

Doctorate in Clinical Communication Science
University College London

Evaluation of a Multidisciplinary
Transitional and Community
Rehabilitation Intervention for
Adults with Severe Acquired
Brain Injury

A Case Series Exploring Community
Integration

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I, Clare Diana Thomas, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed

Date:

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Abstract

Introduction: Healthcare policy in the United Kingdom supports community placement following acquired brain injury (ABI). Evidence supports the efficacy of multidisciplinary neurorehabilitation for this group but is limited for programmes supporting community integration in adults with severe disability. This study describes the development and initial evaluation of a transitional and community intervention in this area.

Methods: The study comprised five repeated measures single case studies as well as semi structured interviews with four of the participants' relatives or friends. Outcomes measures used were the Community Integration Measure, UK Functional Independence Measure/ Functional Assessment Measure and Mayo Portland Adaptability Inventory. Clinical validity was measured using Goal Attainment Scaling.

Results: All participants returned to living in the community with significantly improved functional independence and good goal attainment. One participant reported improved community integration but four did not. Reasons for this include: the impact of insight and anxiety on self-report of community integration; ongoing challenges with independence; and outcome choice. Key successful elements of the intervention were identified including: consistent rehabilitation routines; use of trained support workers; and appropriate use of risk assessment to support independence.

The participants' relatives expressed satisfaction with the intervention and the professional support provided. Concerns raised related to communication of goals and discharge planning, intensity of therapy and the environment of the Transitional Unit.

Conclusions: This study provides an initial positive evaluation of the intervention but indicates the need to complete further evaluation and with additional outcome measures for community integration. Key learning points from the case studies can be replicated in other services, including the use of goal setting protocols, support worker training and protocols for assessment of capacity and risk.

Impact Statement

The aim of this study was to describe the development of a rehabilitation intervention in acquired brain injury and to complete an initial evaluation of the intervention to inform quality improvement.

Community and transitional rehabilitation programmes are often not well described in the published literature and this presents challenges to evidence based service development. The current study provides a detailed description of the core components of the programme with defined key elements that can be replicated by other services.

The findings from this study can inform future quality improvement of acquired brain injury rehabilitation services at a numbers of levels. Firstly the findings are directly applicable to service described in the study and improvements have been made to core elements of that service as a direct result of the conclusions. The findings can also be applied to other similar services by providing evidence about structured components of the intervention that were successful in supporting people with acquired brain injury to return to living in the community. The findings provide a basis to build on the intervention and increase the standardised materials and resources that can be used in acquired brain injury rehabilitation services. The case examples also inform which patients will most benefit from a dedicated transitional rehabilitation. This study can also support that wider discussion of 'what does good practice looks like' because the information provided is detailed and the relative participant interviews provide a useful perspective that is applicable to services beyond the one in this study.

The findings from this study will be disseminated via presentation at conferences and special interest groups. Key elements from the study will be submitted for publication in relevant journals. The participants and relative participants were given verbal feedback about the study and the changes made to the intervention as a result.

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1. Introduction

This study describes the development and initial evaluation of a multidisciplinary transitional and community intervention. The methodology chosen was a combination of repeated measure single case studies and interviews with the participants' relatives or close friends. The study design was selected to provide detailed descriptions of the intervention and how it was delivered to the individual participants as well as gathering a range of perspectives on the clinical intervention that can inform service improvement and future research.

This initial section presents the research questions and structure of the thesis. The healthcare context and terms used are also detailed here.

1.1. Research questions:

The research questions addressed by this study are:

Primary research question:

- For adults with severe acquired brain injury choosing to return to live in the community, is a multidisciplinary transitional and community rehabilitation programme successful in increasing community integration?

Secondary research questions

- What is the relationship between outcomes based on level of impairment and outcomes based on level of community integration?
- What is the experience of close relatives of adults with severe acquired brain injury returning to live in the community?

In order to answer these research questions, this thesis presents:

- The current United Kingdom service context as well as the key terms as they are used in the rest of the thesis (Chapter 1).

- A scoping review of the relevant literature in the area of neurorehabilitation in acquired brain injury, which informed both the development of the clinical intervention and the research design (Chapter 2).
- The development of the research intervention in the context of the evidence presented (Chapter 3).
- The key methodological issues considered and a description of the selected methodology (Chapters 4 and 5).
- Repeated measures case studies that describe in detail how the intervention was delivered and individualised (Chapters 6-10), with presentation of the individual results and analysis (Chapter 11) and the themes from the relative participant interviews (Chapter 12).
- An overall analysis of the case series (Chapter 13) and conclusions of the study, including strengths and weaknesses (Chapter 14).

1.2. Definitions of terms

These terms are used in this thesis to refer to the clinical population, the interventions used and the service designs. The terms are defined here and used consistently throughout the thesis. The literature presented in chapter 2 covers a broad heterogeneous area and terms are not always used consistently. Therefore this section is included here to support understanding of the key concepts discussed throughout the remainder of this thesis.

Acquired Brain Injury (ABI): The term ABI is used here to define the clinical population and incorporates any rapid onset brain injury including vascular injury or stroke, traumatic injury, hypoxic brain damage and infection. In this study, the term ABI has been kept intentionally broad to include a variety of different aetiologies. There is a precedent for this approach in recent literature, and a practical sense in treating complex ABI based on impairments rather than underlying cause. This is discussed in

some detail in the 2015 Cochrane review of neurorehabilitation following ABI (Turner-Stokes et al., 2015) and is consistent with the management of ABI in the National Service Framework (NSF) for Long Term Neurological Conditions (Agrawal & Mitchell, 2005) and the British Society of Rehabilitation Clinical Guidelines for Rehabilitation following Acquired Brain Injury (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003).

ABI is a major cause of disability in the UK, with an estimated 420,000 people aged under 65 living with long term disability following a traumatic brain injury (Agrawal & Mitchell, 2005). Prevalence figures for people living with disability following all types of ABI are difficult to establish accurately due to the variation in types and severity of injury. The brain injury charity, Headway, completed a detailed report into the number of admissions to hospital in the United Kingdom, with an ABI of any cause using International Classification of Diseases (ICD-10)¹ codes over a 10 year period (Headway, 2015). The most recent statistics showed that there were 348,934 cases in the year 2013/14 which equates 566 per 100,000, although this is not an incidence figure as it cannot be assumed they were all single admissions and does not include people who died before they were admitted to hospital. This was an increase of 10% since 2005/06 which indicates this is a growing challenge to health services.

In practice, the research often distinguishes between complex ABI and stroke, as services are often provided separately for these two groups. Some studies focus on narrower populations based on service design or demand (e.g. military funded research into traumatic brain injuries). Adults with ABI are a heterogeneous group and clinical presentation can involve a range of physical and cognitive impairments of differing severities. The population is further complicated by associated factors such as high levels of co-existing drug and alcohol problems or co-diagnoses. When referring to

¹ ICD-10: This is a medical classification system produced by the World Health Organisation. It is on the 10th revision and includes codes for diseases and symptoms.

published research, the clinical population will be described in more detail during the literature review. For the current study, the detailed inclusion criteria given will further define the participant group.

Neurorehabilitation: This term is used to describe the research intervention. In practice, it covers a broad range of approaches and includes interventions from hospital treatment immediately post injury to long term care and support in the community. Neurorehabilitation is usually, but not always, delivered within the context of a multidisciplinary team (see below). Most studies focus on a particular stage of the pathway or defined intervention. The interventions in previous research studies will be defined and compared to the intervention in this study as part of the discussion of the current literature.

The participants in this study have all been through a number of stages of specialist rehabilitation which fit the definition in the Neurorehabilitation Service Standards:

‘the total active care of patients with a disabling condition, and their families, by a multi-professional team who have undergone recognised specialist training in rehabilitation’

(Turner-Stokes, 2010, page 2).

Within this broad definition there are stages of the rehabilitation pathway where the focus of the programme can be further defined as follows:

Acute/ Hyper-acute rehabilitation: Refers to specialist rehabilitation interventions provided during the early acute part of a hospital admission and may be provided whilst a person is still medically unwell or undergoing surgical or medical treatments for other aspects of their conditions.

Post-acute rehabilitation: This refers to a period of in-patient rehabilitation provided in a dedicated rehabilitation unit with a specialist clinical team. This level of rehabilitation is usually targeted at people who are medically stable and demonstrate potential to engage in an intense rehabilitation programme.

Transitional rehabilitation: Rehabilitation designed to support a person to move back to a more independent living situation and reduce dependence on clinical services. It may be provided in an in-patient or community setting.

Community rehabilitation: Refers to rehabilitation support that a person receives in their own home or community location (such as work or leisure facility).

Multidisciplinary team (MDT): This term is used to describe the team that deliver the research intervention. An MDT consists of a number of different professionals with specific areas of expertise working together with a focus on the patient. NHS England describes an MDT approach as:

‘drawing appropriately from multiple disciplines to explore problems outside of normal boundaries and reach solutions based on a new understanding of complex situations’

(NHS England, 2014, page 12)

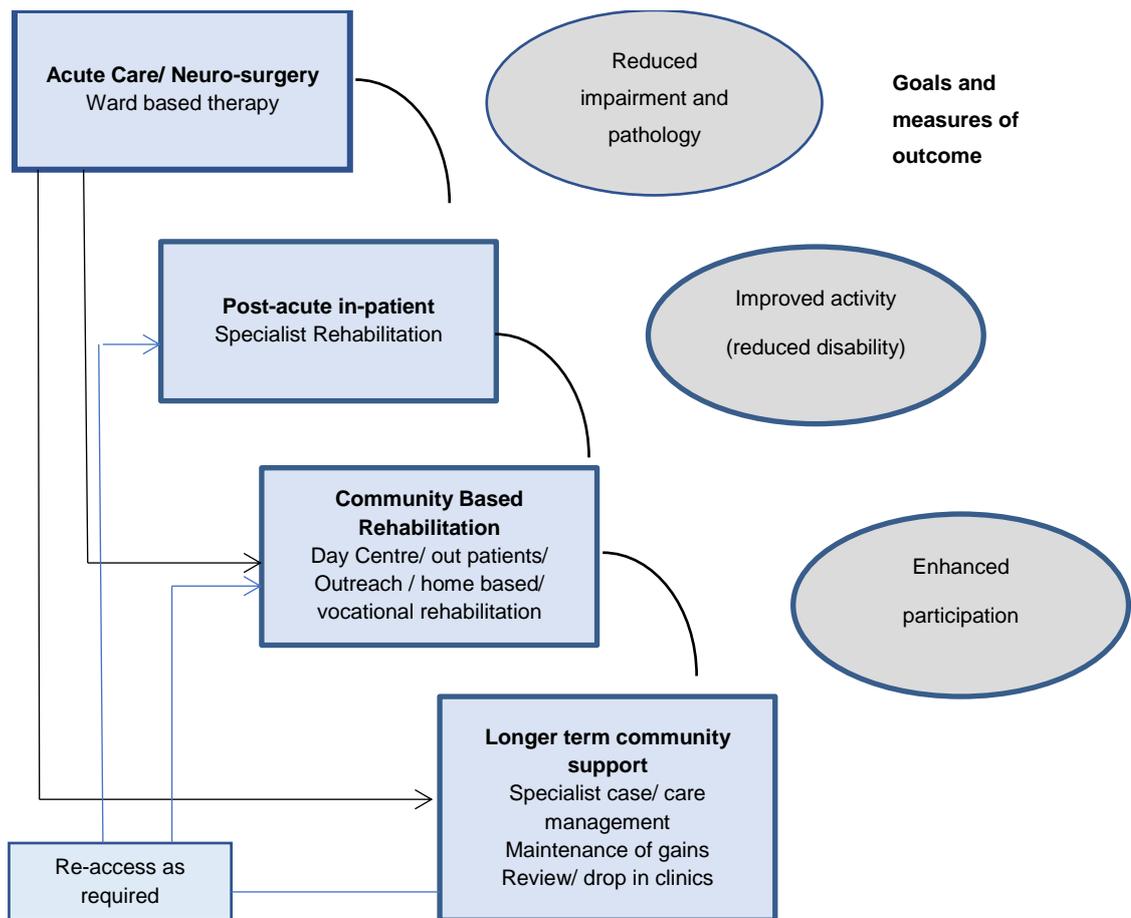
Services and research in neurorehabilitation use different terms to describe teams such as interdisciplinary or transdisciplinary team. These terms can be seen on a continuum indicating to what extent the team retain their individual professional identities and areas of expertise. The intervention described in the current study is delivered around person centred goals. Each professional in the team brings their own expertise to inform assessment and intervention planning but much of the work is carried out collaboratively and with the support of rehabilitation assistants who work across the whole team. When describing other research, the terms used by the authors are used with a brief summary of the teams they describe.

1.3. Neurorehabilitation model

The 2003 National Clinical Guidelines for Rehabilitation Following Acquired Brain Injury, (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003) presents a model of rehabilitation services that is supported in recent literature. The model, described as the Slinky Model of Rehabilitation, is reproduced below. This

model and a brief discussion of the development of ABI pathways in London, United Kingdom (UK), is presented here to provide context to the literature. The model is also presented to place transitional and community rehabilitation in the context of the whole pathway.

Figure 1: Slinky Model of Rehabilitation, reproduced from Royal College of Physicians and British Society of Rehabilitation Medicine, 2003, page 10



The model advocates a smooth transition between stages of rehabilitation, with intervention at each stage provided by a specialist, co-ordinated team. The model assumes most patients will progress from acute to community rehabilitation but with flexibility if a person needs to re-access services at any point. Underlying the model is the principle that, as a person moves from hospital to home, the goals of their

rehabilitation will shift from a focus on reducing impairment and pathology in hospital, to enhanced participation in long term and community settings. This principle is widely supported in the ABI literature (Turner-Stokes et al., 2015), this will be discussed in more detail in Chapter 2.

The model presented above is now widely accepted as a good practice with many of the principles repeated in more recent clinical policy documents (Agrawal & Mitchell, 2005; Royal College of Physicians, 2011)

1.4. Commissioning and organisation of neurorehabilitation services in London, UK

Commissioning in this context refers to the planning, contracting and monitoring of health services. In England, the National Health Service (NHS) is responsible for the commissioning of publicly funded healthcare. At the time of writing, NHS commissioning is managed on a two-tier system. Local commissioning is managed by Clinical Commissioning Groups (CCGs). These consist of groups of member General Practices and are clinically led organisations with the remit to commission services for a patient population linked to practice registration. Highly specialist services, those required by a small number of people across a large geographical area, are commissioned by NHS England (NHSE), a national commissioning organisation.

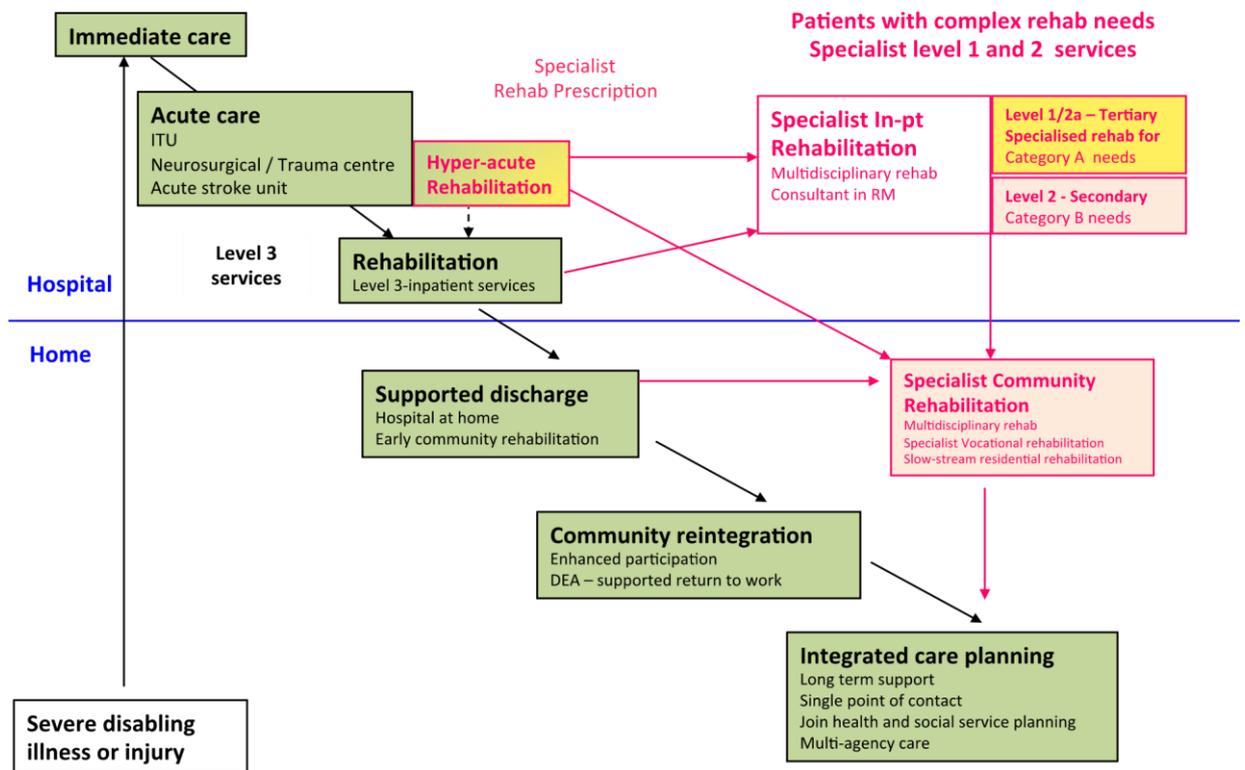
The current study was completed in a central London borough. Based on the 2011 census (London Data Store 2012), London had a population of 8.17 million people who were usually resident. This represented a growth of 14 % over the previous ten years and a number of boroughs, including the one in this study, had seen higher growth of between 21% and 30 %. London has a socially and ethnically diverse population. The density and diversity of the London population presents particular challenges when planning and delivering healthcare. Where relevant, these issues are identified and discussed when describing the research intervention.

Over the last ten years, neurorehabilitation services for people with complex needs following ABI have been organised into co-ordinated networks to ensure efficient use of resource and equity of access. In London, there are several established highly specialist centres for neurorehabilitation and historically there were long waits for these services and delays in patients moving on due to a lack of expertise or appropriate long-term services in the community. The recent developments in defining, co-ordinating and commissioning these services have improved flow through the pathway.

Neurorehabilitation services for people with ABI are now organised in accordance with the NHS Service Specification and the Standards for People with Highly Complex Needs (Turner-Stokes, 2010; Turner-Stokes, 2013). The service specification is based on categorising patient need into four levels (A, B, C and D) indicating the types of presenting impairments and the intensity of care and rehabilitation required. These patient categories are mapped onto five levels of specialist service (1,2a/2b and 3a/3b) based on the expertise and intensity of provision available. These categories and service levels are not presented in detail here but are included in Appendix 1. Level 1 and 2a services are commissioned by NHS E and Level 2b and 3a/ 3b services are CCG commissioned. The specific service types can be mapped onto the Slinky model of rehabilitation to show how the networks of services should deliver the model (see Figure 2).

Following an acute episode, patients are assessed, and if they present with highly complex needs (usually category A or B needs) then they will receive a period of in-patient highly specialist rehabilitation via the NHS E pathway (Level 1/2a services). Following this episode, most patients will need further rehabilitation support, still within the specialist part of the pathway but from a more local team (Level 2b or Level 3/ specialist community services). In London, Level 1/2a services are well established but there is inconsistent Level 2b and specialist community provision.

Figure 2: Pathway for rehabilitation following illness or injury (taken from Turner Stokes 2015, page 2)



Community services for people with ABI include specialist rehabilitation services as described above but also incorporate general health, social care and voluntary services. On discharge from in-patient rehabilitation, people with ABI receive a package of care, based on an assessment of their needs. In England, this care can be funded by either the NHS or the Local Authority department². Needs are assessed against the National Framework for NHS Continuing Healthcare (Department of Health, 2012) and the Care Act (2014). These documents identify what care each organisation is responsible for providing. If a person is deemed eligible for Continuing Healthcare

² Local Authority departments in the UK are part of the structure of local government. They cover small geographical areas such as a city, a section or borough of a large city or a rural area around a central town. They are responsible for a number of local services, key to this study, they are responsible for the provision of social housing and social care services.

(CHC)³ then the NHS will pay for their care. If not, the care will be funded by the Local Authority and the individual may need to make a financial contribution. In either case a package of care can incorporate support for physical, cognitive and social needs and can be provided via a range of services from traditional care agencies and specialist providers.

