational Education and Technology*, *4*(1), pp. 1–15.

Bryman, A. (2007) *Social Research Methods*. 3rd edn. Oxford: Oxford University Press.

Buckmaster, L., and Thomas, M. (2009) *Social inclusion and social citizenship -towards a truly inclusive society*. Available at: http://aphnew.aph.gov.au/binaries/library/pubs/rp/2009-10/10rp08.pdf (Accessed: 14th June, 2016).

Burrows, A. C. and Harkness, S. S. (2015) 'Experiencing action evaluation's cyclic process: partnering conflict, reflection, and action'. *Educational Action Research*, 24(4), pp. 460-470.

Cameron, A. (2006) 'Geographies of welfare and exclusion: Social Inclusion and Exception'. *Progress in Human Geography*, *30*(3), pp. 396–404.

Carpenter, C. (2004) 'The contribution of qualitative research to evidence-based practice', in Hammell, K.W. and Carpenter, C. (eds.) *Qualitative research in evidence-based rehabilitation*. Edinburgh: Churchill Livingstone, pp. 1–13.

Cast, A. D. (2003) 'Power and the Ability to Define the Situation'. *Social Psychology Quarterly*, *66*(3), pp. 185–201.

Centre for Social Justice and Community Action, Banks, S., and Manners, P. (2012) *Community-based participatory research: A guide to ethical principles and practice.* Available at: www.publicengagement.ac.uk/how-we-help/our-publications/ community-based-participatory-research-guide-to-ethical-principle (Accessed: 25th August 2016).

Chambers, R. (2002) *Participatory Workshops: A Sourcebook of 21 Sets of Ideas and Activities Paperback.* Abingdon: Earthscan.

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* Thousand Oaks, CA: Sage Publications Inc.

Charon, J. M. (2009) *Symbolic Interactionism: An Introduction, An Interpretation, An Integration.* 10th edn. New York: Prentice Hall.

Cicerone, K. D. (2012) 'Facts, theories, value: Shaping the course of neurorehabilitation: The 60th John Stanley Coulter Memorial Lecture'. *Archives of Physical Medicine and Rehabilitation*, *93*(2), pp. 188–191.

Claxton, G. (1999) *Wise Up: Learning to live the Learning Life.* Stafford: Network Educational Press Ltd.

Clegg, J., Murphy, E., Almack, K., and Harvey, A. (2008) 'Tensions around inclusion: Reframing the moral horizon'. *Journal of Applied Research in Intellectual Disabilities*, *21*(1), pp. 81–94.

Coffey, A. and Atkinson, S. (1996) *Making Sense of Qualitative Data.* London: Sage Publications Ltd.

Cohen, A. P. (1985) *The Symbolic Nature of Community.* London: Routledge.

Cook, T. and Swain, J. (2001) 'Parent's Perspectives on the Closure of a Special School: Towards Inclusion in Partnership'. *Educational Review*, *53*(2), pp. 191–198.

Cook, T., Swain, J., and French, S. (2001) 'Voices from Segregates Schooling: Towards an Inclusive Education System'. *Disability and Society*, *16*(2), pp. 293–310.

Cook, T. (2004a) 'Reflecting and learning together: action research as a vital element of developing understanding and practice'. *Educational Action Research*, *12*(1), pp. 77–98.

Cook, T. (2004b) 'Starting where we can: using action research to develop inclusive practice'. *International Journal of Early Years Education*, *12*(1), pp. 3–16.

Cook, T. (2009) 'The purpose of mess in action research: building rigour though a messy turn'. *Educational Action Research*, *17*(2), pp. 277–291.

Cook, T., Atkin, H., Carter, L., Mitchell, P., Moore, P., Bell, E., Bond, M. Hutchinson, C., White. A., Piggott, M. and Wilson, B. (2011). *Towards Inclusive Living: A Case Study of the Impact of Inclusive Practice in Neuro-Rehabilitation/ Neuropsychiatry Services*. Available at: http://www.ltnc.org.uk/download_files/final reports/Oct_11/Final_Report_Inclusive_Living.pdf (Accessed: 11th October 2011).

Cook, T. (2012) 'Where Participatory Where Participatory Approaches Meet Pragmatism in Funded (Health) Research : The Challenge of Finding Meaningful Spaces'. FORUM: QUALITATIVE SOCIAL RESEARCH, *13*(1), Art 18

Cook, T., and Inglis, P. (2012) 'Participatory research with men with learning disability: informed consent'. *Tizard Learning Disability Review*, *17*(2), pp. 92–101.

Cook, T., Vougioukalou, S., Buckley, N., and Boote, J. (2012) *Participatory Research Impact and Legacy (APRIL). Project Report.* JISC/National Coordinating Centre for Patient Engagement.

Cooperrider, D. L., Whitney, D, and Stavros, J.M. (2003) *Appreciative Inquiry Handbook: The First in a Series of AI Workbooks for Leaders of Change*. Bedford Heights: Lakeshore Communications Inc.

Cornwall, A. and Jewkes, R. (1995) 'What is participatory research?' *Social Science Medicine*, *41*(12), pp. 1667–1676.

Cornwall, A. (1996) 'Towards participatory practice: participatory rural appraisal (PRA) and the participatory process', in de Koning, K. and Martin, M. (eds.) *Participatory Research in Health. Issues and Experiences.* London: Zed Books, pp. 94–107.

Corring, D. J. and Cook, J. V. (1999) 'Client-centred care means that I am a valued human being'. *Canadian Journal of Occupational Therapy. 66*(4), pp. 71–82.

Cott, C. A. (2004) 'Client Centred Rehabilitation: The Client's Perspective.' *Disability and Rehabilitation* 26(24), pp. 1411-1422.

Cottrell, S. (2011) *Critical Thinking Skills: Developing Effective Analysis and Argument.* 2nd edn. New York: Palgrave Macmillan.

Cresswell, J. W. (2012) *Qualitative inquiry and research design: Choosing among five approaches.* Thousand Oaks, CA: Sage Publications Inc.

Cronin, P., Ryan, F., and Coughlan, M. (2010) 'Concept analysis in healthcare research'. *International Journal of Therapy and Rehabilitation*, *17*(2), pp. 62–68.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process.* London: Sage Publications Ltd.

Cunliffe, A. (2004) 'On Becoming a Critically Reflexive Practitioner'. *Journal of Management Education*, *28*(4), pp. 407–426.

Dadds, M. (2008) 'Empathetic validity in practitioner research'. *Educational Action Research*, *16*(2), pp. 279–290.

Damsgaard, J. B., Norlyk, A., Jorgensen, L. B., and Birkelund, R. (2016) 'Back pain - a feeling of being mistrusted and lack of recognition: A

qualitative study'. *International Journal of Orthopaedic and Trauma Nursing*, *21*(5), pp. 11–20.

Darragh, A. R., Sample, P. L., and Krieger, S. R. (2001) 'The purpose of this study was to identify practitioner qualities and traits that clients with brain injury see as important'. *American Journal of Occupational Therapy*, *55(2)*, pp. 191–199.