The current study describes the development of an NHS Level 2b transitional rehabilitation unit and a specialist community ABI pathway within a Level 3a community team. Five case studies are used to describe and explore the intervention. In each case study, detailed information will be given about the participants' personalised intervention. The care services each participant receives from the NHS, Local Authority or voluntary organisations will also be described. These care services fall outside the research intervention but there is an interaction between the research intervention and care providers. These care services also impact on clinical outcomes and therefore need to be described and discussed as part of the study.

1.5. Summary:

The information presented in this chapter provides the healthcare context and definitions used throughout the thesis. In the next chapter the relevant literature is reviewed with the intention of mapping the evidence relevant to the research questions and demonstrating how this evidence informed the development of the clinical intervention and the research design.

³ CHC is the provision of care funded by the NHS. This is available for people with care needs that are primarily due to a health need rather than a social care need. Full guidance can be found in the National Framework for NHS Continuing Healthcare (DOH, 2012)

2. Literature review

2.1. Introduction

Chapter 1 provided the background context to this study and presented the research questions. This chapter provides a review of the relevant evidence from published research literature and clinical guidelines. The review aims to systematically explore the background topics that relate to the research questions in the current study and demonstrate how these areas informed the study design.

The scope of this review was to explore, evaluate and summarise the literature relating to the participant group (adults with acquired brain injury) and the intervention (neurorehabilitation). The review is not a systematic review as these tend to focus on well-defined research questions within a single area and limit the review to studies using specified methodologies. The primary research question in this thesis relates to community integration following ABI however the inclusion of the secondary research questions extends the topic to consider other factors such as types of outcomes and the experience of family members. The focus of the review is therefore broad to include all of these areas. Studies were included in the review with a broad range of research methodologies to incorporate service model examples and professional, patient and carer experiences that might inform the development and evaluation of the study intervention.

The process followed was to initially identify the research questions as presented in section 1.1, relevant literature was then searched for and refined as described in section 2.2. Once the relevant literature was identified it was themed according to the stage of the rehabilitation pathway that it referred to or the issue addressed. This informed the structure of the current chapter and helped to present the literature in a format that could be easily linked to the design of the intervention. The review signposts points of learning that informed the intervention and research design in the

current study, as well as gaps in the literature that indicate need for further exploration. The review therefore followed a number of the stages defined by Arksey and O'Malley (2005) for completing a scoping review. Scoping reviews have been used to provide a detailed mapping of the literature onto a broad topic in this way in a number of healthcare fields (Pham et al., 2014).

The review was initially completed to inform the design of the intervention and has been repeated and refined alongside the research process to incorporate new evidence.

2.2. Search strategy

Literature in the field of ABI covers several topic areas and is published in a range of journals. Trials of pairing 'acquired brain injury' and 'severe acquired brain injury' with different terms such as 'community rehabilitation', 'transitional rehabilitation', 'community integration' and 'participation' revealed the most useful terms were 'acquired brain injury', 'community integration' and 'transitional rehabilitation'. Other terms either narrowed the search too much (e.g. severe ABI) or produced too many non-relevant results (e.g. participation).

The search was performed in PubMed and Medline, searching for terms in the subject, abstract or title depending on the database. Results were then refined by excluding studies that referred to children and further refined by reviewing all abstracts. Studies were selected if they related to adults with ABI at any stage of the rehabilitation pathway; studies were included with a focus on the design or evaluation of interventions, experiences of patients or experiences of relatives. Further relevant literature was identified from the reference lists of the articles identified and from the evidence based clinical guidelines (Agrawal & Mitchell, 2005; Royal College of Physicians, 2011; Royal College of Physicians and British Society of Rehabilitation Medicine, 2003, Intercolligiate Stroke Working Party, 2016). Studies were not excluded

on the basis of research methodology in line with the aims of the review defined in section 2.1.

Specific interventions and outcome measures were searched for separately to identify literature in these areas. The majority of relevant literature was published in either Brain Injury, Archives of Physical Medicine or the Journal of Neurorehabilitation. Further references were therefore obtained by manually reviewing the contents of these journals. Lastly, searches were performed across a broader topic base than ABI to explore literature that related to the design and evaluation of interventions in healthcare more generally.

2.3. Evidence for the effectiveness of ABI rehabilitation

The literature search produced a range of studies on the effectiveness of interventions in ABI rehabilitation. There is a greater volume of evidence in areas where services are well developed, such as in-patient rehabilitation for younger adults (Turner-Stokes, 2008) and early supported discharge for stroke (Intercollegiate Stroke Working Party 2016). There fewer studies relating to evidence of the benefits of acute (Andelic et al., 2012; Greenwood et al., 2004) and community rehabilitation (Geurtsen et al., 2010; Powell, Heslin, & Greenwood, 2002). A number of reviews of the evidence for rehabilitation after ABI have concluded that there is insufficient large scale randomised control data to support general conclusions about effectiveness and that further trials of this type should be carried out (Cicerone et al., 2008; Kim and Colantonio, 2010).

However these authors and others have argued that in complex clinical fields such as brain injury, valid evidence can be gathered using alternative designs (Turner-Stokes, 2008). For the purpose of this review a broad range of research designs will be considered to ensure detailed service examples and professional, patient and carer experiences are included as described.

Within ABI research, early systematic reviews concluded that there was little or no robust experimental research evidence to support the effectiveness of rehabilitation

(Cicerone et al., 2005). However a more recent Cochrane review has concluded that experimental evidence is available (Turner-Stokes et al., 2015).

The Cochrane Review (Turner-Stokes et al., 2015) looked at experimental studies including randomised controlled trials (RCTs) and controlled clinical trials (CCTs) that compared multidisciplinary rehabilitation interventions with a control group, or compared different levels of intensity or settings. This was the second update of this review, first completed in 2005 and 2008. The review aimed to identify an emerging evidence base for adults of working age with all types of ABI, as much of the previous literature at the time had focused only on stroke. The 2015 update found a total of 19 studies using van Tulder's criteria, which is a checklist of 19 quality criteria (van Tulder et al., 1997). The authors found that studies covered a range of intervention types within the umbrella term of ABI rehabilitation, as well as a heterogeneous group of participants. They grouped the studies into the following areas based on the characteristics of either the participant group or the programme: 1) Milder ambulatory patients, 2) Patients with greater limitations on activities, 3) Effectiveness of community based co-ordinated multidisciplinary rehabilitation, 4) Specialist in-patient rehabilitation 5) Increased intensity of rehabilitation 6) Early versus delayed rehabilitation and 7) Therapeutic milieu based rehabilitation. The last category is a term used in the current literature to refer to a holistic approach to rehabilitation that targets cognitive impairments within specific activities and real contexts to support people to establish successful routines post ABI. These programmes can be provided as in-patient or intensive day programmes (Cicerone et al., 2008). The first five of the categories mirrored the earlier version of the review but the last two were new, based on three new trials included in the updated version (Andelic et al., 2012; Bai et al., 2012; Cicerone et al., 2008). The authors discuss themes that arise, such as the ethical challenges of allocating patients to control or non-treatment group, and the associated difficulties of establishing large trials with good quality randomisation and controls.

They highlight the wide variety of service models even between services that use the same labels. The authors used van Tulder's 2003 assessment of methodological quality to draw conclusions about the strength of the evidence in each topic area; this method considers the number of trials available as well as the quality of the research design. 'Strong evidence' is defined as 'consistent statistically significant findings in outcome measures in two or more high-quality RCTs' (van Tulder et al., 2003). Across the groups, they draw conclusions about the effect of different interventions. Key to the current discussion were the following findings:

- 'Moderate evidence' for the effectiveness of outpatient rehabilitation for stroke with some 'indicative evidence' that this may be effective as long as one-year post stroke.
- 'Limited evidence' for multidisciplinary community rehabilitation targeted at specific goals particularly goals targeting the activity level of the International Classification of Function (ICF)⁴
- 'Limited evidence' to support specialist in-patient rehabilitation to increase activity and reduce carer stress
- 'Strong evidence' for more intensive rehabilitation once medically stable.
- 'Limited evidence' to support the early onset of rehabilitation (in the acute phase)
- 'Strong evidence' for milieu-based rehabilitation

These conclusions support the Slinky model of rehabilitation presented in Chapter 1, as they provide some evidence to support both early and longer term co-ordinated multidisciplinary rehabilitation in hospital and community settings, although the more compelling evidence is still skewed towards in-patient interventions. The authors

⁴ ICF: This is a framework for classifying function and disability published by WHO. It defines disability as a multi-level concept, taking account of body functions and structures, activities, participation and environmental factors.

discuss the need to build on this evidence and to look to a range of research designs to fill some of the current gaps, linking their findings to the broader discussion of the challenges of applying systematic reviews in such complex care pathways. The principle of systematic reviews is that the impact of individual RCTs can be increased by combining all of the research for one treatment or clinical population. The challenge with ABI research, as noted by the authors, is that the interventions and outcomes measures used are broad and the clinical population diverse, making combining findings from different studies difficult. There are ethical challenges associated with allocating people to a control (no- treatment) group following ABI. This issue has been overcome in some instances if the intervention being evaluated is new or if an alternative treatment option exists (Powell et al., 2002) but in some cases, this results in dilution of the control or the allocation process. Finally, associated factors such as dual diagnosis or co-existing drug and alcohol dependency, further complicate the picture with some studies opting to exclude participants to control the number of variables.

The emergence of experimental research in the last 15 years has raised the profile of ABI rehabilitation, contributed to policy development and provided a solid evidence base in some areas. However, increasingly, this traditional approach is combined with a broad range of non-experimental designs, and expert opinion. In generating the evidence for the NSF in Long Term Neurological Conditions, a new approach was used to identify a wider base of evidence (Turner-Stokes et al., 2006). The authors argue that, because the patient group is heterogeneous, interventions will cover a long period of time and will usually be targeted at improving function rather than 'curing' a condition, it is important to consider alternative sources of evidence. They developed a new typology that allowed inclusion of qualitative research, expert, patient and carer experience. As a result, they were able to draw the following additional key conclusions in relation to neurorehabilitation:

- Evidence that early post-acute multidisciplinary rehabilitation leads to better outcomes and shorter lengths of stay (co-morbidity and severity of injury confounding issues)
- Evidence that specialist in-patient rehabilitation is effective in reducing dependence on others, even for participants with very severe levels of disability
- Evidence that behavioural and community rehabilitation programmes lead to improved objective outcomes such as decreased need for participants to be supervised during tasks, as well as subjective reports of improved social participation and adjustment.

The conclusions summarised here present the background to the evidence base for the benefits of co-ordinated multidisciplinary rehabilitation along the lines of the Slinky model. The current study focuses on people choosing to return to the community following severe ABI and therefore the next section of this review will focus on the later stages of rehabilitation, from hospital discharge to long term community support, in more detail.

2.4. Discharge and transition to the community

Discharge from hospital after a long period and return home is recognised as a potentially challenging point in the rehabilitation pathway (Simpson et al., 2004). A recent qualitative review of discharge planning in ABI concluded that discharge planning was often characterised by poor planning and engagement leading to unsatisfactory or disorganised transitional periods (Piccenna et al., 2016). The importance of planning discharge carefully and carrying out research focused on this transitional point was recommended in the Cochrane review (Turner-Stokes et al., 2015). There are services that focus specifically on this transitional period and a small body of evidence relating to evaluation and effectiveness of these services.

An example of an established UK transitional programme for people with complex cognitive and behavioural needs following ABI is described by Jackson and others (Jackson et al., 2014). The Transitional Rehabilitation Unit (TRU) is described in terms of the theoretical framework that underpins it, based on the assumption that people with cognitive impairment require high levels of structure to function effectively. The emphasis of the programme is on supporting people to progress from a point where they can function in an environment where structure is provided by a skilled staff team, to an environment that they can structure themselves. Three levels of structure are used within the programme as follows:

- Anchors – which are fixed points in the day that form a routine such as times to get up, eat meals, rest, participate in activities and go to bed.
- Scaffolding – which describes aids to maintain a structure such as timetables, alarms and memory aids.
- Strategies – which are rules or patterns of behaviour that people can learn to support them to cope in novel situations. These can range from simple strategies such as knowing how to seek help if a new situation is challenging, to structured problem-solving strategies.

The programme is based on a cognitive behavioural approach of goal setting, and problem solving. At the beginning of the programme, a very high level of structure is provided by the staff team to ensure that patients function successfully within the environment, for example they are prompted and assisted to get up at a regular time, come for meals, attend therapeutic sessions and participate in social activities.

Through the programme, the emphasis shifts from the staff providing this structure to the patient using strategies to maintain their own routine. There are similarities with the therapeutic milieu based programmes mentioned above (Cicerone et al., 2008). The TRU team is described as a transdisciplinary team with all staff members receiving a high level of training in brain injury so that the structure and strategies are reinforced

consistently. The paper provides a very useful practical tool to clinicians in this field as it describes in detail the clinical programme, the theoretical evidence base and how this has been translated into a rehabilitation programme with distinct stages of support. The authors do not report a full evaluation of the programme in this context but they do present audit results based on the overall outcome of 103 patients discharged from the service over a five-year period. Outcomes are reported as successful if patients demonstrated improved function as measured by the rehabilitation team on a range of assessments (not reported in detail) and moved on to a less supportive environment. In the sample audited, 88 patients are reported to have successful outcomes. The remaining 15 patients are described by the authors in terms of 'rehabilitation failure' which is a not a term used elsewhere in the literature and it is unclear from the context whether the authors attribute the failure to the individual or the programme. These patients returned to previous care home placements or were admitted under the Mental Health Act to secure hospital environments. The authors acknowledge that these audit results do not provide an evaluation of the programme but use them to support the description of the service. The TRU programme is a specialist cognitive and behavioural programme and patients are often several years post injury when they are referred. It is useful therefore to also consider transitional programmes for people with a wider range of needs post ABI usually provided in the first year after injury.

Simpson and colleagues (2004) provide a description and evaluation of a Transitional Living Unit (TLU) programme in Australia. The programme is in-patient but based within the community and small to replicate the environment of a group home or supported living scheme rather than a hospital unit. The unit is near to shops, transport links and community services, with an emphasis on accessing these community facilities rather than relying on specialist or hospital services. The service admits patients for the following reasons:

- A need for high intensity rehabilitation not available in community

- A need for further assessment (e.g. safety/ risk) prior to community discharge
- Support needs remain too high for a home-based package but the rehabilitation team assess that further independence can be achieved with more intervention
- Late referral after living in residential placement for some time to 'upgrade to more independent living'

The service has a small core multidisciplinary team of an ABI manager, Nurse, Occupational Therapist, and Rehabilitation Assistant with additional professionals coming in from the community such as Physiotherapist, Speech and Language Therapist and Clinical Neuropsychologist. The evaluation of the programme is based on a sample of 50 patients who complete the programme over a 28-month period. The study compares different outcome measures for this stage in the rehabilitation pathway; four different key outcome measures were used in addition to relevant neuropsychological tests pre and post-intervention and discharge destination. The outcomes measures used were:

- Sydney Psychosocial Reintegration Scale (SPRS) (Tate et al., 1999)
- Mayo Portland Adaptability Inventory (MPAI) (Bohac, Malec & Moessner, 1997)
- Brain Injury Community Rehabilitation Outcome Scale (BICRO) (Powell, 1999)
- Assessment of Living Skills and Resources (ASLAR) (Williams et al., 1991)

Evaluation showed that participants' functional independence improved through the course of the programme and that outcomes were positive in terms of proportion of people returning to live in the community. The measures most sensitive to the areas targeted by the rehabilitation programme were the SPRS and the MPAI. The BICRO showed a ceiling effect for some participants at the beginning of the programme and the ASLAR was deemed useful to measure objective change in terms of independence in key activities of daily living. The discussion of outcome choice will be explored in more detail in Chapter 4. This study is useful as it is a reasonably large sample that

allowed analysis of the outcome measures across the group. Whilst a definite causal link between the rehabilitation programme and the change in outcome cannot be stated as there was no control group, the size of the sample along with the correlation reported between areas targeted by the programme and the areas of change on the MPAI and SPRS support the effectiveness of the intervention. The authors note that neither severity of injury or time post injury were significant factors impacting on outcome, suggesting the programme is effective across a range of ABI needs.

The same service is described by Tate and colleagues (Tate, Strettles, & Osoteo, 2004) focussing on the community rehabilitation section of the same service pathway. This study will be discussed in more detail later, but it is interesting to note that the authors describe the co-ordination across the pathway. Staff move between sections of the pathway and there is a single senior clinical leadership team, therefore patients' needs can be matched to the appropriate point in the pathway because the TLU staff are very familiar with the community services and the support available. The TLU accepts referrals for patients with all ABI diagnoses and does not exclude patients with co-morbidities or a history of drug or alcohol use as they recognise this group often has the most challenges with transitioning from the high-level of hospital support to the community. It is relevant to mention this briefly here because it supports the principles of the Slinky model in the high level of co-ordination between elements of the service.

The service described by Simpson and colleagues (2004) is one of two TLU services compared with community rehabilitation (CR) based services in a more recent study (Hopman, Tate & McCluskey, 2012). The study included a total of 41 participants, 21 received TLU intervention and 20 received CR. Participants could not be randomly allocated but were allocated based on service criteria and geographical location in line with normal service eligibility. Both TLU programmes were residential in-patient structured programmes as described above and the CR programmes were delivered to participants living at home, either in their own home or in a community centre (e.g. for

group therapy elements). The TLU programmes were significantly more intensive with one or more interventions per day compared to one or two interventions per week in the CR programme. A battery of eight outcome measures was administered to capture changes in function in key activities of daily living (ADLs) as well as levels of participation and community integration. The outcome measures included three of those used by Simpson and colleagues (2004), the SPRS, MPAI and the ALSAR. The additional 5 measures were:

- The Functional Autonomy Measurement Scale (SMAF) (Hebert, Carrier & Bilodeau, 1988)
- The Community Integration Questionnaire (CIQ) (Willer et al., 1993)
- Community Integration Measure (CIM) (McColl et al., 2001)
- Care and Needs Scale (CANS) (Tate, 2004)
- Care Burden Scale (CBS) (Knight, Devereux & Godfrey., 1997)

Outcomes were measured at the start of the programmes, at 8 weeks (based on the average length of TLU stays) and at 6 months, to monitor maintenance of gains made. Interestingly, there were no significant differences between the TLU group and CR group on the MPAI, SMAF and CANS at point one. Based on the eligibility criteria for the TLU services, it would be logical to conclude that this group would be more dependent at the start of the programme but this is not supported by the measures. The authors do suggest that the TLU group had greater needs in areas such as management of behaviour but that the profile of measures does not demonstrate this. There were three key findings as follows:

- The participants in both groups demonstrated significantly improved function on the measures used at 8 weeks and 6 months but there was no significant difference between the two groups.

- The CR group demonstrated greater productivity (i.e. improved more in terms of independence in key tasks) than the TLU group between 8 weeks and 6 months.
- The TLU group demonstrated greater improvement in community integration than the CR group between 8 weeks and 6 months.

The analysis of the interventions showed that in the first 8 weeks, the TLU group received five times the face to face intervention that the CR group received. Given that there was no significant difference in the outcomes over six months, this has implications for clinical practice, as acknowledged by the authors. There was a reasonable high attrition rate, with only 67 % of participants completing the six month follow up and so repeating this with a larger group would be valuable. It would also be important to capture whether the TLU group does have more complex needs on entry to the programme and the outcome measures used would need to be adjusted to demonstrate this. It does however demonstrate the importance of applying clear criteria to programmes with more intensive resources.

In summary, two examples are presented here of services that actively manage the transition from hospital to home, and whilst differing slightly, they both recognise that the move directly from post- acute rehabilitation to community can be challenging and that dedicated support at this point in the pathway can improve community engagement and outcomes. Further work is required to identify which people most need and will benefit from these services. A 2014 literature review (Turner et al., 2014) concluded that further research, including the 'lived experiences' of people with brain injury and their families, was needed in this area and that innovative transitional interventions should be developed and evaluated.

This section has defined some of the issues relating specifically to the transition between hospital and home which can be supported in both in patient and community

settings. The next section continues to explore rehabilitation programme and evidence relating to dedicated community rehabilitation.

2.5. Community rehabilitation in ABI

Research evidence supporting the effectiveness of community services for ABI is less well developed than in post-acute, hospital settings, but it is a fast-growing field.

Research studies looking at long term outcomes after brain injury are usually longitudinal studies, following people up to five years post injury. These studies tend to show that people report poor quality of life with high incidence of depression and reduced social participation (Huebner et al., 2003; Powell, 1999; Tate et al., 2004). Studies such as these have been used to make the case for more community-based rehabilitation for people after they leave hospital rehabilitation. In the last ten years community rehabilitation services have developed rapidly. Studies examining the effectiveness of community rehabilitation in the chronic stage (usually defined at more than one year post injury) are limited, but good quality studies do exist which show benefit from multidisciplinary programmes. (Huebner et al., 2003; Kim & Colantonio 2010). Some studies have also made the direct link that focussing on increasing activity and community participation can lead to improvements in quality of life (Gerber, Gargaro & McMackin, 2016).

A systematic review in this area identifies 13 studies (RCTs, controlled comparison studies or longitudinal cohort studies) that provide a good level of evidence (Geurtsen et al., 2010). The review used the CONSORT checklist (Schulz et al. 2010)⁵ and a minimum internal validity criteria set by the authors to assess the quality of evidence. The studies identified included a range of residential programmes and community day programmes. Whilst they all provided intervention to clients more than one-year post

⁵ This reference is for the current version of this resource which can be found at <http://www.consort-statement.org/consort-2010>. The reference in the original article links to the website <http://www.consort-statement.org> but the earlier version of the resource is no longer available.

injury, they covered a range of clinical groups including people with complex physical disability and neuro-behavioural needs. Most of the studies found positive results for the treatment group and supported the theory that co-ordinated multi-disciplinary rehabilitation in this chronic stage was effective in either maintaining gains made earlier in rehabilitation or making new gains. The diversity of the programmes and treatment groups, combined with the relatively small total number of studies (and participants) meant the authors were not able to draw general conclusions about the types of programmes that were most effective. This review considers a number of studies not included in other reviews, due to the inclusion of longitudinal cohort studies, focussing on the chronic stage after brain injury. They also describe the interventions in more detail to start to allow discussion of which elements of programmes lead to successful outcomes. In this respect, the review provided a number of clinically useful examples that could be applied to the development of services. The authors conclude that to progress this evidence base, further studies are needed and that it is important to define both the patient group and intervention.

Given the diverse nature of ABI rehabilitation programmes, it is useful to examine individual studies in more detail to start to understand the interventions provided. Four key examples are presented here as they offer different insights to the development of service design and delivery.

The first is a community RCT (Powell et al., 2002). Despite being 15 years old, this study warrants particular mention because it is a large RCT looking specifically at the effectiveness of multidisciplinary community rehabilitation following ABI, with over 50 participants in each of the conditions. It evaluates an intervention provided to people with ABI by a multidisciplinary rehabilitation team, working with patients in their homes and the community. The authors discuss some of the difficulties of identifying a control group and defining intervention for such a heterogeneous group. The study is based on a then new service and the authors are able to randomise participants to treatment or

control groups without withdrawing a previously available service. They provide a single assessment and signposting to alternative services to the control group to further overcome the ethical challenge of not providing treatment to one group. It could be argued that from a pure research perspective this single intervention to the control group dilutes the difference between the groups; however, in the context it allowed the researchers to create a control group in an area where it is difficult to do so. The authors acknowledge that the sample is very heterogeneous and therefore rather than describing a standard intervention, they describe the service model used. This model is a multidisciplinary team comprising neuropsychology, physiotherapy, occupational therapy and speech and language therapy. Clients are seen in their own home or in community locations, such as colleges or work places. The intervention is based on individualised goals set in collaboration with the team and client with an agreed timeframe for intervention. Details are given about the subject areas of the goals, with common areas being community mobility, personal or domestic care, communication, social interaction and vocational rehabilitation. The primary outcome measure used is the BICRO (Powell, 1999) which, in line with the goals, measures changes in function in different subject areas. The results show significantly better outcomes in the treatment group compared to the control. The analysis uses Mann Whitney as the data produced by the BICRO is ordinal. The authors also analyse separately the area where each person has made the most gains and link this back to their key goals of intervention. This is a good example of how reference to individual goals of therapy can provide additional validity when linking outcomes to intervention. This study provided good quality, statistically significant data that has contributed to the evidence to support the effectiveness of community rehabilitation. It also further supports the Slinky model that co-ordinated multidisciplinary rehabilitation is effective. However, it does not offer detailed information about the service that could be used to develop similar programmes or identify key components.

The second example identified takes a different methodological approach and therefore provides a useful contrast. It is the evaluation of a community rehabilitation programme reported by Feeney and others (Feeney et al., 2001). The programme, participants and the challenges of the clinical population are described in detail. The participants are all adults who have had TBI and who have not been able to live successfully in the community due to behavioural or cognitive difficulties. Prior to enrolling in the programme, they are living in in-patient units and, in some cases, have had contact with the criminal justice system. The authors do not exclude participants with co-existing challenging behaviour or drug/ alcohol dependency but explore the challenges of these presentations. The programme itself is based on a treatment developed by the authors, focussing on what they refer to as a 'contextualised everyday routine-based approach'. In this programme, all intervention takes place in the context of the participants' real lives, either in the home, community activities or work environments. The clinical team (Psychologist and SLT) work with the participants and families to identify daily routines and train family members and carers to support participants to achieve goals in the context of these routines. There are parallels between this approach and the approach taken in the TRU programme described in section 2.4 (Jackson et al., 2014), as all staff are trained to understand the participants injury and the structured support they need to achieve success in different contexts. The evaluation of the programme itself is very practical; the primary indicator of success being whether participants are able to live in the community, combined with a financial analysis comparing the cost of the programme with the cost of previous placements. The authors are not able to conclude that there is a causal link between their intervention and the successful community living/ integration because they do not attempt to control variables. They are however able to show a correlation between engagement in the programme and successful community living, they are also able to draw a comparison with breakdown of previous community placements. The sample is large (80 participants), adding weight to the argument, and they are able to show that

the costs are much lower than alternative in-patient environments. It is important to note the context of this evaluation was that the programme had initially been funded as a pilot and the evaluation was to support an argument for long term funding. It is clear that the design matched the needs in this specific context; it is also clear that the detailed description of the participants and programme may be very helpful to other clinicians working in the area on a practical level as the authors explain the roles in the team and how the intervention is delivered. The participants in this study were physically able, with the intervention targeting complex cognitive and language impairments, therefore application of this approach to a group with a broader range of needs would have to take this into account.

A third relevant study evaluated the outcomes of a community multidisciplinary brain injury rehabilitation programme (Curran et al., 2015). The programme is a combination of home and centre based out-patient sessions, the out-patient centre provides facilities for people with physical rehabilitation needs and the participants in this study therefore have broader range of impairments than those in the previous study (Feeney et al., 2001). The study uses the MPAI as the primary outcome measure (Bohac et al., 1997), this measure has three sub sections that measure 1) Abilities in key areas e.g. mobility, 2) Adjustment to disability and 3) Participation. This measure allows for comparison of self-rating, staff rating and significant other rating which provided another perspective on the programme outcomes as staff, participants and relatives were asked to score this measure pre-and post-intervention (time one and two). There were a total of 47 participants with pre-and post-intervention data but only 32 had outcomes completed from all three perspectives, the authors do not explain why this is and it would be useful to understand further if this was due to participant ability, availability of relatives to contribute or other factors. The authors also carried out a follow up questionnaire with a proportion of the participants a year later (time 3), there was a significant drop out at this point (n=47 reduced to n=17). The purpose of this

follow up was to invite feedback on the programme and generate suggested changes. The study showed significantly improved outcomes post rehabilitation (from time one to two) with a large effect size. The data gained from the follow up questionnaire was used to gather feedback about the service from participants and relatives. This type of study would not be included in the Cochrane review above as there was no control group but the challenge in withholding treatment from a control group is difficult to overcome if evaluating an existing programme. The authors acknowledge that the high attrition rate at time 3 is problematic.

The fourth example given here is the study referred to in section 2.4 by Tate and colleagues (2004). This study does not examine the outcomes of the community programme described, although as reported above, studies of this programme examining effectiveness of the intervention are available (Hopman et al., 2012), this study looks in detail at the components of the community programme. The study uses a total sample size of 467, within this, more detailed analysis is carried out for a random sample of 50 participants. For the full sample, data was collected about the number of interventions received from each professional throughout the study period (one year). For the random sample, level of severity of injury was categorised into either 'good recovery' or 'moderate to severe disability' based on the Glasgow Outcome Scale (GOS) (Jennett and Bond, 1975). Review of the notes was then used to categorise the interventions received into three key areas, 1) Occupational activity, 2) Intra/ interpersonal relationships and 3) Living skills. The random sample was also followed up two years later if they were still receiving services.

The results demonstrate that the full sample of participants received a median eight (range 1-167) interventions from the team. This is a very wide range and at the lower end suggests a low intensity programme; however, the authors do not describe how much additional input is provided via support workers or carers, nor do they state whether any participants were discharged during the year. The interventions received

were from a range of professionals within the MDT: physiotherapy, speech and language therapy, occupational therapy, clinical or neuro psychology, case management and social work. By far the most frequent contacts were case management⁶ interventions, received by 66% of the participants. This is worth noting as in the UK, very few community programmes include case managers as a core member of the team. In the random sample, interventions were coded as 44% of participants received intervention for occupational activity, 54% for intra/ interpersonal issues and 66% for living skills. There were not significant differences between the groups based on GOS groupings but the authors note that detailed review of the notes show the interventions are very different within these categories depending on severity of injury.

At the two year follow up point, 22 participants from the random sample were still in receipt of services. Of those discharged, 17 had achieved their goals, six did not attend sessions, three had moved and two were referred on to alternative services. For those still receiving services, the median number of contacts in the year was lower, median 3.5 (range 1-77). Not surprisingly, the group still receiving intervention had more severe brain injury diagnoses initially and had spent longer in post-traumatic amnesia. Overall, this study provides some useful data about how the community intervention is delivered in terms of frequency and length of intervention from different professionals, however to apply this clinically it would be useful to know in more detail about the interventions and the make-up of the team.

Three of the studies described above evaluate whether programmes are successful in supporting gains in function in the community after discharge from hospital, typically over a period of six to twelve months, the fourth focuses on how such intervention is

⁶ Case Manager: In this context a case manager refers to a specialist member of the rehabilitation team, who co-ordinates care and manages some of the complex legal and administrative aspects of a care package.

delivered. Other studies have focussed on a more chronic stage, exploring ongoing maintenance of gains in function after one to five years living at home. A 2012 study (Geurtsen et al., 2012) evaluated community integration at one and three years after the end of a community programme to support transition to living independently. The initial programme consisted of three modules in independent living, vocation and social/emotional support. The programme supported participants in the transition from hospital to home, following discharge no formal support was provided. A total of 67 participants were identified who completed the one year follow up, at three year follow up this had reduced to 63 participants. The follow-up evaluation of 63 participants at the three year point, using the Community Integration Questionnaire (Willer et al., 1993) and a number of quality of life measures, showed that gains made at the one year point were maintained and in some cases, there were small (not statistically significant) gains in employability, community integration and work hours since discharge. The authors argue that this evaluation is supportive of the benefit of the initial, high-cost programme. There is no control group to further support this argument but the cohort of participants are described as having psychosocial problems that hamper community reintegration at the start of the programme which supports the assumption that the improvements made are linked to the targeted intervention provided. The authors describe the severity of injury at the start of the programme based on the GOS as 71.4% severe and 28.6% mild. The fact that most returned to employment and independent living would indicate that the sample was reasonably high functioning by the end of the programme.

Similar findings were reported in an earlier study (Sander et al., 2001) with follow up at one year and over two years showing maintenance of gains measured on the Disability Rating Scale (Rappaport et al., 1982) and CIQ with only annual follow-up support. Again, the sample of participants was high functioning with many returning to employment. Other studies have concluded that a level of support is required to

maintain gains made in rehabilitation and evaluated different support methods, usually with a view to understanding the cost benefits as well as the clinical gains. As with all stages of the pathway the methods employed in offering long term support differ, with models including review clinics, telephone contacts and support groups (Bell et al., 2005; Mclean et al., 2012). Where these studies all agree is in recognising the importance of strong community support systems if a person is to maintain gains made in rehabilitation, whether that is delivered in an in-patient or community environment. All the studies identify that successful return to the community is dependent on supports from either family members, paid carers or specialist teams to facilitate return to social, leisure and vocational activities. This recognition of the need to identify supports within the context of the person's environments leads on to the concept of community integration. This concept links directly to the outcomes of the research intervention and the questions posed in the current study. The literature relating to community integration is therefore explored in more detail in the next section with a view to:

- Understanding current definitions and clinical practice
- Understanding evidence to support efficacy of rehabilitation programmes that focus on community integration
- Identify appropriate methods of evaluating community integration

2.6. Community integration as an outcome of rehabilitation

2.6.1. Defining community integration

This discussion has focussed on the effectiveness of rehabilitation, but also of interest is the goal of rehabilitation in different settings and at different points in the pathway. As per the Slinky model of rehabilitation, there is increasing recognition in the ABI literature that following the initial hospital stage, the focus of rehabilitation should shift so that goals reflect a person's life, priorities and the context that they live in. The Slinky model uses the term 'enhanced participation' as per the World Health

Organisation International Classification of Functioning (ICF). However more recent literature tends to use the broader term, 'community integration' (Geurtsen et al., 2010; Griffen, Hanks, & Meachen, 2010; Reistetter et al., 2005; Sander, Clark, & Pappadis, 2010). This change in language reflects a shift in thinking about chronic disability to a model that looks at enabling people to participate in their communities (McColl et al., 2001) To explore this concept further it is important to consider the term, community integration, in more detail.

The literature in this area gives significant attention to the need to clearly define what is meant by community integration if it is to underpin programmes of rehabilitation. McColl and colleagues (1998) provide a good introduction to this discussion. They explore the concept of community integration and the definitions offered at the time and identify that these are multidimensional and share three common components of 1) relationships with others, 2) independence in living arrangements and 3) occupation, as illustrated by the following quote:

'Community Integration means having something to do, somewhere to live and someone to love'

Jacobs 1993, quoted in McColl et al., 1998 page 16.

McColl and colleagues explored this concept with people with brain injury through a number of focus groups. They sought to explore three aspects of community integration as follows:

- Definitions of community integration used by people with brain injury
- How people with brain injury determine their own level of community integration
- What factors relate to positive or negative feelings of integration.

The groups generated nine core components that reinforced the concepts of relationships, independence and occupation already discussed but expanded on this as presented in Figure 3.

Figure 3: Components of community integration identified by McColl et al (1998)

- | | |
|-------------------------|--------------------|
| • Orientation | • Living situation |
| • Acceptance | • Independence |
| • Conformality | • Productivity and |
| • Close relationships | • Leisure |
| • Diffuse relationships | |

The authors discuss the significance of the first three of these components (orientation, acceptance and conformity) as well as that of diffuse relationships as these were significant themes. Participants referred to a wish to feel they belong, know the local environment (bus routes, locations etc.) and know how to behave and feel accepted. They described the casual community interactions that they have (e.g. at a local shop or café) as being important as well as the more significant relationships with family and friends. They also discuss the concept of independence and how this relates differently to living situation for people with disability than for the rest of the population. For example, the living environment itself is described as less significant than how independent a person can be in that environment. Depending on the individual, physical adaptations to an environment might enable them to shower independently or cook for themselves.

In more recent discussions of community integration the three main components of 1) independent living, 2) social and leisure activity and 3) vocational or meaningful activity, have continued to form the core of definitions (Salter et al., 2008; Salter et al., 2011; Sander et al., 2010). However these and other authors also acknowledge the importance of the more subtle concepts explored by McColl and colleagues with emphasis on the need to consider assimilation or belonging in a community (Sloan, Winkler & Callaway, 2004). The need to consider independence as a very personal concept (Minnes et al., 2003) and the importance of having the perspective of the

person with brain injury to validate definitions (Martelli, Zasler & Tiernan, 2012).

Parvanah and Cocks (2012) explored the concept of community integration by consulting an expert group comprising researchers, clinicians, policy makers, people with brain injury and carers. They used a Delphi method to identify key themes from the contributions of the group and identified the following areas as key to community integration; relationships, community access, acceptance, occupation, being at home, picking up life again and heightened risks and vulnerability, again largely reflecting concepts already discussed.

Discussion of definitions of community integration naturally leads on to consideration of measurement. Literature in brain injury has sought to measure the areas identified above to shape and evaluate rehabilitation programmes in the chronic stage (i.e. more than one-year post injury). Measures often identify specific items as examples of integration (e.g. independence in domestic activities, community activities and social activities). Measures of this type can be described as objective measures and are good for capturing the level of independence someone has in a number of pre-defined areas. However, they are less good at capturing the person's own perspective and what they value in terms of their independence and integration. Measures that explore these aspects can be described as subjective measures (Salter et al., 2011). A full discussion of outcome measurement in this field follows in Chapter 4, but it is important to consider the general principle throughout the review of the literature.

In summary community integration is a complex and multi-dimensional concept but there is reasonable consensus about the components. Rehabilitation programmes to support improved community integration should logically be shaped around these components, whilst also being flexible to individual needs. The following discussion reviews the evidence relating to community integration as an outcome of ABI rehabilitation and starts to explore evidence-based frameworks for building interventions in this area. In reviewing the literature relating to community integration in

ABI rehabilitation it is also clear that terminology is not used consistently and therefore, for the purposes of this review, studies that used the terms 'social integration', 'social participation' or 'enhanced participation' were also included if it was clear from the discussions that these terms were being used to capture a similar range of components to those described above.

2.6.2. Evidence for effective community integration following rehabilitation

A 2005 systematic review (Reistetter & Abreu, 2005) found there were a wide range of programmes relating to community integration and concluded that it was very difficult to predict outcome in this area. The review identified 72 articles of varying research quality which they graded based on the Oxford Centre for Evidence Based Medicine system (OCEBM Levels of Evidence Working Group, 2011)⁷. Of these, 14 were high, 52 medium and 6 low quality. The review identified that most studies examining outcomes related to community integration were prospective studies of medium quality. From the factors explored, key predictors of outcome were; severity of injury, age, gender, education, prior work, living environment, cognition, emotional state and functional performance. The authors explored a number of these factors in more detail, identifying useful information to inform the development of services. For example, cognitive impairment was a factor associated with poor performance on measures of community integration. The authors concluded that there was a need for programmes to continue to target these impairments directly in conjunction with supporting community activities, they also emphasised the need to support family members and paid carers to facilitate strategies in this context. In some areas, there was more agreement across the studies about the intervention approach required than in others. For example, most studies concluded that community integration was enhanced by

⁷ Reference to the current version of this resource. The version used and referenced by Reistetter and Abreu (2005) is no longer available but is as follows: Phillips B, Ball C, Sackett D, Badenoch D, Straus S, Haynes B, Dawes M (2001). Oxford Centre for Evidence-based Medicine Levels of Evidence. http://www.cebm.net/downloads/Oxford_CEBM_Levels_5.rtf [Accessed October 24, 2003].

ensuring the person had a suitable (e.g. wheelchair accessible) environment. In other areas, different intervention approaches were advocated. Despite these differences the review was able to conclude that there were consistent themes that programmes needed to target a number of areas beyond the traditional models of disability and rehabilitation.

It is worth referring again here to the study referenced in section 2.5 reported by Feeney and others (Feeney et al., 2001) based on the New York community brain injury programme, because the objective of that programme was to achieve social integration in the community. The participants had previously been in in-patient or criminal justice settings and a number had previous failed attempts to return to living in the community. The authors contextualised every day routine-based approach is based on a strong theoretical framework and was successful in helping people to maintain community placement. The framework and design of this intervention is therefore relevant in the discussion about community integration and design of rehabilitation programmes.

A 2012 study of young people with ABI (aged 16 – 26) looked at outcome in terms of return to study or work for this group (Kolakowsky-Hayner et al., 2012). The programme was based on a system of specialist mentors supporting participants to access standard community services (support groups, educational establishments and employment support). The authors argue that participating in mainstream community services is important to achieve increased integration but point out that, following ABI, many people need help to understand and navigate the system. They concluded that the programme was effective with a high percentage of participants achieving their educational or vocational goals. The importance of successful return to study or work has been identified in a number of other studies (Reistetter & Abreu, 2005) with return to work identified as significant in the success of hospital discharge and transition to living at home (Nalder et al., 2012).