Davies, H. and Mannion, R. (2013) 'Will prescriptions for cultural change improve the NHS?' *British Medical Journal*, *346* (1st March), pp. 1–4.

Davis, K. (2004) 'The crafting of good clients', in Swain, J., French, S. and Cameron, C. (eds.) *Disabling Barriers-Enabling Environments*. 2nd edn. London: Sage Publications Ltd, pp. 203–205.

D'Cruz, H., Gillingham, P., and Melendez, S. (2007) 'Reflexivity, its meanings and relevance for social work: A critical review of the literature'. *British Journal of Social Work*, *37*(1), pp. 73–90.

D'Cruz, K., Howie, L., and Lentin, P. (2016) 'Client-centred practice: Perspectives of persons with a traumatic brain injury'. *Scandinavian Journal of Occupational Therapy*, *23*(1), pp. 30–38.

DeJong, G. (1979) 'Independent Living : From Social Movement to Analytic Paradigm'. *Archives of Physical Medicine and Rehabilitation*, *60*(10), pp. 435–446.

Denzin, N. (1992) *Symbolic Interactionism and Cultural Studies: The Politics of Interpretation*. Oxford: Blackwell Publishing Ltd.

Denzin, N. K. and Lincoln, Y. S. (2005) 'Paradigms and Perspectives in Contention', in Denzin. N.K., and Lincoln, Y.S. (eds.) SAGE *Handbook of Qualitative Research*. 3rd edn. Thousand Oaks CA: Sage Publications Inc, pp. 183–190.

Deshler, D. (1990) 'Metaphor Analysis: Exorcising Social Ghosts', in *Fostering Critical Reflection in Adulthood: A Guide to Transformative and Emancipatory Learning*. San Francisco: Jossey- Bass, pp. 296–313.

Diller, L. (2005) 'Pushing the frames of reference in traumatic brain injury rehabilitation'. *Archives of Physical Medicine Rehabilitation*, *86*(6), pp. 1075–1080.

Dirkx, J. M. (2008) 'The Meaning and Role of Emotions in Adult Learning', *New Directions for Adult and Continuing Education*, *120*(Winter), pp. 1–18.

Doig, E., Fleming, J., and Kuipers, P. (2008) 'Achieving optimal outcomes in community-based rehabilitation following acquired brain injury: A qualitative investigation of therapists' perspectives'. *British Journal of Occupational Therapy*, *71*(8), pp. 560–370.

D'Silva, D. (2011) *Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management*. London: The Health Foundation.

Edelman, M. (1964) *The Symbolic Use of Politics*. Urbana: University of Illinois Press

Eilertsen, T., Gustafson, N., and Salo, P. (2008) 'Action research and the micropolitics in schools'. *Educational Action Research*, *16*(3), pp. 295–308.

Eliot, T. D. (1937) 'Reactions to Predictive Assumptions', *American Sociological Review*, *2*(4), pp. 508–517.

Emerson, E. and Baines, S. (2010) *Health Inequalities & People with Learning Disabilities in the UK : 2010*. London: Learning Disabilities Observatory.

Emmel, N. (2008) 'Participatory Mapping: An innovative sociological method. *Real Life Methods*. Manchester: ERSC National Centre for Research Methods.

Ennis, R. H. (1982) 'Identifying Implicit Assumptions'. *Synthese*, *51*(1), pp. 61–86.

Equality and Human Rights Commission. (2014) *Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities: The UK Independent Mechanism (UKIM)*. London: Equality and Human Rights Commission.

Eraut, M. (2004) 'The emotional dimension of learning'. *Learning in Health and Social Care*, *3*(1), pp. 1–4.

Evans, K. (2013) *Pathways Through Writing Blocks in the Academic Environment*. Rotterdam: Sense Publishers.

Finlay, L. (2000) 'Multiple Voices, Multiple Paths : Choosing between Qualitative Traditions'. *British Journal of Occupational Therapy*, *63*(12), pp. 580–582.

Finlay, L. (2008) 'Reflecting on " Reflective practice"'. Available at: http://www.open.ac.uk/opencetl/sites/www.open.ac.uk.opencetl/files/files /ecms/web-content/Finlay-(2008)-Reflecting-on-reflective-practice-PBPL-paper-52.pdf (Accessed 13th June, 2016).

Fook, J. (2002) *Social Work: Critical Theory and Practice*. London: Sage Publications Ltd.

Fook, J., White, S., and Gardner, F. (2006) 'Critical reflection : a review of contemporary literature and understandings', in White, S., Fook, J. and Gardner, F. (eds.) *Critical Reflection in Health and Social Care.* Maidenhead: Open University Press, pp. 1–18.

Fook, J. (2012) 'The Challenges of Creating Critically Reflective Groups', *Social Work With Groups*, *35*(3), pp. 218–234.

Foot, C., Gilburt, H., Dunn, P., Jabbal, J., Seale, B., Goodrich, J., Buck, D. and Taylor, J. (2014) *People in control of their own health and care: the state of involvement*. London. Kings Fund.

Forte, J. A. (2007) *Human Behaviour and the Social Environment: Models, Metaphors, and Maps for Applying Theoretical Perspectives to Practice*. Belmont: Thomson Brooks/Cole.

French, S. and Swain, J. (2008) 'On Equal Terms', in Swain, J. and French, S. *Disability on Equal Terms*. London: Sage Publications Ltd, pp.129-141.

Friere, P. (1970) *Pedagogy of the Oppressed*. London: Penguin Books Ltd.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., and Redwood, S. (2013) 'Using the framework method for the analysis of qualitative data in multi-disciplinary health research'. *BMC Medical Research Methodology*, *13*(1), 117.

Genat, B. (2009) 'Building emergent situated knowledges in participatory action research'. *Action Research*, *7*(1), pp. 101–115.

General Medical Council. (2013) *Establish and Maintain Partnership with Patients. Good Medical Practice*. Available at: http://www.gmc-uk.org/guidance/good_medical_practice/partnerships.asp (Accessed 15th July, 2016).

Gillen, G. (2010) 'Rehabilitation research focused on neurorehabilitation'. *The American Journal of Occupational Therapy. 64*(2), pp. 341–56.

Gillespie, A., Reader, T., Cornish, F., and Campbell, C. (2014) 'Beyond ideal speech situations: Adapting to communication asymmetries in health care', *Journal of Health Psychology*, *19*(1), pp. 72–78.

Glasby, J. and Beresford, P. (2006) 'Who knows best ? Evidence-based practice and the service user contribution'. *Critical Social Policy*, *26*(1), pp. 268–284.

Goleman. (1996) *Emotional Intelligence.* London: Bloomsbury Paperbacks.

Goodin, R. E. (1996) 'Inclusion and Exclusion'. *European Journal of Sociology*, *37*(2), pp. 343–371.