A factor that is quite well explored in the recent literature and therefore warrants mention when considering service design is the challenge for clients from ethnic minority backgrounds in achieving community integration post ABI. Many of these studies conclude that it is very important to identify community activities that are culturally relevant, broadly defined as organised within a religious or minority community or a mainstream service that acknowledges the needs of people from specific faith backgrounds (Sander et al., 2009). This is in line with other conclusions in community integration research which identify the need for activity to be relevant to the person and intervention to be person specific. (Doig, Fleming and Tooth, 2001). In practice, this is identified as a challenge in ethnic minority groups as a range and choice of culturally appropriate services may not exist within a single community area. It is important to consider the implications of these findings when designing services.

Another theme to emerge from the recent literature focuses on the use of feedback and the views of people with ABI in designing and improving services. Two of the studies already described (Curran et al., 2015; Parvaneh & Cocks, 2012), consider this theme. Another example is a study into transition to the community, based on interviews with brain injury survivors in community supported living. (O'neil-Pirozzi et al., 2015) The interviews were semi structured based on six questions, seeking the participants' experiences of transition to the community, and identifying support they would have liked or had found useful. The data was organised using thematic analysis and specific suggestions for service improvement were also extracted. Overall the participants expressed a need for balance between receiving the support they needed and the independence they hoped for. They identified specific need for support prior to, during and following transitions, to understand changing environments, structures and expectations.

A dominant theme in the recent literature is the importance of family involvement in rehabilitation. A number of studies have looked at the type of support that family

members require as part of a programme. Fortune and colleagues (Fortune, Rogan & Richards, 2016) describe a structured group training programme for carers of people with ABI. They used a waiting list control group for comparison. The programme was six half days plus three elective sessions for carers with specific needs (e.g. supporting a family member with challenging behaviour). The evaluation of the programme looked at a number of factors including the support needs of different types of family members (spouses or parents), relationships between age of the person with ABI and care giver, and levels of carer strain as measured on the Carer Strain Index (Robinson, 1983), pre and post-intervention as well as at three months follow up. The study demonstrated significant reduction in carer strain in the treatment group compared to the waiting list control, they did not find any significant difference in the needs of spouses vs parents of people with ABI but they did identify that younger carers report higher levels of carer strain and perceive higher levels of criticism from the person with ABI. The authors identified the need to look further at emotional support for carers and how this can be provided.

Other studies have focussed more on this emotional support element for families and carers. Kuipers and colleagues (2014) identified information, practical and emotional support as important to family members and also as significant to the outcome of the person with ABI. This study used a thematic analysis of interviews with family members. A single theme noted in all interviews, despite not being prompted, was titled 'hope' and referred to a wish expressed by family members to feel there was hope that their relative would demonstrate improved function in the future. The feedback from family members emphasised the importance of encouraging hope in the support process which the authors note requires further exploration. This could, at times, feel at odds with therapeutic goal setting where the professional team work with patients and families to agree achievable goals for rehabilitation. However it is an important point to acknowledge and has implications for how goal setting and brain injury education are

delivered. Kitter & Sharman (2015) looked at support needs of carers and their quality of life. They used semi-structured interviews to explore carers' coping strategies and life satisfaction. They identified overarching themes / groups of factors that impeded quality of life and those which improved it. Examples included practical challenges such as lack of resources or financial strain, but also identified positive emotional supports and examples of enriching experiences. In discussing their findings, the authors reference the literature demonstrating a link between improved reported quality of life in family members and their relative with ABI (Gerber et al., 2016; Minnes et al., 2003) and therefore emphasise the importance of further research in this area.

A 2010 study (Sady et al., 2010) looked specifically at the factor of emotional support by examining the impact of carer relationships and family functioning. The study builds on a body of evidence available in paediatric brain injury research which emphasises the importance of family relationships to community integration outcomes after brain injury. The study identifies that better family functioning and strong social support networks for family care-givers is associated with better outcome as measured on the CIQ. These findings can again be applied to the design of services to support clients and families as part of a holistic community integration programme.

Another example relevant to this discussion is a study evaluating community integration outcomes following a structured 12 week social communication training programme for clients and their close relative (Dahlberg et al., 2007). The authors use a measure that relates to social communication, the Social Communication Skills Questionnaire (McGann, Werven & Douglas 1997). This measures a positive effect on social communication skills for both clients and carers following the group, but the interesting point for this discussion is that outcomes also improved on measures of community integration (CIQ). This is again in line with the theme that family members and carers need support to facilitate the person with a brain injury to participate in community activities as highlighted previously.

The programme described and evaluated by Gerber and Gargaro (2015) has a slightly different emphasis and it is a largely social programme aimed at supporting people with ABI towards the end of their rehabilitation pathway. They describe the use of mainstream community services and setting up of activities and routines that can be maintained long term. They look at the impact of this programme on family burden and demonstrate significant reduction in carer burden following the programme. In their discussion, they identify the need to provide people with ABI and their families with strategies that can be maintained to prevent increased carer burden following discharge from formal rehabilitation.

The challenges of supporting family members of people with ABI receiving neurobehavioral rehabilitation was the focus of a recent systematic review (Fisher et al., 2015). The authors identify that, despite the recognition of the challenges faced by these families, there is a lack of quality research in this area. They do, however, identify five studies of a good quality that addressed this area. The programmes provided a mixture of training, information provision, emotional and practical support to family members. The authors conclude there is emerging evidence from these studies that provision of training and involvement of family members in behavioural management has a positive impact on the outcome for people with ABI, and increases the family members' understanding of the goals and strategies. However, they did not find strong evidence of a reduction of carer strain and this requires further investigation.

Inevitably, different services from the examples given focus on different aspects of community intervention, but what is interesting is that most correspond to one or more of the factors identified in the systematic review discussed above (Reistetter & Abreu, 2005). Therefore, what emerges from these studies is a broad blue-print for services to support community integration, with intervention provided in specific contexts, and goals tailored to individual's needs and preferences. The emphasis is on supporting people to access services that exist in the wider community, such as colleges and

community groups, rather than ABI-specific activities. Within this model there is also a need to recognise the importance of supporting family and paid carers to facilitate community access, social interaction and communication.

To date, this model has been applied most widely to services for people with mild to moderate levels of disability following ABI. Clearly any service that focusses on return to education or work is going to be targeted at people with a reasonably high level of function. Where studies have looked in detail at community integration following severe ABI and for people with complex on-going limitations in functions, outcomes have been less good when measured on the widely used measures of community integration such as the CIQ and CIM (Doig et al., 2001; Wagner et al., 2000). The current UK healthcare policy context advocates increased choice for all (Agrawal & Mitchell, 2005) and there is an expectation that people who may have previously lived in long term residential care should be able to choose to return to living at home. Recent improvements in acute trauma and stroke care have also had an impact on the number of people surviving severe ABI. This creates a need and an opportunity to explore services that can support people with severe ABI to achieve good outcomes in terms of community integration, building on what is already understood about supporting community integration from the literature. The themes summarised here helped to inform the design of the clinical intervention described in this study which supports adults with severe ABI returning to the community. One of the aims of the study was to build the research intervention based on a theoretical structure to ensure the intervention was evidence based and replicable. A number of authors have taken the theme presented in this chapter and described theoretical frameworks for interventions in community integration. These frameworks will be explored briefly here with particular reference to how they inform service design.

2.6.3. Theoretical frameworks in community integration rehabilitation

Trudel and colleagues (Trudel, Nidiffer & Barth, 2007) describe the over-arching types of programmes that support community integration. The three main programmes they consider are:

- In-patient / residential programmes for people who still require 24-hour care due to physical, behavioural or cognitive risks.
- Home based programmes with input from a range of professionals and services and
- Holistic, milieu-based day programmes.

They conclude that the evidence is strongest for holistic day programmes where patients attend a regular (up to five days per week) day programme. Martelli and colleagues (2012) also support this principle and describe holistic programmes as those that support recovery after brain injury by focussing on personal psychological and emotional needs as well as activity limitations. They describe three key features of such programmes as the three Ps referring to 1) 'Plan' or Prescriptive activity' – which refers to structured task-based activities in areas of identified need, 2) 'Practice' involving repeated/ structured activity to promote relearning and 3) Promoting motivation to support relearning process. The authors argue that despite the personalised nature of the programme, it is still a structured and evidence-based intervention because it is based on a strong theoretical model. This model is based on detailed knowledge of the brain injury and sequelae in the context of evidence of learning theory, adaptation to disability and evidenced psychological and physical therapies.

Tempest and Jefferson (2015) use the ICF as the basis for designing neurorehabilitation programmes. Whilst the ICF is not a specific community integration framework, it does capture similar principles, as the model incorporates participation and environmental factors and acknowledges the impact of these areas on functioning.

The review considers the implementation of the ICF and reports on two action research projects in this area. The clear advantage of using the ICF as a basis for service design in neurorehabilitation is that it is a globally accepted model and the authors emphasise this point from the literature review. However, they are able to find few practical examples of how it has been implemented clinically. The two action research projects focus on two community stroke and neurorehabilitation teams, identifying themes and recommendations about how the ICF can be used to support the design of rehabilitation programmes. The recommendations cover areas such as use of the ICF to structure assessment, MDT discussions and onward recommendations. There is potential scope with this model to provide some of the consistency across services and outcome measures that the authors of the Cochrane review (Turner-Stokes et al., 2015) recommend. A further study (Ditchman et al., 2016) also argues that the ICF creates a coherent framework that can define the complex range of needs after ABI and help to structure interventions. The study recruited 103 participants who had ABI and were living in the community. The participants completed a questionnaire which included elements designed to reflect the components of the ICF model (demographic, disability, personal, environmental) as well as a measure of current social integration (sub scale of the CIQ). The authors used a regression analysis to identify which factors were predictors of social integration. They found that each element contributed to the variance in social integration outcomes for people with brain injury. Most significant were social economic factors, severity of disability and social support, which were shown to be independent predictors of variance. The personal factors of disability acceptance and self- efficacy and other environmental factors such as perceived stigma, contributed to variance but were not significant as independent factors. This analysis demonstrates the potential use of the ICF to support development of interventions that do not focus purely on the functional aspects of disability but also incorporate support for building social relationships and support. The authors

recommend further research is indicated on the impact of a broader range of factors on social integration and advocate use of the ICF model to define this range of needs.

Following on from their work described in section 2.6.1, Parvaneh and colleagues describe the development of a fidelity to measure to evaluate community integration rehabilitation programmes. (Parvaneh et al., 2015) They use their Community Integration Framework to identify the key themes that rehabilitation programmes need to consider if the intended outcome is to improve community integration. To develop the measure, they consulted a stakeholder group of practitioners, researchers, policy makers, people with ABI and family members. The resulting measure consisted of 21 programme attributes grouped into seven themes. The themes were: person centred planning, relationships, working together, development of skills, community-based practices, support for service users and service atmosphere. The authors argue that, whilst it is important to evaluate programmes based on patient outcomes, there is also a need for more consistency in programme design. This argument would support the development of services with similar standards and outcomes so that they can be compared and evaluated. The authors acknowledge that further analysis of validity of the measure is required.

What starts to emerge from these examples is a framework for designing ABI rehabilitation programme based on coherent evidence. This approach allows the development of interventions that retain a level of standardisation and theoretical underpinning whilst still allowing a person-centred approach to individuals and their needs. In the next chapter this concept will be explored further with specific reference to development of the intervention in the current study.

2.7. Summary and conclusion

This literature review has attempted to summarise the broad evidence base for the neurorehabilitation pathway and then to narrow the discussion to consider programmes that target community integration. Particular focus has been given to the design and

evaluation of interventions in this area. What has emerged is a growing evidence base to support the effectiveness of neurorehabilitation interventions in this field. The evidence does not indicate a single design or intervention approach, and variation in service design and the focus of the research makes it difficult to draw general conclusions across the literature. There is also a lack of detailed service description available that might offer clinically applicable learning for services. However, the evidence does provide themes from different service examples that can be seen as a set of evidence-based principles for developing new services. Read alongside the theoretical frameworks, it is possible to use this evidence base to develop clinical services.

There is a need to further explore how the clinical evidence and theoretical frameworks can shape interventions to support consistency of design. There is also a need to explore how established models of rehabilitation supporting community integration, can be implemented to support people with high levels of need following severe ABI.

In the following chapters, the clinical intervention and research design will be described in this context. Chapter 3 focuses on the development of the research intervention with specific reference to how the principles to emerge from this literature review informed that development. Chapter 4 describes some of the key methodological considerations arising from this review that informed the design of the current study.

3. Developing the research intervention

The discussion in the previous chapter reviewed the current literature in this area and started to explore the theoretical models that underpin rehabilitation programmes in the field of ABI. This chapter further explores frameworks for developing complex rehabilitation interventions and describes the process followed in developing the intervention in this study.

3.1. Frameworks for developing evidence-based interventions

The Medical Research Council Guidance on Developing and Evaluating Complex Interventions (Medical Research Council, 2008) was written to provide guidance on the process of developing complex interventions in healthcare to ensure that they could be robustly evaluated. The guideline describes complex interventions initially as those with several interacting features and goes on to specify that these interventions might be sensitive to local context or be challenging to standardise due to individual need or differences. The guidance makes the case that insufficient time is dedicated to planning and developing such interventions in a robust manner which leads to challenges in evaluation and ultimately does not advance the evidence base in the field.

The authors describe a process of development and evaluation that can be used for any intervention via a cycle summarised below:

- Development: clearly defining the objectives of the intervention and a strong theoretical evidence base that underpins it. Describing the intervention in detail is key to this development stage.
- Feasibility testing and piloting: modelling the service and testing small aspects and assumptions such as demand, capacity and cost effectiveness. The guidance advocates a phased implementation of the intervention from these tests of feasibility to full service delivery.

- Evaluation: robust evaluation of the intervention against pre-defined criteria/objectives
- Implementation (of the evaluation): referring to dissemination of the outcomes and contribution to the evidence base.

This guidance and the case studies contained within it, are based on development of large scale health care interventions that will require robust experimental evaluation. However, the principles of systematic development based on best evidence are equally applicable to a small-scale intervention in a small geographical area as is the case in this study.

Hart (2009) applies this theory of systematic development to the field of neurorehabilitation. She argues that rehabilitation interventions are often poorly defined and therefore poorly evaluated. If the intervention is poorly defined, it does not support a clear framework for development of professionals and skill within the team and therefore skill and knowledge builds organically but may not be sustained. She also addresses the challenge of ensuring a rehabilitation intervention can be individualised with the demand to make it standardised and evidenced based. The steps defined by Hart are as follows:

1. Define the 'active ingredients': these are the core components that make the intervention fit the objectives set. Therefore, key to this step is articulating and evidencing the hypothesis that links one to the other. For example, in the intervention for the current study, an active ingredient is the use of mainstream services in the community to ensure patients have a robust community network prior to discharge from rehabilitation. The hypothesis that supports this is that if the patient has support from the rehabilitation team to access a service that they can continue to access long term, this will help to maintain function and integration following discharge, based on evidence from previous studies (Kolakowsky-Hayner et al., 2012)

2. 'Operationalise the model': this step involves defining what both the patient and the rehabilitation team will do to implement the active ingredients. In the example given above this would include a commitment from the patient to engage in identifying appropriate activities and attend sessions with support, it may require a commitment to use appropriate transport or accept a support package to ensure that the activity can be accessed. The rehabilitation team would commit to supporting the exploration of activities, sign posting and assessing suitability, identifying the obstacles to access and working with the patient via clear goals to tackle these obstacles.
3. Detailed definition of the treatment and materials: This step further defines how the active ingredients are implemented by specifying the process followed and providing detailed materials or even a manual. The materials should make it easier for someone new to the intervention to replicate the active ingredients. In the example given this might include, a detailed directory of services available in the community, the access and eligibility requirements of each, examples of enablers within local services, such as community transport, and a sample contract for starting to access the activity and commitments from both patient and therapist.

There is clearly a tension at step 3 between the need for a detailed specification to ensure the intervention is standardised and replicable and the need to flex the service to individual needs. Hart argues that the intervention can be 'tightly specified' if it is a short, targeted intervention to a homogenous group but acknowledges that for complex interventions for a heterogeneous population the materials will need to allow for the necessary flexibility. In the example used above, the types of materials suggested would increase the standardisation and replicability of the intervention, as they would ensure all therapists have access to the same directory of services and consider a full range of obstacles and enablers without assuming that everyone will access the same

service in the same timescales. In this respect step three could be more accurately described as a tool kit rather than a manual.

The processes described above can therefore be used, in conjunction with the more specific clinical evidence described in Chapter 2, to maximise the standardisation and evidence base within even a complex and individualised intervention.

3.2. Developing the study intervention

The community ABI rehabilitation pathway in the current study was developed over several years in response to the neurorehabilitation commissioning context presented in the introduction. The demand for specialist community rehabilitation increased due to the prioritisation of in-patient rehabilitation for those with the most complex needs following ABI. At the same time, there was an increase in the number of patients expressing a wish to return home or to a community placement, despite high levels of ongoing disability.

A specialist ABI pathway was developed as an extension to the existing community neurorehabilitation service. The focus of this pathway was to support patients to return to living in their local community as independently as possible and to integrate into the community, moving from a medical model of support provided via rehabilitation to a long term sustainable support programme.

Development of the intervention followed a pattern of identifying theoretical underpinning, small scale trials and refinement as per the Medical Research Council guidelines (2008), however due to the small number of patients and limited resource, this cycle of development took place over two to three years. The initial principles of the pathway were identified based on a literature review at the time of community integration programmes. A number of key components or 'active ingredients' were identified, as follows:

- The rehabilitation programme would be based on a model of project based or context specific interventions
- The programme would be goal focussed and individualised to the patient's needs.
- People with ABI would be supported to access mainstream services in the community and overcome barriers to access
- Support would be provided to families and carers during the transition and community periods of intervention
- The focus of the programme would be to facilitate social interaction and successful communication and integration
- The programme would maximise independence in the home environment through appropriate support, equipment and care.

Initial cases were treated as single-cases or trials of the pathway with senior clinical support in planning discharge, liaising with people with ABI and families and supporting goal setting. These initial cases were successful in terms of maintaining a community placement and achieving goals, but the intervention was long with significant delays at various points and was highly individualised with little replicability, standardisation or guidance to new staff to manage these cases. Ongoing maintenance of this pathway was too reliant on senior individuals within the core service and partner organisations. Modelling at this point demonstrated that the service would not be sustainable because of this.

At this stage in the development, a number of actions were taken to refine the pathway as follows:

- Staff feedback and reflection sessions were held, based on the initial cases. Staff were invited to reflect on what went well and what went badly or was challenging. They were asked to identify aspects of the clinical intervention that

were key to achieving successful community placement and what skills or competencies they required to deliver such a service. These sessions were informal sessions based on brainstorming and feedback. Broad conclusions and actions were agreed in the sessions.

- Detailed reviews of the cases were carried out to identify where there had been delays and what impact this had on the timing of intervention, independence within the home and access to the community.
- Informal feedback was sought from family members about their experiences of supporting their relative to return home or to a community placement.

At the same time, a number of the processes used by the Community Team for all pathways were also reviewed, these were particularly relevant to the complex pathways such as the brain injury pathway and therefore are key to this discussion:

- The team documentation was reviewed to ensure that the assessment supported staff to identify a person's needs. The form was based on the ICF framework and included prompts relating to personal and environmental factors. The assessment provided a summary of functioning in different areas that was informed by the objective assessments completed, the MDT observations and the reports of patients and family members.
- The team used Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968) to set and review goals for all patients. This goal setting system is described in detail in Chapter 4. At this point, audit data had shown that the system was not being used consistently and therefore further GAS training was carried out and a regular GAS lead was identified. A training session was added to the induction and in-service training programmes.
- Senior clinical goal reviews were introduced to support quality of goal setting and review as well as discussion of complex management, for example of risk or mental capacity issues.

- A Psychology 'drop in' session was introduced so team members could bring challenges relating to cognitive and emotional presentations to discuss with a senior clinician.

These actions contributed to the definition of a two-part intervention which can be considered equivalent of Hart's operationalising of the active ingredients. The rationale for defining two intervention stages was based on the team feedback and review of previous cases. What came out of these exercises was an acknowledgement that it is often challenging to focus on goals relating to community access and integration when there are practical challenges with provision of equipment, training of carers and establishing of a home routine. The focus of Intervention 1 was on ensuring all necessary support and equipment was in place and on maximising functional ability, whilst Intervention 2 focussed on maximising participation and community integration.

At this stage in the development a proposal was made to establish a transitional rehabilitation facility to deliver Intervention 1. It was possible to deliver this intervention stage in the community but review of previous cases had demonstrated that the transition from a highly supportive in-patient environment to home was very challenging for both the patient and their family or carers. Patients and their families had reported the sudden reduction in intensity of support was difficult to manage. Also, the move straight from hospital to home often meant that care packages, equipment and support activities were un-tested before the patient returned home and so the first few weeks were spent resolving issues in these areas. The team identified that during discharge planning from the hospital, it was challenging to understand and assess the level of risk in the community.

The transitional service was planned as an integrated part of the community service and despite being an in-patient facility, the aim was to maintain the same community integration focus. Consistent with the model described by Simpson and colleagues (2004), the unit was small, based in a community with a focus on accessing services

within that community rather than in-patient facilities. The development of the transitional service allowed the team to add the following additional components or active ingredients:

- Medical and nursing input to support transition of medical management to a level sustainable in the community.
- Detailed and repeated risk assessment as part of the planning for discharge home or to a community placement (e.g. supported living scheme)
- Focus on support for people with fluctuating capacity to make decisions or manage in a community environment
- Graded period between hospital and home with trials of care packages and equipment included in the transitional service.

At this point, the intervention stages were further defined with materials and standard practices developed to support the team to deliver individualised programme within a robust, evidence-based framework.

Specific materials included:

- Standardised assessment for intervention 1 and 2 that were carried out by the multidisciplinary team. These were based on the ICF as described above.
- Community Risk assessment
- Assessment of capacity – including an ‘in the moment’ script for junior staff to support assessment of people with fluctuating capacity.
- Refined goal setting guidance– including example goals and example goal negotiating scripts to support the team to have a consistent goal setting approach
- Refinement of 6 weekly goal review programme with standardised documentation
- Development of a directory of community services available

The new transitional service was piloted and evaluated separately to the whole pathway. This evaluation was designed to meet the requirement of securing ongoing funding and therefore examined this section of the intervention in isolation.

The clinical benefit of the transitional service was analysed using outcome data collection. The outcome measures used were taken from the UK Rehabilitation Outcomes Collaborative (UKROC) data set which is the data set collected by all level 1, 2a and 2b units in London. Additional functional and community integration measures were added, the full list was as follows:

- Northwick Park Nursing and Therapy Dependency Score (NWPDS/ NWPTDA) (Turner-Stokes et al., 1998)
- UK Functional Independence Measure/ Functional Assessment Measure (UKFIM/FAM) (Turner-stokes, 1999)
- Mayo Portland Adaptability Inventory IV (MPAI) ((Malec & Lezak, 2003)
- Community Integration Measure (CIM) (McColl et al., 2001)
- Carer Strain Index (CSI) (Knight et al., 1997)

All outcome measures were completed by the team pre-and post-intervention. All the measures used produced non-parametric, ordinal data and were therefore analysed using the Wilcoxon signed rank test, significance was measured at $p < 0.05$ and effect size was calculated for significant changes using Cohen's criteria (large effect $r > +/- 0.5$, medium effect $r = +/- 0.3-0.5$, small effect $r < +/- 0.3$). The results were as follows:

- **NWPDS:** Discharge dependency was lower than admission dependency but this difference was not significant ($p = 0.123$). These scores show that overall patients were less dependent on nurses or carers at discharge than they were at admission. The main reason that this difference is not more significant is that the therapy programme included an enabling approach to managing personal and domestic routines. This means that patients were supported to do as much

of the task as possible themselves, which can increase the time taken to complete a task temporarily.

- **UKFIM/FAM:** This showed a significant increase in functional independence on discharge compared to admission ($p= 0.001$) with a large effect ($r = 0.594$) In practical terms this means that people needed less care support on discharge.
- **MPAI:** Discharge dependency was significantly lower than admission ($p < 0.001$) with a large effect size ($r= -0.604$). This scale has three sub sections, abilities, adjustment and participation. The significant difference in scores shows improved abilities and increased participation in functional activities.
- **Carer Strain Index:** This showed significantly lower carer strain at discharge than admission ($p=0.007$) with a medium effect size ($r= -0.447$)
- **Community Integration Measure:** This is a self-rated scale and showed significantly higher self-report of integration at discharge than admission ($p= 0.03$) with a medium effect size ($r=0.384$)

The evaluation demonstrated positive clinical outcome based on a number of measures capturing changes in level of impairment, activity, participation and carer strain. The transitional service was then commissioned on a substantive basis which supports the ongoing development of the whole community pathway.

In summary therefore, the intervention in this study has been developed in stages over a number of years and based on a combination of research evidence, local context and need.

3.3. Describing the study intervention

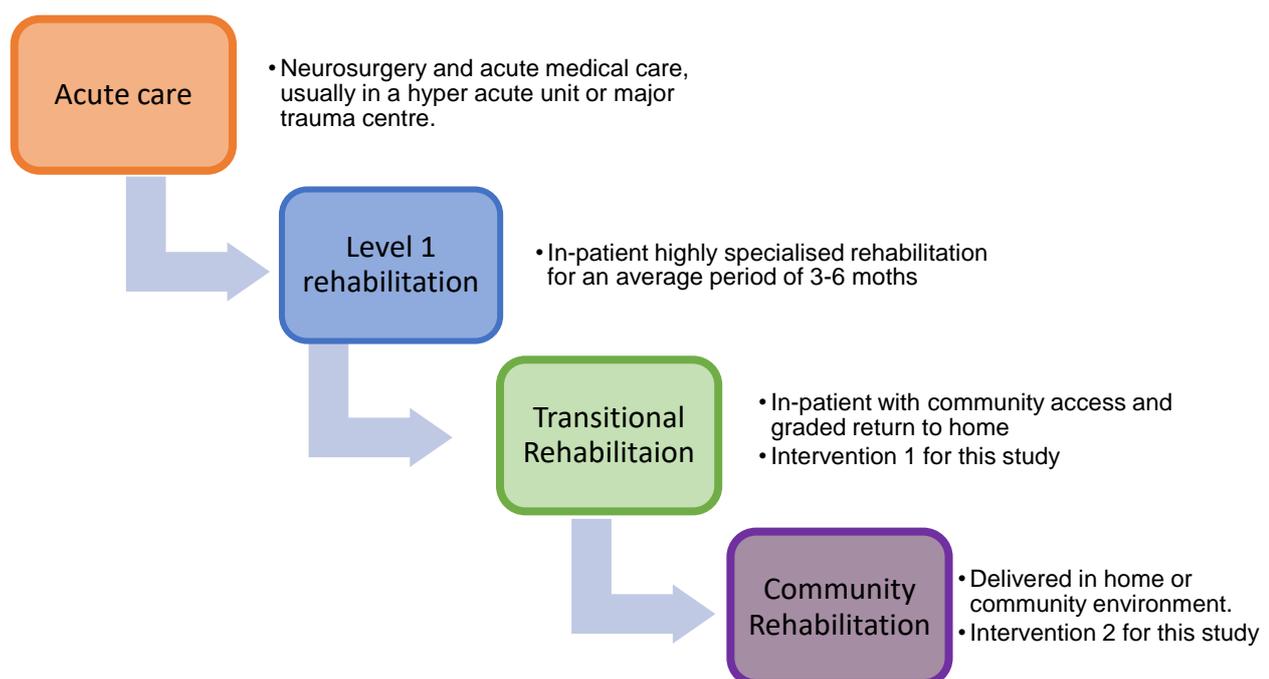
To frame the discussion in the rest of this report, a detailed summary of the intervention is presented here. It is worth a brief note here on the language used in this description to refer to the people receiving the intervention, who are described as 'patients' during Intervention 1 and 'clients' during Intervention 2. Within the literature and within

services, different terms are favoured to describe people receiving health care interventions such as patients, clients or service users. In this transitional service, people are referred to as patients. This decision was taken when the service was set up in consultation with the initial patient group who reported they were comfortable with this term and found it clear. People receiving Intervention 2 are referred to as ‘clients’ based on the acknowledgement that by this point in the pathway, the focus has moved on from a hospital model of care.

3.3.1. Rehabilitation pathway

Figure 4 provides a basic summary of the rehabilitation pathway that each person takes following an acute ABI to place the study intervention in the context of the wider pathway. The stages in this pathway can be mapped onto the Slinky pathway (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003), where Level 1 rehabilitation is equivalent to *Post-acute Rehabilitation* and Community Rehabilitation is equivalent to *Community Based Rehabilitation* on the Slinky model. The pathway in the current study adds a distinct transitional rehabilitation stage that is not defined separately in the Slinky model.

Figure 4 Standard rehabilitation pathway



3.3.2. Rehabilitation teams

The two sections of the study intervention are both part of the same service but provided as distinct sections. There is a shared management and senior clinical leadership for both but the day to day delivery is separate. Therefore, the overarching structure will be described and then the makeup and organisation of the two sections will be presented separately.

The brain injury pathway is one of the specialist pathways within the broader community rehabilitation team in an inner London borough. The team is therapy led with a single head of service with a background in physiotherapy. The brain injury pathway sits in the wider neurological services within this team and the clinical leadership for this pathway is provided by an Allied Health Professional (AHP) Consultant and a Principal Clinical Neuropsychologist. The AHP Consultant has a clinical background in speech and language therapy with specialist experience within neurological rehabilitation.

The brain injury pathway is also supported by a Consultant Neurologist who provides a monthly clinic or ward round to both sections of the pathway. There is not a social worker or case manager attached to the team but for both interventions, the team works closely with the Local Authority or the continuing healthcare team to ensure that there is co-ordination between rehabilitation and provision of care. At both intervention stages, the team can refer to other health services such as specialist nurses.

The team delivering Intervention 1 is therapy led with a clinical lead with a background in physiotherapy. The service is supported by a General Practitioner (GP) who provides a twice weekly ward round as well as on call response. The transitional service has seven beds and the team consists of:

- Nurse lead

- Rehabilitation nurses
- Specialist Occupational Therapist (OT)
- Specialist Speech and Language Therapist (SLT)
- Specialist Physiotherapist (PT)
- Clinical Neuropsychologist
- Rehabilitation Assistants (RAs)

The team delivering Intervention 2 is part of the neurological service in the Community Team. Specific staff are not allocated to the brain injury pathway but skill mix is agreed on a referral by referral basis to ensure that each client has one or two senior members of staff on the treating team. The Intervention 2 team consists of:

- Specialist OT
- Specialist SLT
- Specialist PT
- Clinical Neuropsychologist
- RAs

3.3.3. Intervention 1

Referrals to Intervention 1 are agreed as part of the discharge planning from Level 1 units. The service also accepts referrals from other sources (e.g. Stroke Units or from the community) but all the participants in this study had been through a Level 1 service. The discharge planning process is co-ordinated by the AHP Consultant and where possible, a patient and their family will visit the transitional service and are involved in the decision making.

On admission, all patients receive a period of assessment which is individually tailored but includes:

- Recording of UKROC admission outcomes and other outcome measures collected by the service

- Completion of the Intervention 1 assessment summary developed as part of the intervention (described in section 3.1)
- Completion of specific objective assessment measures relevant to the patient's presentation
- Completion of community risk assessment and initial assessment of capacity to consent to the rehabilitation intervention.

Multidisciplinary goals are set in collaboration with patients and their families within two weeks of admission. These goals are influenced by the assessments completed but are centred on the patient's priorities. Therefore, not all areas identified in the assessments will have a goal, if not a priority for the patient. The overall aim of the transitional programme is to achieve successful return to living in the community and therefore the level of care and likely delivery of a support package in community is included in the discussion of goals. For most people, the goals will therefore be a combination of practical goals to achieve a smooth transition to the community and more personal goals based on the patient's priorities. For example, practical goal areas might include:

- Transition of nursing support with diabetes management from the level provided in hospital to the level that will be provided in the community.
- Transition of dependence on support in personal care from the level available in hospital to the pattern provided as part of a community care package
- Transition to self-medication management
- Identification of most appropriate equipment to support home independence

More personally identified goals areas might include:

- Focus on an area of rehabilitation where a patient is most motivated such as mobility, speech or completion of an activity (e.g. cooking).
- Access to activities such as a gym, swimming pool or social club

- Contact with groups of friends or family members
- Specific activities personal to the patient (e.g. speaking to a particular friend on the phone, preparing for a forthcoming important social event).

A likely timeframe for Intervention 1 is set at this point. The average length of stay during the evaluation of the transitional pathway was 12 weeks (range 2 – 26 weeks). The length of intervention is based on an estimate of time to achieve goals. The length of intervention is sometimes influenced by practical considerations such as rehousing or access to care services. Goals are reviewed by the team every two weeks to ensure they remain appropriate and progress is being made.

The individual goals dictate how Intervention 1 is delivered and which team members are involved but for most patients, all members of the team are involved to a greater or lesser extent. The intervention is delivered in context whenever possible. Many patients are also supported by a brain injury support worker during Intervention 1. This service is provided by a local brain injury specialist charity. During Intervention 1, this service is funded by the Transitional Unit but when the patient is discharged it needs to be funded by the Local Authority or NHS as part of the care package as described in section 1.3. This element of the service is only put in place if it is likely that it will be maintained on discharge, in other words, if the patient is likely to be eligible for this to be funded on discharge as part of a Local Authority or Continuing Healthcare (CHC) package. The transitional team then provide tailored training to the support workers as they start to provide support during Intervention 1 that will continue during Intervention 2.

Patients receive the majority of their intervention on a one to one basis but there are some groups delivered as part of the transitional service, dependent on the patient mix at the time, these include communication, current affairs and social planning groups. There is a regular patient participation group to allow feedback about the service. For most patients, there are the following common components to how the intervention is delivered:

- Personal care support provided to maximise independence with or without equipment. The likely care support to be provided in the community is replicated as soon as possible and facilities used are matched to those in the home where possible (for example, a shower will not be used in the Transitional Unit unless there will be one available and accessible at home).
- Support to transition to a community level of medical and nursing support.
- Specific impairment-based therapy targeting areas identified in the goals
- Support to maximise access to the community, including addressing physical and cognitive barriers. This is likely to include a regularly reviewed community risk assessment, support to identify the best form of physical access (e.g. walking with or without equipment, use of a wheelchair etc.).
- Support to maximise access to chosen activities. As above this will include consideration of the physical and cognitive challenges of accessing this activity and strategies to overcome these.
- Support to plan a daily routine, taking into account the care available on discharge, the need for periods of activity and rest as well as the priority activities identified.
- Support to identify both specialist and mainstream services that will be helpful on discharge.
- Support for the patient and family members to understand the brain injury and the support required, as well as emotional support during the transition.

The team receive regular support with goal planning and problem solving complex challenges from the Principal Neuropsychologist and AHP Consultant. The monthly Consultant Neurology ward round is carried out jointly with the GP who supports the unit to ensure that medical care is co-ordinated.

For most patients, the final few weeks of Intervention 1 is a graded discharge period where they spend increasing lengths of time at home (either a previous home or new

property). This allows them to trial equipment and care and allows for a period of training and feedback with new carers or support workers. End of Intervention 1 outcome measures are completed during this discharge period.

3.3.4. Intervention 2

Intervention 2 is provided by a separate team as described above but because there is joint management and clinical input to the teams, the two interventions are co-ordinated. There is a period of handover, usually coinciding with the graded discharge period when the therapists from both teams will work jointly. This usually involves a number of sessions in the home when the therapists from both teams are present and the Transitional Unit team handover strategies. These sessions are also an opportunity for informal discussion about the goals for Intervention 2 and allow the patient to start to think about what their priorities are now they have returned home. There is a formal referral made from the Intervention 1 to Intervention 2 but all referrals on the brain injury pathway are co-ordinated by the AHP Consultant and so there is no wait between the two sections of the pathway.

In addition to the period of handover, the Intervention 2 team will carry out their own set of initial assessments. Again, this includes a combination of the team's own assessment forms and specific objective assessments in the areas of impairment identified. The assessment period at this stage is usually shorter as there has been such a comprehensive period of handover, however some reassessment is necessary because presentations change slightly once a person returns home and their priorities may also change. The Intervention 2 team does not need to collect the UKROC outcomes as they are not currently collected for community services. The primary outcome for this team is the use of GAS to measure change towards the client's own goals.

The process of goal setting in collaboration with the client and family is very similar to Intervention 1 and the principle of basing goals around the client's priorities is the

same. However, the goals in Intervention 2 have less focus on practical aspects of returning to the community and more focus on community integration, reflecting the fact that the client should have met these practical goals in Intervention 1.

As in Intervention 1, likely length of input is considered based on the goals set. For clients with complex needs, including those on the brain injury pathway, there are 6 weekly goal reviews with senior clinicians on the team to ensure goals remain appropriate and progress is ongoing. Reflecting the fact that clients are now living at home, these goal reviews often include a broader range of professionals from other organisations such as social workers, community or specialist nurses and voluntary organisations.

Typical goals in Intervention 2 are likely to focus on areas such as:

- Independence in the home and in the local community
- Access to and maintenance of community leisure and social activities
- Building regular contact and relationships with family and friends
- Exploring vocational rehabilitation where appropriate
- Ongoing focus on areas of impairment where the client is particularly motivated.

The intervention 2 team visits clients in their own home, in community locations such as gyms, at work places or in the out-patient facilities. Out-patient appointments are primarily used if there is equipment in the gym that a client needs or if they are participating in a group. A number of groups are run by the team, some of which are open to a broader group of clients than just those on the brain injury pathway examples include balance, communication and brain injury education.

As above, the delivery of Intervention 2 is dictated by the goals set but it is more common for clients to not need intervention from all members of the team because at this point in their rehabilitation, they tend to want to focus on specific areas of priority. The therapy provided in Intervention 2 is less intensive than Intervention 1 to reflect the

stage of the pathway. Where possible the team work closely with clients' families and any support workers or carers visiting them. In some cases, Intervention 2 will still involve a programme of defined therapy led intervention if the client has specific goals for example to develop communication strategies in a particular context or to achieve a specific physical goal. More commonly in Intervention 2, therapy is delivered through a combination of direct work with the team and indirect work where the team provide training and advice to support workers or carers. The rationale for this is that it moves towards a long term and sustainable form of support for the client.

At this stage in the rehabilitation pathway it is harder to define core components of the intervention because clients have very varied priorities and needs long term, however some key aspects are as follows:

- Support to maximise independence in the home, building on gains made in Intervention1.
- Support to maximise access to the local community building on gains made in Intervention 1
- Support to use public transport or access appropriate community transport services
- Support to plan a sustainable routine in the community
- Support to access identified leisure activities
- Support to consider vocational options and access rehabilitation in this area if indicated. Vocational rehabilitation can be provided directly by the team but in some cases, they work indirectly with employer's occupational health departments or refer to specialist services if an intensive vocational programme is indicated.
- Ongoing support for the patient and family members to understand the brain injury and the support required, as well as emotional support at this stage in the pathway

Intervention length varies greatly at this stage depending on the client's needs.

Intervention is not formally time limited but must always have a clear goal to remain valid. A number of factors impact on length of intervention such as progress made, family support available, intensity of support needed and client choice. On the brain injury pathway, intervention 2 is almost always over 12 weeks and may be as long as 52, however intensity might well be tailed off in an intervention of that length.

Intervention 2 ends when all goals have been achieved or if the client chooses to stop receiving therapy. Clients can self-refer back to the service if they identify new goals or their condition changes.

3.4. Summary

This section has explored how the research intervention was developed and structured, as well as describing the delivery of the intervention in details. This study aims to evaluate the intervention as part of an ongoing process of learning, development and refinement. The next chapter will explore in more detail how this evaluation was carried out.

4. Methodological considerations in study design

Relevant methodological considerations were explored to ensure that the design appropriately matched the research questions. It was important that the design allowed detailed exploration of the intervention and how it was individualised and applied to a heterogeneous group. It was also essential that the research could be carried out alongside clinical practice and that the learning be clinically applicable to support service improvement. This discussion summarises the methodological considerations taken into account.

4.1. Research design

As presented in Chapter 2, there is a growing body of evidence that supports the effectiveness of rehabilitation programmes for people with ABI. In the last 15 years, this research has increasingly included large scale experimental designs, including randomised controlled trials (Andelic et al., 2012; Bai et al., 2012; Cicerone et al., 2008; Powell et al., 2002; Turner-Stokes et al., 2015). This type of large scale experimental design has the most significant impact on the overall body of evidence in an area, however it is important that a number of standards are met to ensure the design is truly experimental and robust. These standards include ensuring a large sample size, clear criteria of inclusion and clinical intervention. The studies cited above do navigate these complex issues, demonstrating that this is possible in the field, however for a number of reasons outlined below, it would not be appropriate to use an RCT or other experimental design in this study.