Grant, M. J. and Booth, A. (2009) 'A typology of reviews: an analysis of 14 review types and associated methodologies'. *Health Information and Libraries Journal*, *26*(2), pp. 91–108.

Great Britain. Department of Health. (1999) *Patient and Public Involvement in the New NHS.* London: Department of Health.

Great Britain. Department of Health. (2001) *Valuing people: A new strategy for learning disability for the 21st century.* London: Department of Health.

Great Britain. Department of Health. (2005a) *National Service Framework: Neurological Long Term Conditions.* London: Department of Health.

Great Britain. Department of Health. (2005b) *Self Care – A Real Choice Self Care Support – A Practical Option.* London: Department of Health.

Great Britain. Department of Health. (2006a) *National Health and Social Care Act (Section 242).* London, England. Available at: http://www.legislation.gov.uk/ukpga/2006/41/pdfs/ukpga_20060041_en. pdf. (Accessed 20th July 2010).

Great Britain. Department of Health. (2006b) *Supporting people with long term conditions to self care.* London: Department of Health.

Great Britain. Department of Health. (2007a) *Capabilities for Inclusive Practice.* London: Department of Health.

Great Britain. Department of Health. (2007b) *Keeping it Personal: Clinical case for change : Report by David Colin-Thome, National Director for Primary Care.* London: Department of Health.

Great Britain. Department of Health. (2008a) *Real Involvement: Working with People to Improve Health Services.* London: Department of Health.

Great Britain. Department of Health. (2008b) *High quality care for all: NHS Next Stage Review final report.* London: Department of Health.

Great Britain. Department of Health. (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: Department of Health.

Great Britain. Department of Health. (2010) *Equity and Excellence: Liberating the NHS.* London: Department of Health.

Great Britain. Department of Health. (2012) *Transforming care: A national response to Winterbourne View Hospital*. London: Department of Health.

Great Britain. Department of Health. (2012b) *Understanding Personal Health Budgets*. London: Department of Health.

Great Britain. Department of Health. (2014) *Five Year Forward View*. London: Department of Health.

Great Britain. Department of Health. (2015) *The NHS Constitution for England: The NHS belongs to us all*. London: Department of Health.

Great Britain. Prime Ministers Strategy Unit. (2005) *Improving the Life Chances of Disabled People*. London: Prime Ministers Strategy Unit.

Greenhalgh, T., Robb, N., and Scambler, G. (2006) 'Communicative and strategic action in interpreted consultations in primary health care: A Habermasian perspective'*. Social Science and Medicine*, 63(5), 1170–1187

Greenhalgh, T., Howick, J., and Maskrey, N. (2014) 'Evidence based medicine: a movement in crisis?' *BMJ*, *348*, g3725, pp.1-7.

Green, K. (1999) 'Defining the field of literature in action research: a personal approach'. *Educational Action Research*, *7*(1), pp. 105–124.

Guba, E. and Lincoln, Y. (2005) 'Paradigmatic Controversies, Contradictions and Emerging Confluences', in *Handbook of Qualitative Research, 3rd edn.* Thousand Oaks, CA: Sage Publications Inc, pp.191-215.

Gustafsson, L., Molineux, M., and Bennett, S. (2015) 'Contemporary occupational therapy practice: The challenges of being evidence based and philosophically congruent'. *Australian Occupational Therapy Journal*, 62(3), pp. 219-222

Habermas, J. (1984) *The Theory of Communicative Action Vol. 1: Reason and rationalization of society.* Boston: Beacon Press.

Habermas, J. (1987) *The Theory of Communicative Action Vol. 2: Lifeworld and System: A Critique of Functionalist Reason. (T. McCarthy, Trans. Original text in German 1981 1st edn.).* Cambridge: Polity Press.

Habermas, J. (2008) *Between naturalism and religion: Philosophical essays.* Cambridge: Polity Press.

Hammell, K. W. (2004) 'Deviating from the norm: a sceptical interrogation of the classificatory practices of the ICF'. *British Journal of Occupational Therapy*, *67*(9), pp. 408–411.

Hammell, K. W. (2006) *Perspectives on Disability and Rehabilitation: contesting assumptions; challenging practice.* London: Churchill Livingstone.

Hammell, K. W. (2007) 'Client-Centred Practice: Ethical Obligation or Professional Obfuscation?' *The British Journal of Occupational Therapy*, *70*(6), pp. 264–266.

Hammell, K. W. (2009) 'Sacred texts: a sceptical exploration of the assumptions underpinning theories of occupation', *Canadian Journal of Occupational Therapy*, *76*(1), pp. 6–13.

Hammell, K. W. (2011) 'Resisting theoretical imperialism in the disciplines of occupational science and occupational therapy', *British Journal of Occupational Therapy*, *74*(1), pp. 27–33.

Hammell, K. W. (2013) 'Client-centred practice in occupational therapy: Critical reflections'. *Scandinavian Journal of Occupational Therapy*, *20*(3), pp. 174–81.

Hammell, K. W. (2015) 'Rethinking Rehabilitation's Assumptions: Challenging "Thinking -as-Usual" and Envisioning and Relevant Future', in McPherson, K., Gibson, B.E. and Leplege. A. (eds.) *Rethinking Rehabilitation: Theory and Practice*. Boco Raton: CRC Press, pp. 45-68.

Handberg, C., Thorne, S., Midtgaard, J., Nielsen, C. V., and Lomborg, K. (2015) 'Revisiting symbolic interactionism as a theoretical framework beyond the grounded theory tradition'. *Qualitative Health Research*, *25*(8), pp. 1023–1032.

Harra, T. and Salminen, A. L. (2015) 'Using reciprocal relationships to avoid the inclusion trap'. *World Federation of Occupational Therapists Bulletin*, *71*(2), pp. 96–100.

Hernandez, M and Hodges, S. (2006) 'Applying a Theory of Change approach to Interagency Planning in Child Mental Health'. *American Journal of Community Psychology*, *38*, pp. 165–173.

Heron, J. and Reason, P. (1997) 'A participatory inquiry paradigm'. *Qualitative Inquiry*, *3*(3), pp. 274–294.

Herr, K. and Anderson, G. (2005) *The Action Research Dissertation: A Guide for Students and Faculty*. London: Sage Publications Ltd.

Hewitt, J. P. (1988) *Self and Society: A Symbolic Interactionist Social Psychology* 4th edn. London: Allyn and Bacon.

Higgs, J. (2001) 'Charting standpoints in qualitative research', in Byrne-Armstrong, H., Higgs, J., and Horsefall, D. (eds.) *Critical Moments in Qualitative Research*. Oxford: Heinemann, pp. 44-67

Higgs, J., Titchen, A. and Neville, V. (2001) 'Professional practice and knowledge', in Higgs, J. and Titchen, A. (eds.) *Practice Knowledge and Expertise in the Health Professions*. Oxford: Butterworth-Heinemann, pp.3–9.