In the current study, the aim was to both evaluate and explore a new intervention with the objective of informing future service development. The number of people who receive this intervention is small and the service was already being offered and therefore randomising participants to conditions or offering a control group was not possible. The intervention is also long with most people remaining in the intervention

for several months removing the potential to control period of intervention with periods of non-intervention. Lastly, experimental designs rely on standardisation of participants and conditions, often requiring participants to be excluded if they have dual diagnosis or co-existing drug, alcohol or social needs. The intervention described in this study does not exclude patients on these bases and one of the aims of the study was to explore how well the needs of this particularly challenging group was met.

Whilst experimental designs are considered to have the most impact on the evidence base, there is wide spread acknowledgement in the field of brain injury that these designs do not always suit evaluation research (Turner-Stokes et al., 2015). In the specific area of community integration following ABI, there are multiple examples of studies that offer important insight into service design that are not based on experimental designs as summarised previously.

It is relevant therefore to consider more descriptive designs with qualitative methods, cost benefit analysis or case study designs. Descriptive designs are particularly appropriate to report a new treatment or effect observed. It is also essential to match the design to the specific objectives of the research. A relevant example from the ABI literature is the evaluation of a community rehabilitation programme previously described in section 2.5 (Feeney et al., 2001). The authors describe the programme and participants in detail as well as discussing the service challenges that the clinical population present. As previously noted, the purpose of this evaluation was to secure long-term funding and it is clear that the design matched the needs in this specific context.

It is rare that research aims to only describe a treatment given and the effects observed. Instead researchers will usually try to apply an experimental approach as far as is possible, even if aspects of the design are descriptive. Mixed methods research of this type is common in ABI research and other similar clinical areas. Common examples would be evaluation of outcomes in a small sample of participants with

repeated use of standard outcome measures or experimental single case designs (Thompson, 2006; Lyon et al., 1997). These designs allow description of a small sample of participants with similar clinical presentations and the treatment they receive, repeated use of standard outcome measures provides data that can be compared and analysed. An independent control group and random assignment to conditions is not possible but periods of treatment / no treatment can be used to isolate the treatment effect to some extent. Primary analysis of outcome can be combined with other descriptive information such as user or family feedback or cost benefit analysis. Studies of this type are unlikely, in isolation, to provide robust evidence for a treatment or programme; they do however lend themselves more easily to comparison across a number of studies where similar methods or outcome measures were used.

Within the brain injury literature there is some support for use of in-depth case studies and semi structured interviews to provide detailed information about the 'lived experiences' of people with brain injury (Fraser, 1999; Turner et al., 2007). Sloan and colleagues (2004) use a single case study very effectively to illustrate an intervention. The authors review the literature and frameworks for designing community integration interventions in brain injury. They then summarise the key points of their 'Community Approach to Participation'. They summarise the key aspects of the intervention and for each component they illustrate how this was delivered via a single case study that runs through the report. This use of the case study increases the clinical applicability of presenting the theoretical framework and allows the authors to describe the approach more effectively.

Yin (2014) provides a comprehensive guide to carrying out case study research in all fields. He argues that whilst statistical generalisation cannot be made from case studies, if they are based on a theoretical framework and carried out in a systematic way, they can be used to generalise lessons in a similar context. This fits well with the aim to make the research clinically applicable. In addition, Yin states that case studies

are a valid methodology if the questions being answered involve exploring concepts of 'how' an intervention is developed and 'why' it is or is not successful.

In addition to providing a clear theoretical framework, Yin argues that use of multiple sources of evidence to build the case study will ensure that the final picture presented can be evidenced from this range of sources, he also advocates review of the study or the concepts by key people familiar with the case to ensure it provides an accurate description. Finally Yin and other authors argue for the need to have a clear protocol for carrying out the case study (Tate et al., 2016; Thompson, 2006; Yin, 2014)

Tate and colleagues (2016) report the development of a Guideline for Single Case Reporting. This guideline was developed to be applied to experimental case study methodology, referring to cases where repeated outcome measures are taken and the intervention is manipulated in an experimentally controlled manner across discrete phases. They argue that this provides a framework to guide researchers when carrying out or reviewing case study research. In considering whether a truly experimental design can be applied to case studies in the current study it is important to consider that the intervention is part of a current clinical service, available to all eligible patients in the geographical area. It was therefore not possible to manipulate the intervention multiple times or introduce a non-intervention period prior to starting the intervention as this would have amounted to withholding all or part of an available service. However, Tate and colleagues (2016) provide a detailed checklist covering all areas of design and reporting and therefore a framework that can be adhered to as much as possible within the clinical context. This framework was published very recently and therefore was not used in the design of the current study but provides a useful framework for discussing the impact of the findings.

Finally, when considering the purpose of single case designs it is useful to consider whether using more than one case adds anything further to the evidence that can be generated. Yin (2014) recommends that multiple case studies or case series are

appropriate if the population is very varied as these will demonstrate the differences as well as the similarities between examples.

The discussion above is brief and not intended as a comprehensive debate on experimental versus non-experimental designs but, taken in the context of the literature already discussed, forms a basis for choosing a design that best fits the research aims stated.

In the current study, a new intervention was being described and evaluated with a view to informing future practice and service improvement. It was important to match the design with the objectives of the research to maximise the applicability to future clinical practice and research. It was therefore appropriate to use detailed case studies, as in the example above from Sloan and colleagues (2004), to both practically illustrate the intervention and to start to evaluate and improve it. A case study design also allowed comparison of the standardised elements of the intervention individual application.

4.2. Choice of outcome measures:

The success of small sample experimental designs of this sort lies, in part, in the appropriate use of outcome measures to ensure that conclusions are robust. It is therefore relevant to look at this specific area in more detail.

When considering outcome choice it is important to consider whether the outcomes are a 'good match' to the questions being asked by the research, whether an objective or subjective (or both) measure will be more appropriate and whether the measure is sensitive to the participant group (Whiteneck, 2010). It is also important to consider whether a measure that is useful in clinical practice will also demonstrate clinically significant change in a research context or lend itself to robust analysis (Greenhalgh et al., 2008).

A variety of outcome measures are used within ABI to reflect the breadth of presentations, these measures vary greatly in the type of data they produce and the

level of reliability and validity that they have been shown to have. (Tate, 2010). Simple measures that are not highly dependent on the expertise of the assessor have been shown to be the most reliable. However, the information generated by these tends to give fairly basic information about the participant. For example, the Barthel Index (Mahoney & Barthel, 1965) has a high level of reliability and validity and has been extensively used in research. This provides a measure on independence on a number of activities of daily living. However, in many areas only gives two possible options (dependent/ independent) which means that it has little capacity to reflect small changes during treatment. Such assessments have also been shown to have high floor and ceiling effects with the ABI population (Greenwood, 1999). Other measures have a more detailed range of options or rely on subjective report of the participant, carer or clinician. These measures may be more sensitive to change but it is obviously more challenging to achieve consistent use and scoring (Tate, 2010). This tension in terms of validity vs. sensitivity reflects the same principle as the discussion above relating to experimental vs qualitative study design. Choosing a number of measures from across the spectrum is a potential solution to get the best of both types of measures but if this approach is taken it is important to consider the relationship between measures and how analysis will be carried out (Minnes et al., 2003).

In the current study, the primary research question relates to outcomes of community integration and therefore the primary measures should reflect this. Whiteneck (2010) identifies as many as 30 measures that relate to participation in brain injury, but the two measures used most often in UK research in this area are the Community Integration Questionnaire (CIQ) (Willer et al., 1993) and the Community Integration Measure (CIM) (McColl et al., 2001) and these will therefore both be considered here.

The CIQ is a 15-item questionnaire with items grouped into three areas to reflect the core components of the definition of community integration: home integration, social integration and productive activities. It can be completed face to face or via telephone

by either the person with brain injury, a proxy such as a family member or a carer/professional. The items are based on activities/behaviours rather than perception of integration so a higher score reflects independence in key tasks or a frequency of social contacts. It is the better researched and evaluated of the two measures reviewed here and has demonstrated robust reliability and validity (Winkler et al., 2006). However as the measure does not reflect the person's own perspective it is not able to reflect feelings of integration or belonging (Brown et al., 2004). It is also not possible to reflect supported independence positively in the scoring because items are scored on how frequently a task can be completed entirely independently (Minnes et al., 2003).

The CIM was developed with input from people with brain injuries based on the focus groups completed by McColl and colleagues (1998) and previously described. There are 10 items and these reflect the broader range of community integration components arising from this work. The items are entirely subjective and relate to the person's own feelings of integration and belonging. The scale can only be completed by the person with brain injury. The scale has not been used as frequently in research as the CIQ but it has been shown to have good reliability and criterion validity (Griffen et al., 2010). A number of studies have shown it to be sensitive to changes in a person's subjective feelings of integration and a number of items correlate with quality of life measures (Millis et al., 2014; Gerber et al., 2016). As the scale does not assume the importance of prescribed activities it is sensitive to the person's own perspective and allows for mutual or supported independence to be credited (Salter et al., 2008). It is a very brief and easy to administer measure which has been identified as both an advantage and a disadvantage as it may be too simple to demonstrate the full breadth of feelings of community integration and can show ceiling effects (Salter et al., 2008; Millis et al., 2014).

The participants in this study were all people who had chosen to return to living in the community with very high levels of disability, it was therefore important that the primary measure reflected their own concepts of integration and reflected supported independence positively. The best match in this instance was therefore the CIM as a primary measure.

The study participants had varying degrees of cognitive, communication and physical impairments and it was important to consider how the measure would be administered to this group. A concern with the CIM is that some studies using it have excluded people with more severe cognitive impairments because the statements included in the measure refer to complex concepts (Reistetter et al., 2005). The measure does not have an administration manual and so there are no clear instructions to guide researchers in these circumstances. In order to address this concern, as part of the current research, an associated study explored how the CIM could be made accessible for people with communication impairments and whether it was appropriate to develop a protocol for administering the measure (Clay, 2015). The author of this associated study carried out three focus groups with experienced SLTs, researchers with expertise in language and communication and people with communication impairments. The participants for the focus groups were recruited from a London academic department of Communication Science and a clinical speech and language therapy service from an inner London borough. The focus groups covered key topics to explore the content of the measure and elicit discussion about how the measure could be adapted to ensure people with communication impairments would be able to respond, and whether such adaptations would impact on the reliability of the measure. Example materials such as pictures and visual analogue scales were used to support the discussion. A thematic analysis was performed on the data from the focus groups. A number of themes emerged about ways the measure could be adapted to overcome potential linguistic and physical barriers to administering the measure. Examples include, explaining and

re-explaining the task, breaking down complex statements and using large font to aid understanding. The clinician and researcher groups generated several ideas and themes about ways that the measure could be appropriately adapted to meet a person's needs that went beyond these practical suggestions and included supporting wider understanding of the measure, the concepts contained within it and the emotional impact the statements might have. These themes included the need to build a therapeutic rapport, ensure the person was comfortable with the measure and check back responses. In most cases, the group of people with communication impairments supported the ideas generated by the professional groups. Overall the focus groups did not conclude that a standard protocol should be used to administer the measure but emphasised the need to adapt administration to the individual's needs, using the themes generated. The themes generated by this study can be viewed as a toolkit of ideas for adapting the measure when administered to people with communication or cognitive impairments, but the conclusions also emphasise the need for the measure to be administered by a skilled professional who can tailor the measure appropriately without compromising the validity. The themes generated by Clay (2015) were used to provide a framework for administration of the measure in the current study.

One of the secondary research questions in this study explores the interaction between community integration and level of impairment. In order to address this question, it was important to have further measures that could be contrasted to the subjective data that was generated by the CIM. The secondary measures chosen needed to reflect the participants' level of impairment or objective independence in tasks across a range of activities.

The secondary measures identified were the UK Functional Independence Measure Functional Assessment Measure (UKFIMFAM) (Turner-stokes et al., 1999) and the Mayo Portland Adaptability Scale (MPAI) (Bohac et al., 1997), Version 4 (Malec & Lezak, 2003).

The UK FIMFAM is an adaptation of the Functional Independence Measure and Functional Assessment Measure (FIM+FAM). It is a 30-item scale that rates independence in a number of personal and domestic tasks as well as cognitive and communication abilities. There are a further six items of extended activities of daily living that can be completed making a total of 36 items. Each item is scored on a seven-point scale indicating the level of assistance required in an area of function. The UK version has a detailed standardised manual, has demonstrated very good inter-rater reliability across different multidisciplinary teams, is well researched and appropriate for use with adults with ABI (Tate, 2010; Turner-Stokes et al., 1999). The participants in this study had all been through the specialist neurorehabilitation pathway described in Chapter 1 and the UK FIMFAM is one of the bundle of measures collected throughout this pathway as part of the UKROC data. It was therefore a sensible measure to use to contrast to the subjective primary measure. However it would not have been appropriate as the only secondary measure as it has demonstrated significant floor and ceiling effects in the ABI population (Powell, 1999) and is based largely on personal and domestic activities and therefore does not reflect the breadth of activities that are likely to form the basis for rehabilitation goals and intervention (Tempest & Jefferson, 2015).

The MPAI can be considered a more global measure of function after brain injury. It has 29 items over three sub scales (abilities, adjustment and participation). Each item is scored on a five-point scale indicating level of impairment or assistance required in an area of function. There is a fourth subscale to record pre-injury conditions but this is not scored. The items are based on the known sequelae of traumatic brain injury and has well documented psychometric properties (McGilloway et al., 2016). It was initially designed for use as part of an in-patient rehabilitation programme but has been used extensively within community programmes and demonstrated sensitivity to the changes targeted (Curran et al., 2015; Simpson et al., 2004; Kolakowsky-Hayner et al., 2012;

Geurtsen et al., 2012). The adjustment and participation sub scales cover areas not included in the UK FIMFAM but it is still an objective assessment based on frequency of problems/ level of independence in a task and can therefore also be contrasted with the primary outcome measure. This scale was also chosen instead of others that cover similar areas because the clinical team were already familiar with it and it is suitable for use in both in-patient and community environments.

The final issue to consider in this discussion of outcomes is a measure of clinical significance. This is an issue discussed by Powell and colleagues (2002) in their RCT but not discussed widely in the brain injury literature. Researchers often indicate the clinical effect that they are anticipating from an intervention but it is important to ensure that the outcome measures used are sensitive to this change. Powell and colleagues discuss what their expectation of a clinically meaningful change would be and how this would be demonstrated on their primary outcome measure. As previously described, they used the BICRO as the primary outcome measure, this is a 39-item measure, each item is scored on a 6-point Likert scale and the items are arranged in 8 sections (Personal Care, Mobility, Self-Organisation, Contact with partner or children, Contact with parents or siblings, Socialising, Productive employment and Psychological well-being). The measure was developed by the service in the study specifically for use in the community and therefore the areas measured reflected the goal areas used by the team. Based on previous trials of using the measure, the authors defined a clinically significant change as a move of 2 points on the Likert scale in a target goal area. This allowed them to measure whether this clinically significant change had occurred for the specific goal areas for each participant in the two groups, in addition to the primary analysis. This additional analysis supported the argument that the research intervention had contributed to the changes made.

In the case of this study the number of participants was small and their needs and goals were varied, it is therefore very difficult to state at the start of the intervention

what a standard measure of clinical significance would be. For this reason, rather than defining clinical significance on a standard scale, Goal Attainment Scaling (GAS) was used as a validity measure to ensure that the intervention achieves what was intended for each participant and that the outcome measures reflect this.

GAS is a method of scoring the extent to which a goal has been achieved. It was a technique originally developed for use in mental health settings (Kiresuk & Sherman, 1968). It is not a standardised measure as the goals are person specific, but there is a standardised method for measuring achievement against the goals based on a 5-point scale. In a recent systematic scoping review, that identified worldwide literature published in English, it was found to be the most widely used goal setting framework in ABI rehabilitation (Prescott, Fleming & Doig, 2015). There is general consensus within the literature that goal setting should be a core element of all rehabilitation programmes provided that a robust framework is used and the clinicians have sufficient skill in setting appropriate and measurable goals (Wade, 2009; Playford et al., 2009). There is also detailed published guidance available in using GAS in rehabilitation settings (Bovend'Eerd, Botell, & Wade, 2009; Turner-Stokes, 2009).

The rehabilitation team in the current study have used GAS as an outcome measure for over 15 years and have regular training and peer review to ensure the quality of the goals set. In the context of the study the GAS scoring was therefore used as a validity measure to check the primary and secondary outcome measures are sensitive to the changes targeted by the intervention.

The teams in the current study use GAS as described in Turner- Stokes (2009). The process involves a collaboration between the patient, family and MDT, to identify goals that reflect the patient's priorities. The MDT support the process to ensure that the goals set are SMART (Specific, Measurable, Achievable, Realistic and Time specified). The five-point scale is from -2 to +2, the baseline level of performance is usually set at -1 and the predicted level of outcome is defined as 0. The point at -2 allows for

performance against the goal to deteriorate and points 1 and 2 allow for the expected level of attainment to be exceeded. All the goals from a single episode of rehabilitation can be combined and represented by a standardised score based on a normal distribution (t-score) with a mean of 50 and a standard distribution of 10. To use the standardised scores, goals must be rated and scored in this way. The MDTs in the current study use a qualitative description of 'partially achieved' when reporting goals to demonstrate that a patient moved some way towards achieving the expected outcome. However, to maintain the standardisation of the scoring, partially achieved goals are scored as -1 (i.e. no change from baseline). For the current study, the process was therefore followed as per normal practice.

4.3. Summary

In conclusion, this discussion has framed some of the methodological issues the design of this research and identified an evidence base for the choices made to ensure that the design was well matched to the research questions, included a range of suitable outcome measures and considered the question of clinical significance and applicability.

5. Methodology

5.1. Research questions

Primary research question:

For adults with severe acquired brain injury choosing to return to live in the community, is a multidisciplinary transitional and community rehabilitation programme successful in increasing community integration?

Secondary research questions:

- What is the relationship between outcomes based on level of impairment and outcomes based on level of community integration?
- What is the experience of close relatives of adults with severe acquired brain injury returning to live in the community?

5.2. Research design

This study evaluated a multidisciplinary team (MDT) rehabilitation programme provided to adults returning to live in the community following severe ABI. It was a mixed method case series design based on collection of detailed case information and repeated measure design single-case studies. Outcome measures were repeated twice at baseline, at the end of each of two intervention phases and after a period of non-intervention. A range of outcome measures was used to explore outcomes relating community integration, independence in activities of daily living and level of impairment.

A close relative or friend of each participant, referred to as a relative participant, was interviewed based on a semi-structured interview schedule to identify themes regarding their experiences of transition from hospital to home.

5.3. Ethical considerations

Ethics approval was obtained from The Health Research Authority, National Research Ethics Service Committee London (reference 14/LO/0436). The committee was held on 20th March 2014 and a Favourable Opinion was granted on 25th March 2014 with the condition that the participant information sheets and consent forms be amended to acknowledge the researchers' duty to follow standard safeguarding policy. The amended forms were approved on 12th January 2015.

The study was approved by UCL on 15th January 2014 (reference number 12/0408). The study was also reviewed and approved by the sponsoring organisation, approval was granted on 21st May 2014 (reference RN 1402).

5.3.1. Protection of confidentiality

The confidentiality of the participants was protected by following the guidance provided by the National Research Council (Citro, Ilgen & Marrett, 2003). The participants were deemed to be vulnerable due to their cognitive and communication impairments and therefore the following precautions were taken:

- Informed consent: All information was provided in an appropriate manner to facilitate informed consent and understanding of how the data would be used and disseminated. Care was taken to explain to participants that their data would be anonymised prior to any reporting or dissemination of the results.
- Protection from harm: Information sheets made clear the responsibility of the researcher to protect participants from harm and follow standard safeguarding procedures used within the clinical service.
- Privacy and Confidentiality: Identifiable data collected was kept on the NHS clinical systems, either in handwritten or computer based secure notes systems, in compliance with the Clinical Trust's data protection policy. Patient identifiable information was not removed from this system. Summary data was transferred from

this system to enable reporting of the case studies, this data was anonymised prior to removal from this system in the following ways:

- All names were pseudonymised and all other personal information such as address, date of birth and NHS number were removed from documents.
- References to specific hospitals, areas of London and members of staff were generalised
- Key pieces of personal background information for participants such as their specific occupation or religion were not reported

5.4. Participants

5.4.1. Recruitment

Participants were identified from the group of residents of an inner London borough who received level 1 specialist in-patient neurorehabilitation under NHS England commissioning arrangements, as defined in Chapter 1. The principal researcher was involved with co-ordinating the care of this group and invited participants to be involved in the study during discharge planning from the level 1 unit, if they met the eligibility criteria.

The clinical team working with the participants provided verbal information about the study and this was followed up by a meeting with the principal researcher to provide detailed written information. Copies of the participant information sheets and consent forms can be found in Appendices 2 and 3. Capacity to consent to the intervention was assessed at this point by the principal researcher in collaboration with the treating clinical team (see below for further details). A second meeting was arranged after a two-week period to answer questions and gain consent. The relative participant was also invited to be present at these meetings and consent to participate in the interviews was gained from them either at this point or during the research intervention.

The sample size of 5 was determined by feasibility, as this was the number of participants who met the inclusion criteria in the recruitment period.

5.4.2. Capacity to consent

All participants in this study had cognitive and communication impairments and therefore it was important to establish capacity to consent. Based on the guidance in the Mental Capacity Act (2005), capacity must be assessed on a decision specific basis. In this study, participants could only be included if they were assessed to have the capacity to make the following two key decisions:

- To choose to return to living in the community (previous home, new home or supported living scheme) rather than a long-term care facility
- To consent to the research.

Capacity to consent in these areas was assessed by the Level 1, in-patient treating team in conjunction with the principal researcher who provided information about the study, presented in a format appropriate to the person's cognitive and communication abilities. These materials were individualised as appropriate but a standard symbol-based information sheet and consent form were developed. The researcher is an experienced SLT specialising in ABI and is therefore well qualified to provide this information in an accessible format.

During the intervention, assessment of capacity on these two decisions was reviewed if the clinical team identified any change in the participant's presentation. Capacity to make other decisions was assessed by the clinical team at appropriate points in the intervention. If a participant was assessed to not have capacity to make a decision in a specific area, for example to identify what level of care support they required at home, then the clinical team followed a Best Interests process in line with the MCA. When this occurred, the capacity to consent to the research was peer reviewed by the Principal Clinical Neuropsychologist within the clinical service who was also the MCA training

lead for the department and supported the clinical team with complex assessments. This peer review ensured consistency of assessment between the clinical team and the principal researcher.

5.4.3. Participant criteria

Inclusion criteria were as follows:

Adults of working age who:

- were living in the geographical area of the research
- had an ABI of any cause
- had received a period of 4-6 months Level 1 rehabilitation under NHSE commissioning arrangements
- had a score on the Rehabilitation Complexity Scale – Extended version 13 (RCS -E) (Turner-Stokes, 2012), greater than 9/22 indicating on-going need for care, ongoing complex nursing or medical care, regular therapy intervention from four or more professionals and some level of cognitive or behavioural risks.
- were choosing to return to live in the community, either in their own home, a new property or a supported living environment
- had the capacity to consent to the research

Potential participants were excluded if they:

- were unable to consent to research
- had chosen to live in residential or nursing home

5.4.4. Participant information

The background information for each participant is summarised in Table 1.

Table 1: Participant summary information

Name (pseudonym)	Age at start of study	Gender	Time post injury at start of study	Diagnosis	Relative participant	RCS-E Score at start of study
Billy	57	Male	11 months	<ul style="list-style-type: none"> Left Middle Cerebral Artery (MCA) Infarct Hypertension Shoulder Pain Peripheral neuropathy secondary to diabetes and previous chemotherapy 	Close friend	10
Richard	32	Male	16 months	<ul style="list-style-type: none"> Frontal, parietal and temporal haemorrhage Subdural haematoma 	Mother	10
Nathan	35	Male	10 months	<ul style="list-style-type: none"> Subarachnoid haemorrhage Subdural haemorrhage 	Mother and Father	13
Louise	48	Female	10 months	<ul style="list-style-type: none"> Right hemispheric ischemic stroke Chronic fatigue syndrome 10-year history of fatigue and non-specific pain with associated profound deconditioning Malnourishment Hypertension 	Relative did not consent to interview	14
Simon	50	Male	33 months	<ul style="list-style-type: none"> Left occipital and left temporal fracture, associated with underlying contusions and subdural haematoma 	Mother and Father	10

5.5. Materials

5.5.1. Battery of initial assessments

An initial multidisciplinary assessment was completed by the team at the start of the study. A standard proforma, developed by the team, was completed which included a summary of the participant's or relative's report of function, a summary of the objective assessments, a home visit report (if applicable) and a community risk assessment. Each member of the team identified appropriate objective assessments to inform this initial assessment, from the following battery of commonly used measures:

- Arm Activity Measure (Ashford et al., 2013)
- 9 Hole Peg test (Mathiowetz et al., 1985)
- Problem Solving Inventory (Heppner & Petersen, 1982)
- Rivermead Behavioural Memory Test (Koltai, Bowler & Shore 1996)
- Communication Effectiveness Index (Lomas et al., 1989)
- LaTrobe Communication Questionnaire (Douglas, O'Flaherty and Snow, 2000)
- Measure of Cognitive Linguistic Assessment (Ellmo et al., 1995)
- Berg Balance Scale (Berg et al., 1989)
- Rivermead MobilityScale (Collen et al., 1991)

5.5.2. Outcome measures

Primary outcome measure: Community Integration Measure –CIM (McColl et al., 2001). The protocol described in Chapter 4 was adopted to ensure that the measure was delivered appropriately to participants with communication impairment (Clay, 2015). The CIM was completed by the principal researcher who was an experienced SLT specialising in ABI and was therefore an appropriate professional to follow the protocol. Each administration of the primary outcome measure was videoed to confirm that the protocol was followed. The videos captured the principal researcher introducing the measure and reading the statements, they also captured any materials used and the participant responses.

A simple proforma was developed for peer review of the videos of the CIM being administered (see Appendix 4). It consisted of a brief summary of the protocol from Clay (2015) and two key questions:

- Did the assessor use materials or strategies appropriate to the participant's cognitive and communication needs to support the participant to engage in the measure?
- Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?

Secondary outcome measures:

- UK Functional Independence Measure/ Functional Assessment Measure (UK FIMFAM) (Turner-stokes et al.,1999):
- Mayo Portland Adaptability Index Version 4 (MPAI) (Malec & Lezak, 2003)

Additional validity measure: Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968). The procedure for GAS described in Turner Stokes (2009) was used, as summarised in section 4.2

5.5.3. Interview schedule

An interview schedule was developed to structure the interview with relative participants (see Appendix 5). The interview schedule asked open questions about the relative or friend's experience at each discrete phase of the programme. Prompt questions were based on the feedback received from families of previous patients and therefore focused on whether they were involved in discharge planning and aware of goals, also whether there had been delays with equipment or services.

5.6. Procedure

A standard procedure was followed for each case as summarised in Table 2.

Table 2: Summary of research procedure

Item	Description	Completed by
Initial Assessment	Initial assessment completed on admission to the transitional service (start of Intervention 1)	Transitional service MDT
Outcome measures 1	Outcome measures completed on admission to the transitional services (start of intervention 1)	Transitional service MDT and principal researcher
Outcome measures 2	Repeat outcome measures completed within 2 weeks of admission to the transitional service (start of Intervention 1)	Transitional service MDT and principal researcher
Intervention 1	Delivered as described in Chapter 3	Transitional service MDT
Outcome measures 3	Completed at the end of Intervention 1	Transitional service MDT and principal researcher
Intervention 2	Delivered as described in Chapter 3.	Community service MDT
Outcome measures 4	Completed at the end of Intervention 2	Community service MDT and principal researcher
Non-intervention period	Period without MDT intervention (12 weeks)	Not applicable
Outcome Measure 5	Completed at the end of no intervention period	Principal researcher with care and support staff
Interview with relative	Semi structured interview relating to the experience of the participant and family during the transition from hospital to home and the community intervention.	Member of Community MDT not involved in the intervention

5.6.1. Initial assessment

A battery of initial assessments was carried out by the Transitional Unit MDT immediately post discharge from hospital (as per the examples in section 5.5.1) and these were used to inform the completion of the MDT initial assessment as described in section 3.1. These assessments described the participants' abilities in detail. They were all assessments that would be carried out as appropriate during the course of rehabilitation.

5.6.2. Intervention

The intervention was delivered as per the normal clinical service described in detail in Chapter 3.

Intervention 1: This was delivered in the Transitional Unit as described in Chapter 3.

The intervention was individualised for each participant and this will be described in the case study reports (Chapters 6-10).

The MDT used GAS to set and review goals in conjunction with participants and their relatives. The length of Intervention 1 for each participant was based on the time specified during the goal setting process.

Intervention 2: This was delivered by the specialist Community Team as described in Chapter 3. The intervention was individualised for each participant and this will be described in the case study reports (Chapters 6-10).

The MDT used GAS to set and review goals in conjunction with participants and their relatives. The length of Intervention 2 for each participant was based on the time specified during the goal setting process.

Non-intervention period: Following Intervention 2, participants had a period of approximately 12 weeks without therapy to monitor whether any gains made were maintained.

5.6.3. Outcome measurement

The primary and secondary outcome measures were completed twice within a two-week period at the start of the intervention to provide a repeated baseline measure. The MDT within the transitional rehabilitation service completed the UK FIMFAM and MPAAI with support from the principal researcher. The team were not able to see their previous scores whilst rating for the second time. The CIM was completed by the principal researcher using the protocol described in section 4.2 (Clay, 2015).

Primary and secondary outcome measures were repeated after completion of Intervention 1, and 2. As above the treating team completed the UK FIMFAM and MPAAI and the CIM was completed by the principal researcher.

As the current study was evaluating actual clinical practice, it was not possible for the treating teams in Intervention 1 and 2 to be 'blind' to the intervention time (pre or post intervention). This created a risk of bias in completion of the measures which was mitigated by providing senior clinical support to the MDTs to complete the measures and ensuring consistent use of the decision trees for the UKFIMFAM and MPAAI.

A final set of outcome measures was completed after the non-intervention period. As there was no longer a treating team in place at this stage, the outcome measures were completed by the principal researcher with input from the participants' care staff or support workers. As the care staff and support workers were not familiar with the measures, the principal researcher completed them but used the decision trees and guidelines within the appropriate manuals to support the staff to provide the relevant information. As above, the principal researcher completed the CIM.

The administration of the CIM was videoed to allow peer review of the protocol. From the 25 videos, one per participant was selected at random and reviewed by a specialist SLT with access to the protocol, using the proforma in Appendix 4. The reviewing SLT

had knowledge of the participants' presentations but had not been the primary treating therapist.

5.7. Semi-structured interview with relative participants

The close relative or friend of each participant was invited to complete a semi-structured interview about the intervention process. The interviews were conducted by a member of the MDT not involved in the intervention.

The interviews were transcribed by a member of the research team not involved in the clinical intervention. The interviews were transcribed verbatim, including long pauses and key non-verbal communication such as laughter, where it was considered to add value to the content. More detailed features were not transcribed (for example, noting length of pauses, brief overlap in speaker, background noise, interruptions mumbled or garbled sentences etc.). These transcripts form the interview data.

5.8. Data collection

The data for the case studies was gathered from a number of sources as follows:

- Background clinical reports (e.g. from the Level 1 units) and referral form for the Transitional Unit
- Clinical notes from the Transitional Unit and community Team
- Clinic letters and reports completed during the intervention (e.g. Consultant reviews and home visit reports).
- Goal review meeting records
- Staff feedback from the transitional and community MDTs
- Outcome measure data
- Interview data.

The principal researcher discussed the detailed case reports with the service lead from the Transitional Unit to ensure that the key themes had been captured.

5.9. Data analysis

A collective statistical analysis of the data from all five cases was not possible due to the small sample size. With a small sample of participants with different starting profiles, no analysis would be sensitive enough to show change across the group (Thompson, 2006).

Pre- and post-intervention outcomes were analysed on a single-case, within participant basis using the Wilcoxon signed rank. Each question on the primary and secondary outcome measures was counted as a separate item to allow comparison across the different outcome measure points. The data generated by the measures was all ordinal data and therefore a non-parametric test was required. As the data was analysed within-participants, a test for related samples was required. There is standardised data available for the MPAI but this is only available for the subscale and total scores and therefore the raw scores were used for the Wilcoxon signed rank analysis.

Significance was measured as $p \leq 0.05$ on a 2-tailed test. The primary outcome measure (CIM) only has 10 items and this was a relatively small sample to show significance. Trial analysis was therefore carried out to check that this method of analysis was able to demonstrate statistically significant change. This trial analysis was completed for two patients who had previously completed the ABI pathway and this demonstrated a statistically significant change ($p \leq 0.05$) within participants on the primary outcome measure. Additional artificial analysis was carried out to identify what level of change would be required to show statistically significant change. This demonstrated that scores on the primary outcome measure (CIM) needed to improve by one point across four or more items to show significance ($p \leq 0.05$), indicating that the method of analysis should be sensitive to clinical changes anticipated.

The MPAI has of 29 items but a total of 31 questions: a score is only allocated for either paid employment (item 28a) or unpaid employment (item 28b) and when calculating the test total raw score, only one communication item (either 7a verbal

communication or 7b non-verbal communication) is used. For the purpose of this analysis, both communication items were used as all five participants had goals that related to both verbal and non-verbal communication. This gives a total of 30 items for the analysis. The MPAI has a subscale for pre-existing and associated conditions which provides clinical information but is not included in the scoring and was therefore not included in the analysis.

The UKFIMFAM has 36 items, including the Extended Activities of Daily Living items, but a total of 39 questions. When scoring only the lowest score is counted regarding bladder management (8.1 level of assistance or 8.2 frequency) and bowel management (9.1 level of assistance or 9.2 frequency), and only the most frequent form of locomotion (14.1 walking or 14.2 wheelchair). The analysis followed this pattern giving 36 items for analysis.

Scores were analysed across the whole intervention and for each intervention or non-intervention stage as summarised in Table 3.

Table 3: Outcome measure points for analysis of intervention and non-intervention stages

Outcome measure points	Intervention stage assessed
2 (repeated baseline) to 4 (end of Intervention 2)	Whole intervention
2 (repeated baseline) to 3 (end of Intervention 1)	Intervention 1
3 (end of Intervention 1) to 4 (end of Intervention 2)	Intervention 2
1 (initial baseline) to 2 (repeated baseline)	Baseline period
4 (end of Intervention 2) to 5 (end of non-intervention period)	Non-intervention period

Correlation between total scores on the different outcome measures at the five outcome points was analysed using Spearman's Rho correlation co-efficient. A 2-tailed test was carried out and significance was measured as $p \leq 0.05$. Five points is a very small sample for exploring correlation and therefore non-statistically significant results

were interpreted with caution and considered within the context of the other information available about the participant outcomes.

The sensitivity of the outcome measures to the changes targeted was also checked by comparing change on the outcome measures to GAS outcomes as a validity indicator. GAS t-scores were calculated for the beginning and end of each intervention using the formula given in Turner Stokes (2009). An outcome GAS t-score within the standard deviation measure of 40-60 was taken to indicate overall goal attainment (Turner-Stokes, 2009; Bovend'Eerd et al., 2009)

The data from the interviews was analysed using thematic analysis as described by Braun and Clarke (Braun & Clarke, 2006). The process followed is defined in Table 4. The thematic analysis was carried out by a member of the research team who was not involved in the clinical intervention, to ensure objectivity. The principal researcher provided support to explain the rehabilitation pathway for each participant and to provide definitions of services or individuals referred to during the interviews.

Table 4: Phases in thematic analysis (adapted from Braun and Clarke, 2006)

Phase	Detailed activity
Phase 1: familiarisation with the data	<ul style="list-style-type: none"> • Interviews transcribed. • Repeated reading of the transcripts in an active way looking for meaning and patterns. • Initial list of ideas about patterns in the data generated in preparation for coding.
Phase 2: Generating initial codes	<ul style="list-style-type: none"> • Conducted systematic coding using NVivo qualitative data analysis Software (QSR International Pty Ltd. Version 10, 2014). • Data organised into small, meaningful units (codes) according to the topic or interesting features of the data. • Data coded line by line giving “full and equal attention given to each line of data” (Braun and Clark, 2006). • Software used to ‘tag’ selections of text under different codes. • Extracts coded inclusively i.e. with a little of the surrounding data to retain context. • Notes about the codes and coding process kept. • Units of text could be included under more than one code or not coded. • Coding carried out following transcription of all four interviews.
Phase 3: Searching for themes	<ul style="list-style-type: none"> • List of initial codes generated. • Six codes, not relevant to the research aims, were discarded. • Several codes were merged. • Remaining 86 codes grouped into initial themes and sub-themes by arranging different codes (and a brief description) visually to enable emerging dominant themes to be identified. • Codes sorted into potential themes according to relationships between them. • Relationship between themes and sub-themes considered and (broadly and inclusively) mapped.
Phase 4: Reviewing	<ul style="list-style-type: none"> • Examined themes for “internal homogeneity and external heterogeneity” (Patton, 1990 in Braun & Clark, 2006) to ensure themes cohered together meaningfully and are sufficiently clear and identifiable from one another. • All collated extracts for each theme reviewed to ensure the candidate thematic map formed a coherent pattern. • Coded extracts reviewed to ensure all the coded extracts had been captured within themes. • Entire data set re-read to ensure validity of individual themes.
Phase 5: Defining and naming themes	<ul style="list-style-type: none"> • Essence of what each theme is about was identified by reviewing collated data extracts for each theme. • The content, meaning and points of interest for each theme were identified and summarised to tell the ‘story’ of the data, within and across themes. • Name chosen for each theme to provide sense of what it is about.
Phase 6: producing the report	<ul style="list-style-type: none"> • Evidence of the themes within the data provided. • Themes used to make arguments in relation to research questions.

5.10. Research hypotheses

The hypotheses being tested by the case studies in this research are as follows:

- Hypothesis 1: There will be significant change on all outcome measures across the whole intervention measured from the repeated baseline to the end of Intervention 2 (outcome points 2 to 4) indicating improved subjective report of community integration and improved function.
- Hypothesis 2: There will be no significant change on the primary or secondary outcome measures during the baseline period (outcome points 1 to 2)
- Hypothesis 3: There will be a pattern of greatest change on the secondary outcome measures during Intervention 1 (outcome points 2 to 3) when impairments and independence in function are being targeted.
- Hypothesis 4: There will be a pattern of greatest change on the primary outcome measure during Intervention 2 (outcome points 3 to 4) when participants return home.
- Hypothesis 5: There will be no significant change on the outcome measures during the non-intervention period (outcome points 4 to 5).
- Hypothesis 6: There will be a significant correlation between the scores on the two secondary outcome measures which both reflect ability in function.
- Hypothesis 7: There will be no significant correlation between the scores on the primary outcome measure and the secondary measures as the primary measure is a subjective scale and will not necessarily reflect independence in function.
- Hypothesis 8: All outcome standardised (t scores) for Goal Attainment Scaling will fall within the standard deviation range of 40-60 for both intervention stages, demonstrating overall goal achievement.

5.11. Data reporting and presentation of case studies

The case studies are reported separately in detail in Chapters 6-10. These individual reports include a detailed account of each case, the personalised intervention delivered, the goals for each intervention stage and the description of goal outcome.

The cases are presented individually in this way to provide a narrative that incorporates the information from the various data sources to demonstrate the complexities and issues arising in each case. Yin (2014) advocates presenting detailed case studies in this way to ensure the reader gains an in-depth understanding of each case (see section 4.1).

The outcome measures and analysis are presented separately in Chapter 11 and the themes from the interviews with relative participants are presented in Chapter 12. A collective review of the whole case series is then presented in Chapter 13.

6. Case study: Billy

6.1. Background

Billy, a 57-year-old man, lived on his own in a flat in London prior to his brain injury. He had a group of close friends locally, went out regularly and had a network of acquaintances in the local areas, such as people he knew in local shops and businesses. He previously worked in retail but had taken medical retirement due to earlier health problems. Billy had two sisters who he saw infrequently as they lived out of London.

Billy presented to his local hyper acute⁸ stroke service with right facial droop, right hemiparesis, decreased sensation and severe aphasia. Computerised tomography (CT) scan revealed a left middle cerebral artery (MCA) infarct. He received a full young stroke assessment.⁹ Of note, carotid dopplers showed complete occlusion of the left internal carotid artery and blood tests revealed borderline Lupus Syndrome. He was treated with warfarin but his international normalized ratio (INR)¹⁰ remained challenging to control and this continued throughout his rehabilitation.