Hocking, C. (2012) 'Through the looking glass: Reflecting on occupational scientists ontological assumptions', in Whiteford, G. and Hocking, C. (eds.) *Occupational Science, Society, Inclusion, Participation.* Oxford: Blackwell Publishing Ltd, pp. 54–66.

Hooper, B. (1997) 'The Relationship Between Pre-theoretical Assumptions and Clinical reasoning'. *American Journal of Occupational Therapy*, *51*(5), pp. 328–338.

Hooper, B. and Wood, W. (2002) 'Pragmatism and structuralism in occupational therapy: the long conversation'. *The American Journal of Occupational Therapy*, *56*(1), pp. 40–50.

House of Commons Committee of Public Accounts. (2012) 'Written evidence from the Association of British Neurologists: Response of the Association of British Neurologists to the National Audit Office'. *Report on the National Service Framework for Long Term Neurological Conditions*. Available at: http://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc /1759/1759we02.htm (Accessed March 10, 2016)

Hughes, B. (2012) 'Fear, pity and disgust: emotions and the non-disabled', in Watson, N., Roulstone, A., and Thomas, C. (eds.) *Routledge Handbook of Disability Studies*. Abingdon: Routledge, pp. 67–77.

Hughes, J. C., Bamford, C., and May, C. (2008) 'Types of centredness in health care: Themes and concepts'. *Medicine, Health Care and Philosophy*, *11*(4), pp. 455–463.

Hui, A. and Stickley, T. (2007) 'Mental health policy and mental health service user perspectives on involvement: A discourse analysis'. *Journal of Advanced Nursing*, *59*(4), pp. 416–426.

Hunt, A. W., Le Dorze, G., Polatajko, H., Bottari, C., and Dawson, D. R. (2015) 'Communication during goal-setting in brain injury rehabilitation: What helps and what hinders?' *British Journal of Occupational Therapy*, *78*(8), pp. 488-498

Hyder, E. and Tissot, C. (2013) ''That's definite discrimination': practice under the umbrella of inclusion'. *Disability and Society*, *28*(1), pp. 1–13.

Iezzoni, L. I. (2006) 'Make no assumptions: communication between persons with disabilities and clinicians', *Assistive Technology*, *18*(2), pp. 212–9.

Ikiugu, M. and Schultz, S. (2006) 'An argument for pragmatism as a foundational philosophy of occupational therapy'. *Canadian Journal of Occupational Therapy*, *2*(73), pp. 86–97.

International Collaboration for Participatory Health Research (ICPHR). (2013) *Position Paper 1: What is Participatory Health Research?* Berlin: International Collaboration for Participatory Health Research.

INVOLVE. (2012) *Diversity and inclusion : What's it about and why is it important for public involvement in research?* Eastleigh: INVOLVE.

INVOLVE. (2017) What is public involvement in research? Available at: http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/ (Accessed March 31, 2017).

Jackson, J. (2000) 'Understanding the Experience of Non-inclusive Occupational Therapy Clinics: Lesbians' Perspectives'. *American Journal of Occupational Therapy*, *54*(1), pp. 26-35.

Jesson, J. and Lacey, F. (2006) 'How to do (or not to do) a critical literature review'. *Pharmacy Education*, *6*(2), pp. 139–148.

Kayes, N. M. and McPherson, K. M. (2012) 'Human technologies in rehabilitation: "Who" and "How" we are with clients'. *Disability and Rehabilitation*, *34*(22), pp. 1907–1911.

Kayes, N., Mudge, S., Bright, F. A., and McPherson, K. M. (2015) 'Whose Behaviour Matters? Rethinking Practitioner Behaviour and Its Influence on Rehabilitation Outcomes', in McPherson, KA, Gibson, B., and Leplege, A. (eds.) *Rethinking Rehabilitation: Theory and Practice.* Boco Raton: CRC Press, pp. 249–271

Kemmis, S. (2001) 'Exploring the Relevance of Critical Theory for Action Research: emancipatory action research in the footsteps of Jurgen Habermas', in Reason, P. and Bradbury, H. (eds.) *Handbook of Action Research*) London: Sage Publications Ltd, pp. 356–362.

Kemmis, S. and McTaggart, R. (1988) *The Action Research Planner*. 3rd edn. Victoria: Deakin University Press.

Kemmis, S. and McTaggart, R. (2005) 'Participatory Action Research', in Denzin, N. and Lincoln, Y.S. (eds.) *The SAGE Handbook of Qualitative Research* (3rd edn.). Thousand Oaks, CA: Sage Publications, Inc, pp. 559–603

Kemmis, S. (2009) 'Action research as a practice-based practice'. *Educational Action Research*, *17*(3), pp. 463–474.

Kendall, E. and Rogers, A. (2007) 'Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme'. *Disability & Society*, *22*(2), pp. 129–143.

Kies, D. (1997) *Underlying assumptions*. Available at:
http://papyr.com/hypertextbooks/comp2/assume.htm (Accessed: 15th
May 2016).

Kielhofner, G. (1997) *Conceptual Foundations of Occupational Therapy*.
Philadelphia: F.A.Davies.

Kindon, S., Pain, R., and Kesby, M. (2010) *Participatory Action Research
Approaches and Methods: Connecting people, participation and place*.
Abingdon: Routledge.

Kinsella, E. (2012) 'Reflections on Reflective Practice'. *Canadian Journal of
Occupational Therapy*, *68*(3), pp. 195–198.

Kitchin, R. (1998) '"Out of Place", "Knowing One's Place": Space, power and
the exclusion of disabled people'. *Disability and Society*, *13*(3), pp. 343–
356.

Kitzinger, J. (1995) 'Introducing focus groups'. *British Medical Journal*,
311(29th July), pp. 299–302.

Koch , T. and Kralik, D. (2006) *Participatory Action Research in Health Care*.
Oxford: Blackwell Publishing Ltd.

Kovecses, Z. (2010). *Metaphor*. 2nd edn. Oxford: Oxford University Press.

Krueger, R. (1994) *Focus Groups: A Practical Guide for Applied Research*.
2nd edn. Thousand Oaks: Sage Publications Inc.

Labonte, R. (2004) 'Social Inclusion/Exclusion: Dancing the dialectic'. *Health
Promotion International*, *19*(1), pp. 115–121.

Labonté, R., Hadi, A., and Kauffmann, X. E. (2011) *Indicators of Social
Exclusion and Inclusion : A Critical and Comparative Analysis of the
Literature*. Ottowa: University of Ottowa.

Lakoff, G. and Johnson, M. (1980) *Metaphors We Live By*. Chicago: University of Chicago Press.

Lamiani, G., Meyer, E. C., Rider, E. Browning, D. M., Vegni, E., Mauri, E.,Moja E., and Truog, R. D. (2008) 'Assumptions and blind spots in patient-centredness: action research between American and Italian health care professionals', *Medical Education*, *42*(7), pp. 712–20.

Lather, P. (1986) 'Issues of validity in openly ideological research: Between a rock and a soft place'. *Interchange*, *17*(4), pp. 63–84.

Law, M., Baptiste, S., and Mills, J. (1995) 'Client-centred practice: What does it mean and does it make a difference?' *Canadian Journal of Occupational Therapy*, *62*, pp. 250–257.

Leplege, A. and Hunt, S. (1997) 'The problem of quality of life in medicine'. *Journal of American Medical Association*, *1*, pp. 47–50.

Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B., and Ville, I. (2007) 'Person-centredness: conceptual and historical perspectives'. *Disability and Rehabilitation*, *29*(20-21), pp. 155–165.

Leplege, A., Barral, C., and McPherson, K. M. (2015) 'Conceptualizing disability to inform rehabilitation: Historical and epistemological perspectives', in McPherson, K.E. Gibson, B.E and Lelplege, A. (eds.) *Rethinking Rehabilitation: Theory and Practice*. Boca Raton: CRC Press.

Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E., and Patsios, D. (2007) *The Multi-Dimensional Analysis of Social Exclusion*. Bristol: Bristol University.

Levitas, R. (1996) 'The concept of social exclusion and the new Durkheimian hegemony'. *Critical Social Policy*, *16*, pp. 5–20.

Lewinter, M. and Mikkelsen, S. (1995) Patients' experience of rehabilitation after stroke. *Disability and Rehabilitation*, *17*(1), pp. 3–9.

Lewis, L. (2009) 'Politics of Recognition: What Can a Human Rights Perspective Contribute to Understanding Users' Experiences of Involvement in Mental Health Services?' *Social Policy & Society*, *8*(2), pp. 257–274.

Liu, C., Thompson. A., and Playford, E. D. (2004) 'Patient dissatisfaction: insights into the rehabilitation process.' *Journal of Neurology*, *251*(9), pp. 1094–1097.

Lloyd, V. W. and Rose, G. (2008) 'An interview with Gillian Rose'. *Theory, Culture & Society*, *25*(7–8), pp. 201–218.

Lombe, M. and Sherraden, M. (2008) 'Inclusion in the Policy Process: An Agenda for Participation of the Marginalized'. *Journal of Policy Practice*, *7*(2/3), pp. 199–213.

Luker, J., Lynch, E., Benhardsson, S., Bennett, L., and Bernhardt, J. (2015) 'Stroke Survivors' Experiences of Physical Rehabilitation: A Systematic review of Qualitative Studies'. *Archives of Physical Medicine and Rehabilitation*, *96*,(9) pp. 1698–1708.

Manley, K. and McCormack, B. (2003) 'Practice development : purpose, methodology, facilitation and evaluation', *Nursing in Critical Care*, *8*(1), pp. 22–29.

McBean, D. and van Wijck, F. (2013) *Applied Neurosciences for the Allied Health Professionals*. Edinburgh: Elsevier Ltd.

McIntyre, A. (2008) *Participatory Action Research*. Thousand Oaks CA: Sage Publications Inc.

McKeown, J., Clarke, A., Ingleton, C., and Repper, J. (2010) 'Actively involving people with dementia in qualitative research'. *Journal of Clinical Nursing*, *19*(13–14), pp. 1935–1943.

McKnight, J. (1977) 'Professionalized Service and Disabling Help', in Illich, I. (ed.), *Disabling Professions*. London: Marion Boyars Publishers Ltd., pp. 69-91.

McLain, B. (1988) 'Collaborative practice: A critical theory perspective', *Research in Nursing and Health*, *11*(6), pp. 393–398.

McNiff, J. (2010) *Action Research for Professional Development: Concise advice for new and experienced action researchers*. Dorset: September Books.

McPhail, J. C. and Freeman, J. G. (2005) 'Beyond Prejudice: Thinking Toward Genuine Inclusion'. *Learning Disabilities Research and Practice*, *20*(4), pp. 254–267.

McPherson, K. M., Kayes, N., and Weatherall, M. (2009) 'A pilot study of self-regulation informed goal setting in people with traumatic brain injury'. *Clinical Rehabilitation*, *23*(4), pp. 296–309.

McPherson, K., Gibson, B., and Leplege, A. (2015) 'Rethinking Rehabilitation: Theory, Practice, History - And the Future', in *Rethinking Rehabilitation: Theory and Practice*. Boco Raton: CRC Press, pp. 3-20.

McTaggart, R. (1996) 'Issues for Participatory Researchers', in Zuber-Skerritt, O. (ed.) *New Directions in Action Research*. London: The Pamer Press, pp. 243–257.

McTaggart, R. (1998) 'Is validity really an issue for participatory action research'. *Studies in Cultures, Organisations and Societies*, *4*(2), pp. 211–236.

Maguire, P. (1987) *Doing participatory research: A feminist approach*. Amherst: University of Massachusetts.

Mattingly, C. and Fleming, M. H. (1994) *Clinical Reasoning: Forms of Therapeutic Inquiry*. Philadelphia: F.A.Davies Company.

Mays, N. and Pope, C. (1995) 'Rigour and qualitative research'. *British Medical Journal*, *311*(July), pp. 109–112.

Mead, G. H. (1934) *Mind, Self, & Society: From the standpoint of the social behaviourist*. Chicago: University of Chicago Press.

Meyer, T., Gutenbrunner, C., Bickenbach, J., Cieza, A., Melvin, J., and Stucki, G. (2011) 'Towards a conceptual description of rehabilitation as a health strategy'. *Journal of Rehabilitation Medicine*, *43*(9), pp. 765–769.

Mezirow, J. (1990) 'How Critical Reflection Triggers Transformative Learning', in *Fostering Critical Reflection in Adulthood: A Guide to Transformative and Emancipatory Learning.* San Francisco: Jossey Bass, pp. 1–19.

Mezirow, J. (1997) 'Transformative Learning: Theory to Practice'. *New Directions for Adult and Continuing Education*, *1997*(74), pp. 5–12.

Mikkelsen, T. H., Soendergaard, J., Jensen, A. B., and Olesen, F. (2008) 'Cancer surviving patients' rehabilitation - understanding failure through application of theoretical perspectives from Habermas', *BMC Health Services Research*, *8*,(122), pp. 1-8.

Miles, M., and Huberman, M. (1994) *Qualitative Data Analysis* 2nd edn. Thousand Oaks, CA: Sage Publications Inc.

Mortenson, W. B., and Dyck, I. (2006) 'Power and client-centred practice: An insider exploration of occupational therapists' experiences'. *Canadian Journal of Occupational Therapy*, *73*(5), pp. 261–271.

Mudge, S., Stretton, C., and Kayes, N. (2014) 'Are physiotherapists comfortable with person-centred practice? An auto-ethnographic insight'. *Disability and Rehabilitation*, *36*(6), pp. 457–463.

National Audit Office. (2011) *Delivering efficiency savings in the NHS*. London: National Audit Office.

National Audit Office. (2015) *Services for people with neurological conditions*. London. Available at: https://www.nao.org.uk/wpcontent/uploads/2015/07/Services-for-people-with-neurological-conditions-progress-review.pdf. (Accessed: 20th September 2015).

Nicholls, D., Gibson, B., and Fadyl, J. K. (2015) 'Rethinking Movement: Postmodern reflections on a Dominant Rehabilitation Discourse', in McPherson, K., Gibson, B.E. and Leplege, A. (eds.) *Rethinking Rehabilitation: Theory and Practice*. Boco Raton: CRC Press, pp. 97–116.

Nieuwenhuijsen, E. R. (2009) 'An insider's view on person-centred rehabilitation: a case study'. *Disability and Rehabilitation*, *31*(18), pp. 1529–39.

Nind, M. (2013) 'Understanding quality in inclusive research : a process of dialogue'. *Nordic Network on Disability Research Conference*. Turku, Finland 30-31May 2013. Available at http://eprints.soton.ac.uk/352715/ (Accessed: 26 August 2014)

Nkwake, A. M. and Morrow, N. (2016) 'Clarifying concepts and categories of assumptions for use in evaluation'. *Evaluation and Program Planning*, 59(12), pp. 97–101.

Northumbria University. (2017*) Ethics in Research Policy Statement*. Available at: https://www.northumbria.ac.uk/research/ethics-and-governance/ (Accessed: 20th April, 2017).

Nussbaum, M. C. (2001) *Upheavals of Thought: The Intelligence of Emotions.* Cambridge: Cambridge University Press.

Ocloo, J., and Matthews, R. (2016). 'From tokenism to empowerment: progressing patient and public involvement in healthcare improvement'. Available at: http://doi.org/10.1136/bmjqs-2015-004839. (Accessed 15th May 2017)

Oliver, M. (1990) *The politics of disablement.* Basingstoke, UK: Macmillan Press.

Oliver, M. (1992) 'Changing the Social Relations of Research Production?' *Disability, Handicap and Society, 7*(2), pp. 101–114.

Oliver, M. (1993) 'Disability and dependency: a creation of industrial societies?', in Swain, J., Finkelstein, V., French, S., and Oliver, M. (eds.) *Disabling Barriers-Enabling Environments* 1st edn. London: Sage Publications Limited, pp.49-60.

Oliver, M. (1996) *Understanding disability: from theory to practice.* London: MacMillan.

Oliver, M. (2003) 'A Different Viewpoint-Who Needs Rehabilitating', in Greenwood, R.J., Barnes, M.P., McMillan, T.M. and Ward, C.D. (eds.), *Handbook of Neurological Rehabilitation.* Hove: Psychological Press, pp. 38–39.

O'Reilly, D. (2005) 'Social Inclusion: A Philosophical Anthropology'. *Politics, 25*(2), pp. 80–88.

Oxford Dictionary (2014) 'Assumptions'. Available at: http://oxforddictionaries.com/definition/english/assumption (Accessed 10th September 2014).

Oxford Dictionary (2015) 'Attitude'. Available at:
https://en.oxforddictionaries.com/definition/attitude (Accessed 20th
September 2015).

Oxford Dictionary. (2015) 'Belief'. Available at:
https://en.oxforddictionaries.com/definition/belief (Accessed 20th
September 2015).

Palmadottir, G. (2006) 'Client-therapist relationships: Experiences of
occupational therapy clients in rehabilitation'. *British Journal of
Occupational Therapy*, *69*(9), pp. 394–401.

Park, D. and Moro, Y. (2006) 'Dynamics of Situation Definition'. *Mind, Culture
and Activity*, *13*(2), pp. 101–129.

Patton, M. Q. (2002) *Qualitative Research and Evaluation Methods* 3rd edn.
Thousand Oaks, CA: Sage Publications Inc.

Paul, R. W. (1993) 'The Logic of Creative and Critical Thinking', *American
Behavioural Scientist*, *37*(21), pp. 21–39.

Paul, R. W. and Elder, L. (2006) 'Critical Thinking: The Nature of Critical and
Creative Thought', *Journal of Developmental Education*, *30*(2), pp. 34–
35.

Peoples, H., Satink, T., and Steultjens, E. (2011) 'Stroke survivors'
experiences of rehabilitation: A systematic review of qualitative studies'.
Scandinavian Journal of Occupational Therapy, *18*(3), pp. 163–171.

Powell, J. M. (2016) 'Special Issue on Occupational Therapy for Adults With
Traumatic Brain Injury'. *American Journal of Occupational Therapy*,
70(3), pp. 1–4.

Reason, P. (2001) Learning and Change through Action Research, in Henry,
J. (ed.), *Creative Management* 2nd edn. London: Sage Publications
Limited, pp. 182–194.

Reeve, D. (2002) 'Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity Constructions'. *Disability and Society*, *17*(5), pp. 493–508.

Richardson, L. and St. Pierre, E. A. (2000) 'Writing: A Method of Inquiry', in Denzin, N.K. and Lincoln, Y. S. (eds.) SAGE *Handbook of Qualitative Research*. 2nd edn. London: Sage Publications Limited. pp. 923–948.

Robinson, A. J., DePalma, M. T., and McCall, M. (1994) 'Physical therapists' perceptions of the roles of the physical therapist assistant'. *Physical Therapy*, *74*(6), pp. 571–582.

Rose, A., Rosewilliam, S., and Soundy, A. (2016) 'Shared decision making within goal setting in rehabilitation settings: A systematic review'. *Patient Education and Counselling*, 100(1), pp. 65–75

Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., and Roskell, C. A. (2016) 'Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study'. *Clinical Rehabilitation*, *30*(5), pp. 508–519.

Roscigno, C. I. and Van Liew, K. (2008) 'Pushed to the Margins and Pushing Back: A Case Study of One Adult's Reflections on Social Interactions After a Traumatic Brain Injury Sustained as an Adolescent'. *Journal of Neuroscience Nursing*, *40*(4), pp. 212–221.

Rorty, R. (1991) *Objectivity, Realism and Truth*. Cambridge: Cambridge University Press.

Roush, S. E. and Sharby, N. (2011) 'Disability reconsidered: the paradox of physical therapy'. *Physical Therapy*, *91*(12), pp. 1715–27.

Rowlands, A. (2001) 'Ability or Disability? Strengths Based Practice in the Area of Traumatic Brain Injury'. *Families in Society*, *82*(3), pp. 273–286.

Salminen, A. L., Kanelisto, K. J., and Karhula, M. E. (2014) 'Disability and Rehabilitation What components of rehabilitation are helpful from the perspective of individuals with multiple sclerosis?' *Disability and Rehabilitation, 36*(23), pp. 1983–1989.

Saunders, J. (1997) 'Walking a mile in their shoes... Symbolic interactionism for families living with severe mental illness'. *Journal of Psychosocial Nursing and Mental Health Services, 35*(6), pp. 8–13.

Schiellerup, P. (2008) 'Stop making sense : the trials and tribulations of qualitative data analysis'. *Area, 40*(2), pp. 163–171.

Schon, D. (1983) *The Reflective Practitioner: How Professionals Think in Action.* New York: Basic Books.

Scott, T., Mannion, R., Davies, H., and Marshall, M. N. (2003) 'Implementing culture change in health care: theory and practice'. *International Journal for Quality in Health Care : Journal of the International Society for Quality in Health Care, 15*(2), pp. 111–118.

Scrambler, G. (2001) *Habermas, Critical Theory and Health.* London: Routledge.

Senge, P. M. (1990) *The Fifth Discipline: The Art and Practice of the Learning Organisation.* London: Random House Business Books.

Shakespeare, T. (2005) 'Review article: Disability studies today and tomorrow'. *Sociology of Health & Illness, 27*(1), pp. 138–148.

Shakespeare, T. (2006) *Disability Rights and Wrongs.* Abingdon: Routledge.

Shakespeare, T., Iezzoni, L. I., and Groce, N. E. (2009) 'Disability and the training of health professionals'. *The Lancet, 374*(9704), pp. 1815–1816.

Shakespeare, T. and Officer, A. (2014) 'Breaking the barriers, filling the gaps'. *Disability and Rehabilitation, 36*(18), pp. 1487–1488.

Shakespeare, T., Watson, N., and Alghaib, O. A. (2016) 'Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability'. *Critical Social Policy*, *36*(4), pp. 1–20.

Silverman, D. (2011) *Interpreting qualitative data: a guide to the principles of qualitative research*. London: Sage Publications Limited.

Sim, J. and Snell, J. (1996) 'Focus Groups in Physiotherapy Evaluation and Research'. *Physiotherapy*, *82*(3), pp. 189–198.

Sim, J. (1998) 'Respect for autonomy : issues in neurological rehabilitation'. *Clinical Rehabilitation*, *12*, pp. 3–10.

Sixsmith, J., Callender, M., Hobbs, G., Corr, S., and Huber, J. W. (2014) 'Implementing the National Service Framework for Long-Term (Neurological) Conditions: service user and service provider experiences'. *Disability and Rehabilitation*, *36*(7), pp. 563–72.

Somekh, B. (2002) 'Inhabiting Each Other's Castles: towards knowledge and mutual growth through collaboration, in Day, C., Elliott, J., Somekh, B., and Winter, R. (eds.) *Theory and Practice in Action Research: some international perspectives.* UK: Symposium Books.

Springett, J. (2010) 'Integrating Values: Research and Knowledge Development through the use of Participatory Evaluation in Community Based Health Promotion'. *Estudios Sobre Las Culturas Contemporaneas*, *16*(31), pp. 277–297.

Springett, J., Atkey, K., Kongats, K., Zulla, R., & Wilkins, E. (2016) 'Conceptualizing Quality in Participatory Health Research : A Phenomenographic Inquiry'. FORUM QUALITATIVE SOCIAL RESEARCH, *17*(2), Art 27.

Staley, K. (2009) *Exploring impact: Public involvement in NHS, public health and social care*. Eastleigh: INVOLVE.

Stanmore, E., Ormrod, S., and Waterman, H. (2006) 'New roles in rehabilitation - The implications for nurses and other professionals'. *Journal of Evaluation in Clinical Practice*, *12*(6), pp. 656–664.

Stewart, J. E. (2014) *Living with brain injury: narrative, community and women's renegotiation of identity*. New York: New York University Press.

Stickley, T. (2006) 'Should service user involvement be consigned to history? A critical realist perspective'. *Journal of Psychiatric and Mental Health Nursing*, *13*(5), pp. 570–577.

Stonehouse, D. (2015) 'Reflective practice : Ensuring quality care'. *British Journal of Healthcare Management*, *21*(5), pp. 237–241.

Stucki, G., Cieza, A., and Melvin, J. (2007) 'The International Classification of Functioning, Disability and Health: a unifying code for the conceptual description of the rehabilitation strategy'. *Journal of Rehabilitation Medicine*, *39*, pp. 279–285.

Suddick, K. M. and De Souza, L. H. (2007) 'Therapists' experiences and perceptions of teamwork in neurological rehabilitation: critical happenings in effective and ineffective teamwork'. *Journal of Interprofessional Care*, *21*(6), pp. 669–86.

Sugavanam, T., Mead, G., Bulleya, C., Donaghy, M., and van Wijck, F. (2013) 'The effects and experiences of goal setting in stroke rehabilitation – a systematic review'. *Disability and Rehabilitation*, *35*(3), pp. 177–190.

Sumsion, T. and Law, M. (2006) 'A review of evidence on the conceptual elements informing client-centred practice'. *Canadian Journal of Occupational Therapy*, *73*(3), pp. 153–162.

Swain, J., French, S., and Cameron, C. (2003) *Controversial Issues in a Disabling Society*. Buckingham: Open University Press.

Swain, J., French, S., Cameron, C., and Cook, T. (2003) 'Policy: is inclusion better than integration?' in Swain, J., French, S., and Cameron, C. (eds.), *Controversial Issues in a Disabling Society.* Maidenhead: Open University Press, pp. 111–121.

Swain, J. and French, S. (2004) 'Who's tragedy? Towards a Personal Non-Tragedy View of Disability', in Swain, J., French, S., Barnes, C., and Thomas, C. (eds.), *Disabling Barriers-Enabling Environments*. 2nd edn. London: Sage Publications Limited, pp.34–40.

The Aspen Institute. (2003) *Theory of Change: Guided Example Project Superwomen*. New York: ActKnoweldge and Aspen Institute Roundtable on Community Change.

Thomas C. (1999) *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.

Thomas, C. (2004a) 'Developing the social relational in the social model of disability: a theoretical agenda', in Barnes, C. (ed.) *The Social Model of Disability - Theory and Research*. Leeds: The Disability Press, pp.32–47

Thomas, C. (2004b) 'Rescuing a social relational understanding of disability'. *Scandinavian Journal of Disability Research*, *6*(1), pp. 22–36.

Thomas, C., Atkin, H., and Thomson, L. (2015) 'Emancipatory research as occupation – is it a pathway to recovery, health and wellbeing?' *Health and Wellbeing through Occupation 3rd International Occupational Science Europe Conference*. Bournemouth University: Occupational Science Europe.

Tilburt, J. and Geller, G. (2007) 'Viewpoint: The Importance of Worldviews for Medical Education', *Academic Medicine: 82*(8), pp. 819–822.

Titchen, A. (1994) 'Roles and relationships in collaborative research'. *Surgical Nurse*, *7*(5), pp. 15–19.

Townsend, A. (2013) 'Principled challenges for a participatory discipline'. *Educational Action Research*, *21*(3), pp. 326–342.

Townsend, E. A. and Polatajko, H. (2007) *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Wellbeing and Justice through Occupation*. Ottowa, Ontario: CAOT Publications ACE.

Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., Hoes, A., and Schuurmans, M. (2013) 'Self-management: one size does not fit all'. *Patient Education and Counselling*, *2*(1), pp. 134–7.

Trede, F. (2012) 'Emancipatory physiotherapy practice', *Physiotherapy Theory and Practice*, *28*(6), pp. 466–473.

Twohig, P. L. and Putnam, W. (2002) 'Group interviews in primary care research: advancing the state of the art or ritualized research?' *Family Practice*, *19*(3), pp. 278–84.

United Nations. (1948) *Universal Declaration of Human Rights*. Geneva: United Nations.

United Nations. (2007) *Convention on the Rights of Persons with Disabilities and Optional Protocol* (Vol. 2515). Geneva: United Nations.

van de Weyer, R. C., Ballinger, C., and Playford, E. D. (2010) 'Goal setting in neurological rehabilitation; staff perspective'. *Disability and Rehabilitation*, 32(17), pp. 1419–1427.

van den Broek, M. D. (2005) 'Why does neurorehabilitation fail?' *The Journal of Head Trauma Rehabilitation*, *20*(5), pp. 464–473.

van Langenhove, L. and Harre, R. (1999) 'Positioning and the production and use of stereotypes', in L. Harre, R. and van Langenhove (eds.) *Positioning theory: moral contexts of international action.* Oxford; Blackwell, pp. 127–137.

Vasilachis De Gialdino, I. (2011) 'Ontological and Epistemological Foundations of Qualitative Research'. *FORUM : QUALITATIVE SOCIAL RESEARCH*, *10*(2), Art. 30.

Vobruba, G. (2000) 'Actors in Processes of Inclusion and Exclusion: Towards a Dynamic Approach'. *Social Policy and Administration*, *34*(3), pp. 601-613.

Wade, D. and de Jong, B. (2000) 'Recent advances in rehabilitation'. *British Medical Journal*, (20 May), pp. 1385–1388.

Wade, D. T. and Halligan, P. W. (2004) 'Do biomedical models of illness make for good healthcare systems? Importance of models for understanding illness'. *British Medical Journal*, *329*(11 December), pp. 1398–1401.

Wade, D. (2009) 'Principles of neurological rehabilitation', in Donaghy, M. (ed.) *Brain's Diseases of the Nervous System.* Oxford: Oxford University Press, pp. 165–179.

Wade, D.T. (2015) 'Rehabilitation - a new approach. Overview and Part One: the problems'. *Clinical Rehabilitation*, *29*(11), pp. 1041–50.

Wadsworth, Y. (2006) 'The Mirror, the Magnifying Glass, the Compass and the Map: Facilitating Participatory Action Research', in Reason, P. and Bradbury, H (eds.), SAGE *Handbook of Action Research*. London: Sage Publications, Ltd pp.322–334.

Wain, H., Kneebone, I., and Billings, J. (2008) 'Patient Experience of Neurological Rehabilitation: A Qualitative Investigation'. *Archives of Physical Medicine and Rehabilitation*, *89*, pp. 1366–1371.

Walker, L. and Avant, K. (2010) *Strategies for Theory Construction in Nursing.* 5th edn. New Jersey: Prentice Hall.

Walmsley, J. and Johnson, K. (2003) *Inclusive research with people with learning disabilities: Past, present and futures.* London: Jessica Kingsley.

Walseth, L. and Schei, E. (2011) 'Effecting change through dialogue: Habermas' theory of communicative action as a tool in medical lifestyle interventions. *Medicine, Health Care and Philosophy*, *14*(1), pp. 81–90.

Wang, C. and Burris, M. A. (1997) 'Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment'. *Health Education Behaviour*, *24*(3), pp. 369–387.

Wanless, D. (2002) *Securing our future public health: taking a long term view.* London: H.M.Treasury

Warsi, A., Wang, P., LaValley, M., Avorn, J., and Solomon, D. (2004) 'Self-management Education Programs in Chronic Disease A Systematic Review and Methodological Critique of the Literature'. *Archives of Internal Medicine*, *164*(9), pp. 1641–1649.

Waterman, H. Tillen, D., Dickson, R., and de Koning, K. (2001) 'Action Research: a systematic review and guidance for assessment'. *Health Technology Assessment*, *5*(23), pp. i-69.

Watson, N. (2002) 'Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and Disability'. *Disability and Society*, *17*(5), pp. 509–527.

Weick, K. E., Sutcliffe, K. M., and Obstfeld, D. (2005) Organizing and the Process of Sensemaking. *Organization Science*, *16*(4), pp. 409–421.

Weiss, C. (1995) 'Nothing as Practical as a Good Theory: Exploring Theory-based Evaluation for Comprehensive Community Initiatives for Children and Families', in Connel, J.P., Kubisch, A.C., Schorr, L.B., and Weiss C. H. (ed.), *New Approaches to Evaluating Community Initiatives: Volume I, Concepts, Methods and Contexts*. Washington DC: The Aspen Institute.

Welsh, E. (2002) 'Dealing with data: Using NVivo in the qualitative data analysis process'. FORUM: QUALITATIVE SOCIAL RESEARCH, *3*(2), Art 26.

Whiteford, G. and Pereira, R. (2012) 'Occupation, inclusion and participation', in Whiteford, G. and Hocking, C. (eds.), *Occupational Science: Society, Inclusion and Participation*. Oxford: Blackwell Publishing Ltd, pp. 187–207

Wilson, B. and Gracey, F. (2009) 'Towards a comprehensive model of neuropsychological rehabilitation', in Wilson, B.A. Gracey, F. and Evans, J. (eds.), *Neuropsychological Rehabilitation: Theory, Models, Therapy and Outcome*. Cambridge: Cambridge University Press.

Winter, R. (1998) 'Finding a voice – thinking with others : a conception of action research Finding a Voice – Thinking with Others : a conception of action research'. *Educational Action Research*, *6*(1), pp. 53–68.

Winter, R. (2002) 'Truth or fiction: problems of validity and authenticity in narratives of action research'. *Educational Action Research*, *10*(1), pp. 143–154.

Winter, R., and Munn-Giddings, C. (2001) *A Handbook for Action Research in Health and Social Care*. London: Routledge.

World Health Organization. (2001) *International Classification of Functioning, Disability and Health. ICFDH*. Geneva: WHO.

Yancher, S.C. and Slife, B. D. (2004) 'Teaching Critical Thinking by Examining Assumptions', *Teaching of Psychology*, *31*(2), pp. 85–90.

Ylvisaker, M., Jacobs, H. E., and Feeney, T. (2003) 'Positive supports for people who experience behavioral and cognitive disability after brain injury: a review'. *The Journal of Head Trauma Rehabilitation*, *18*(1), pp. 7–32.

Young, I. M. (2000) *Inclusion and Democracy.* Oxford: Oxford University Press.

Young, C. A., Manmathan, G. P., and Ward, J. C. R. (2008) 'Perceptions of goal setting in a neurological rehabilitation unit: A qualitative study of patients, carers and staff'. *Journal of Rehabilitation Medicine*, *40*(3), pp. 190–194.