His diagnosis was as follows:

- Left MCA infarct secondary to antiphospholipid syndrome¹¹
- Hypertension
- Shoulder Pain
- Peripheral Neuropathy secondary to diabetes and previous chemotherapy

Billy's rehabilitation pathway is summarised in Figure 5.

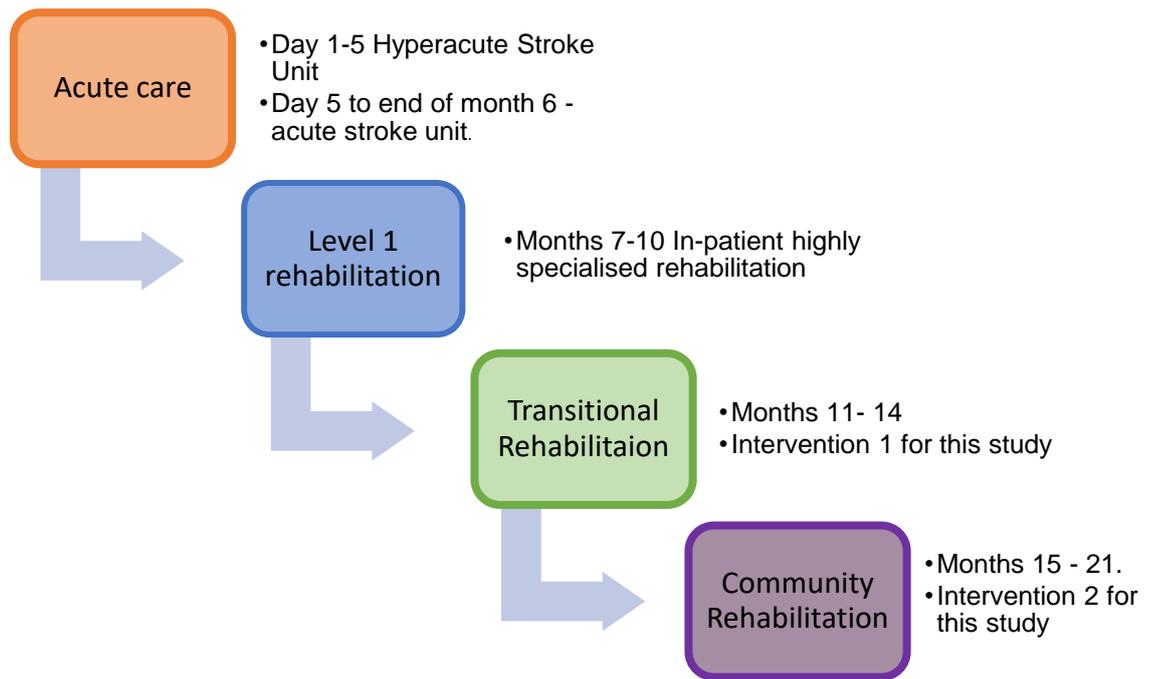
⁸ Hyper Acute Stroke Unit is a regional unit that provides rapid access to specialist treatment in the first 72 hours post stroke

⁹ Young Stroke Assessment is a series of additional diagnostic tests carried out to identify causes of stroke more common in the young (under 60 years old) population.

¹⁰ INR is a measure of how long it takes the blood to clot. It is used to monitor the level of anticoagulation required.

¹¹ Antiphospholipid syndrome is an autoimmune condition that increases the risk of blood clots

Figure 5: Billy rehabilitation pathway



6.2. Acute care and rehabilitation prior to the study intervention

Billy was transferred to a local stroke unit where he received nearly six months of acute rehabilitation. His acute stay was longer than planned due to the difficulty stabilising his INR, he then also had to wait for an available Level 1 bed. He was transferred for specialised neurorehabilitation (Level 1) despite this long acute period due to the complexity of his combined medical and rehabilitation need. He received four months of Level 1 rehabilitation, it took three to four weeks to establish a therapeutic rapport, felt to be due to the severity of his expressive aphasia, but he then engaged in his programme and goal setting.

At the point of discharge from the Level 1 unit his INR remained difficult to regulate on Warfarin, alternatives had been explored but deemed unsuitable due to the diagnosis of antiphospholipid syndrome. He used a one arm drive wheelchair and he could propel himself for short distances indoors. Fatigue limited his ability to mobilise independently. Billy required assistance from one person for most personal and domestic tasks. He remained severely aphasic but had a simple total communication system in place that allowed him to express himself effectively with skilled facilitation and extra time. This

consisted of a printed A4 size booklet that contained pages of written single words and symbols to help him to communicate. The booklet was organised into areas of function, for example there was a page with items he might want to ask for personal care. The booklet also contained symbols or single words to indicate issues that Billy often found frustrating (e.g. to indicate if he could not reach an item from his wheelchair). He had episodes of low mood and frustration throughout his Level 1 stay.

6.3. Entering the research study and gaining consent

Billy consistently expressed a wish to return to living independently but was unable to return to his previous property as it was unsuitable for his physical needs. He was identified as being at high risk of social isolation and low mood, therefore a period of transitional rehabilitation was recommended to identify the level of support required in a new property and to provide ongoing rehabilitation to increase independence and to focus on his key goal of returning to regular social activity.

Billy was assessed by the Level 1 team as having the capacity to make the decision to return to living in the community and to accept the transitional rehabilitation admission. Due to his aphasia, his treating SLT supported him through the assessment and he was provided with pictures to support him to respond and ask questions. The researcher met with Billy three times during the discharge planning period and provided verbal, written and pictorial information regarding the research project (see Appendix 2). Billy was assessed by the principal researcher to have the capacity to consent to the research and this was corroborated by his Level 1 treating SLT. Billy consented to the research prior to transfer to the transitional rehabilitation unit (Intervention1).

At the start of the intervention, Billy was not sure who he would like to nominate as a close relative or friend to complete the interview. The principal researcher discussed this with him at the end of Intervention 1 and early in Intervention 2. At this point he suggested a close friend as that was the person who had been most involved in supporting him through the intervention and in his new flat. The researcher made

contact with the friend via telephone and followed up with an emailed information sheet (see Appendix 2) and a face to face conversation following a review meeting. Billy's friend consented to the interview during Intervention 2.

6.4. Initial assessment

On entry to Intervention1 Billy received a full multidisciplinary assessment which revealed the following:

- **Mobility and physical ability:** Billy had right sided weakness of his upper and lower limb. He was able to self-propel his wheelchair for short distances indoors but was limited by fatigue. Billy was able to stand with assistance and take a few steps holding his wheelchair and with assistance from one person. This was limited by difficulty using a prescribed foot splint which Billy found uncomfortable. He had an anterior subluxation of right shoulder with associated pain.
- **Activities of daily living (ADLs):** Billy was able to wash independently with adapted environment and set up, but required assistance of one with dressing. He was dependent on others for all domestic tasks (cooking, tidying etc)
- **Medical management:** Billy was dependent on others for medication management including regular skilled monitoring of INR.
- **Communication:** Billy had moderate receptive aphasia (unreliable following two stage commands) and severe oral and verbal dyspraxia. He had expressive aphasia which was challenging to assess due to the interaction with his dyspraxia. He was able to comprehend single written words and write some single words to support communication but made errors in letter formation and spelling.
- **Cognition:** On assessment, Billy demonstrated good visual memory and attention in a quiet environment. He had reduced processing speed, impaired high-level attention and impaired executive function, demonstrating evidence of

fixed/ rigid thinking and reduced problem solving ability in both assessment and functional tasks.

- Mood: Billy experienced episodes of low mood, and frustration. His frustrated responses often appeared to be triggered by challenges with communication but longer periods of low mood and disengagement (up to several days) did not demonstrate a clear pattern.

6.5. Intervention 1

Billy was admitted to the transitional service for just under four months, this included a short period of graded discharge. Billy's goals for Intervention 1, were set for a period of 12-14 weeks and were as follows:

- I will be able to independently take money out from a cash machine with physical assistance to get to the bank.
- I will be independent with my morning routine, including getting to the bathroom, organising my things and completing all personal care.
- I will be able to mobilise indoors with a quad stick between my bedroom and the communal areas of the unit.
- I will attend two community leisure activities per week.
- I will understand and be involved in decision making around discharge with support from one person to understand the options available and express my preferences.
- I will be able to self-medicate using a blister pack provided to me on a weekly basis for four weeks prior to moving to my flat.
- I will be able to give the appropriate money in a shop using strategies.
- I will be able to buy a lottery ticket using total communication strategies

When planning how the intervention would be tailored to Billy's needs, there were two key factors that needed to be considered. The first was that, as previously stated, Billy

had a large social network with involvement from his sisters and a number of friends, but did not live with anyone. His intervention therefore needed to support him to reach a level of independence that would allow him to be in a property on his own for periods of time. This had implications for training and support of close others and carers as it was likely that Billy's social integration would need to be supported as part of his care package with social care staff rather than by a family member. The second related factor was that Billy demonstrated periods of low mood, usually characterised by frustration and/ or despondency. It was usually possible to identify the cause of frustration related to challenges in communication, but not always. Again, this had implications for the support that Billy would need and the training/ support that carers would need when working with him in the community.

Billy took two to three weeks to settle and build rapport with the team as he had on previous admissions. However, having settled, he was actively involved in setting the priorities for his rehabilitation. He consistently expressed that his overall goal was to return to live in a familiar part of London. He wanted to return to spending time with friends, both at home and in the community and he wanted to return to accessing the community regularly, including using public transport and going into Central London to shop and eat. Billy's sisters were involved in his goal setting and discharge planning but were not able to visit regularly due to travel distance. He had regular visits from friends and one close friend actively supported his rehabilitation and worked with the team closely.

Throughout Intervention 1 there were periods when Billy would become very frustrated with staff and this would sometimes last a few days. At these points in his intervention he could be quite intimidating to staff, particularly more junior staff and would physically block access to his room, use aggressive gestures and disengage from sessions. Billy and the team were supported to manage these episodes by the SLT and Neuropsychologist. The SLT provided a clear total communication framework using

spoken, written, pictorial and gesture communication strategies to support Billy's understanding and expression. This system supported staff to enable Billy to express the source of his frustration. One-to-one neuropsychology sessions also helped him to manage this frustration. The team used a consistent approach of acknowledging how frustrating something was to Billy and that it would probably take some time to establish the underlying cause using the total communication strategies consistently. Over time this supported a reduction in frustration.

Billy's programme was structured to replicate the care package he would receive in the community and to build periods of independence in-between care visits. His intervention was based on his individual goals, a number of which continued to directly target independence in function and use of strategies as per his previous in-patient programme but several moved on to target areas that would be important to ensure a successful move to the community.

The key components of Intervention 1 (taken from the standard list defined in section 3.2.3) for Billy were as follows:

- Personal care support provided to maximise independence. The care support to be provided in the community was replicated and facilities used matched to those in the discharge destination.
- Support to transition to a community level of medical and nursing support.
- Specific impairment-based therapy targeting areas identified in the goals
- Support to maximise access to the community, including addressing physical and cognitive barriers. This included support to identify the best form of physical access (e.g. walking with or without equipment, use of a wheelchair etc).
- Support to maximise access to chosen activities. This included consideration of the physical and cognitive challenges of accessing activities.

- Support to identify both specialist and mainstream services that would be helpful on discharge.
- Support for the patient and family members to understand the brain injury and the support required, as well as emotional support during the transition.

Billy's goal related interventions are presented in Table 5.

During Intervention 1, ongoing assessment and supported discussions concluded that Billy would benefit from an independent flat within a supported living scheme (SLS). This is a housing block with an onsite staff team and access to carers. He was allocated a SLS property for discharge. The allocation of Billy's flat was delayed which prolonged this stage of his intervention by two weeks and caused him additional frustration. Once allocated, the planned period of graded discharge had to be reduced because of the delay.

On discharge Billy moved into a one bedroom flat with an accessible bathroom, sitting room and adjoined open-plan kitchenette. The flat was within a block with 24-hour staff. The onsite staff team provided personal and domestic care calls as required (supervision only for personal care and assistance with more complex meal preparation). Billy also had a brain injury support worker twice per week to enable him to access the community for longer periods and build independence in use of public transport and in shops and restaurants.

Table 5: Billy Intervention 1 goals

Functional Therapy Goal	Goal Specific Interventions	Outcome
I will be able to independently take money out from a cash machine with physical assistance to get to the bank	<ul style="list-style-type: none"> • Reading comprehension sessions with SLT focussing on short phrases found on a cash machine • Regular practice within the community with RA 	Achieved
I will be independent with my morning routine, including getting to the bathroom, organising my things and completing all personal care	<ul style="list-style-type: none"> • Sessions facilitated by OT and RA incorporating one-armed techniques to increase independence in washing/dressing and preparing breakfast. • Reverse chaining and graded intervention approach used to manage frustrations with dependence • Total communication and regular explanation of purpose of sessions to encourage motivation. 	Achieved
I will be able to mobilise indoors with a quad stick between my bedroom and the communal areas of the unit.	<ul style="list-style-type: none"> • Exercise programme with PT and RAs • Daily practice mobility between areas in the unit using a quad stick, with support from all staff on the unit 	Achieved
I will attend two community leisure activities per week.	<ul style="list-style-type: none"> • Allocated a specialist brain injury support worker to help access to the community. • Training and support provided to the specialist support workers by all team members to ensure that they understood Billy's needs and could use strategies to facilitate communication and reduce frustration when initial communication attempts were unsuccessful. • Funding agreed through MDT functional report and presentation at Local Authority panel for continued brain injury support worker input. • Referred to a specialist gym to continue engagement in an exercise programme • Referred to a stroke group for support with accessing the local transport links, exercise classes and communication classes 	Partially achieved Pending waiting list for services including taxi card.

Functional Therapy Goal	Goal Specific Interventions	Outcome
I will understand and be involved in decision making around discharge with support from one person to understand the options available and express my preferences	<ul style="list-style-type: none"> • Regular one-to-one sessions with Neuropsychologist, using total communication strategies to explain next steps and the responsibilities of each party involved (including Billy) to aid understanding and manage frustrations at perceived lack of progress. • Two visits completed to proposed discharge destination to review specific flat and local area. • Meeting facilitated with next of kin, SLT and OT to explain financial elements, responsibilities and alternative options to enable individual choice. • Meetings facilitated with Housing Officers to introduce new staff and explain financial requirements • Referral made to benefits support worker to aid with optimising income. • Meeting with social worker facilitated by SLT 	Achieved
I will be able to self-medicate using a blister pack provided to me on a weekly basis for four weeks prior to moving to my flat.	<ul style="list-style-type: none"> • Supported to be responsible for own administration of medications with training from rehabilitation nurse, including understanding management of warfarin. • Programme established including visual and phone alarm reminders to prompt 	Achieved
I will be able to give the appropriate money in a shop using strategies	<ul style="list-style-type: none"> • Therapy programme devised by SLT to focus on comprehension of numbers, calculation and shop language. • Regular RA practice sessions on the unit and in the community 	Achieved
I will be able to buy a lottery ticket using total communication strategies	<ul style="list-style-type: none"> • Updated 'aphasia card' and practice of total communication strategies within conversation with SLT. • Regular RA practice 	Achieved

6.6. Intervention 2

On discharge to his SLS flat, Billy had a personal and domestic care package provided by the SLS team and a brain injury support worker twice per week. Billy's care was provided by the Local Authority and he made a financial contribution.

Billy received ongoing support from the Community Team who had also been involved in his graded discharge period from Intervention 1. In total Intervention 2 was seven months long but this included a three-month tailed discharge period. Billy moved into his flat successfully, but for four weeks he had frustrations with the environment in the communal corridors and the timing of care visits. The initial period of his intervention was therefore focussed on supporting management of some of these issues and ensuring Billy could communicate his needs and wishes.

Billy's Intervention 2 goals continued to focus on enabling increased independence in the home and accessing more leisure or social activity. There were a number of key achievements that Billy wanted to include, such as verbalising names of people close to him. Billy's Intervention 2 goals were set for a period of 20 weeks and were as follows:

- I will be able to order a drink in a café using a tablet computer application independently.
- I will be able to express basic needs and wants to carers and to reduce communication breakdown and frustration when attempting to communicate, measured by self-report and number of confrontations per care visit (goal less than 2 per week).
- I will be able to (verbally) produce the names of friends and family as well as short phrases used to greet people (95% success during sessions and spontaneous use with key friends).
- I will have a self-management plan in place to practise speech independently using a tablet computer twice per week.
- I will be able to mobilise to the local café using a quad stick with support from one person for supervision
- I will be engaged in a long-term exercise programme in the community once per week as part of my care package

- I will be able to make a meal independently using the cooker.

Billy continued to express frustration with elements of his living situation and at times he became fixed on these (e.g. the decorative appearance of communal hallways).

This could be a barrier to engaging with both the therapy team and support workers. A consistent approach to recording and reinforcing information was set up by the SLT and the Community Team provided on-going training to the support workers. Billy developed positive relationships with a number of the on-site care staff and these staff were also included in review meetings and training.

The key components of Intervention 2 (taken from the standard list defined in section 3.2.4) for Billy were as follows:

- Support to maximise independence in the home, building on gains made in Intervention1.
- Support to maximise access to the local community building on gains made in Intervention 1
- Support to use public transport or access appropriate community transport services
- Support to plan a sustainable routine in the community
- Support to access identified leisure activities
- Ongoing support for the patient and family members to understand the brain injury, and the support required as well as emotional support at this stage in the pathway

Table 6 summarises the goal focussed interventions for Billy (for Intervention 2).

Table 6: Billy Intervention 2 goals

Functional Therapy Goal	Goal Specific Intervention	Outcome
I will be able to order a drink in a café using a tablet computer application independently.	<ul style="list-style-type: none"> • One-to-one SLT sessions to practice use of an application, visual aid and script provided, role play of script. • Opportunity to practice within a café environment. 	Exceeded Billy was able to use a combination of speech and the tablet computer to complete this task
I will be able to express basic needs and wants to carers and to reduce communication breakdown and frustration when attempting to communicate, measured by self-report and number of confrontations per care visit (less than 2 per week).	<ul style="list-style-type: none"> • Communication guidelines established with Billy. Meetings and training sessions held by SLT with all carers involved, feedback received from carers. • Training provided by SLT to brain injury support workers on how to support Billy's communication in specific contexts. • Record of incidents and regular feedback sessions with Billy and SLT. 	Achieved
I will be able to (verbally) produce the names of friends and family as well as short phrases used to greet people (95% success during sessions and spontaneous use with key friends).	<ul style="list-style-type: none"> • Regular one-to-one SLT sessions using dyspraxia therapy to focus on accurate productions in repetition and role play of using these in natural scenarios. • Training provided by SLT to brain injury support workers and friend in order to ensure this therapy is carried out regularly. 	Partially achieved Billy was able to repeat these names and phrases with a 95% accuracy but has difficulty using spontaneously
I will have a self-management plan in place to practise speech independently using a tablet computer twice per week	<ul style="list-style-type: none"> • Appropriate speech therapy applications downloaded by SLT. • Billy and friend trained on how to access these • Goals established and frequency of self-directed sessions established and documented. • Monitoring sheet in place completed by Billy 	Achieved

Functional Therapy Goal	Goal Specific Intervention	Outcome
I will be able to mobilise to the local café using a quad stick with support from one person for supervision	<ul style="list-style-type: none"> • One-to-one PT sessions • One-to-one sessions with RA for specific pelvic and trunk strengthening • Trial of functional electrical stimulation (FES) to support gait pattern • Joint sessions with brain injury support workers • Trials with a walking stick • Steps/stair practice with RAs 	Partly achieved Billy was able to mobilise outdoors with his quad stick and support but not as far as the cafe
I will be engaged in a long-term exercise programme in the community once per week	<ul style="list-style-type: none"> • Referral to a specialist gym • Joint sessions with PT and gym staff to handover supervision and support needs • Schedule of attendance written and agreed as part of care plan. 	Achieved
I will be able to make a meal independently using the cooker	<ul style="list-style-type: none"> • One to one OT cooking sessions: • Repetitive practice of complex component tasks with the RAs. • Trial of equipment/use of strategies to assist planning and cooking tasks. • Handover to SLS Carers. 	Achieved

During discussions with the Community Team, Billy expressed high levels of anxiety about reducing support and resisted discharge from the service. To address this, a reasonably long period (three months) of graded discharge was used with increasing length of time between visits (from several times per week, to monthly review). On the visit at the end of the non-intervention period, Billy indicated he was continuing to receive good support from the SLS staff and his support workers.

6.7. Outcome summary

Overall Billy achieved his goals in both intervention periods and was successful in returning to the community. At both stages, his intervention was longer than anticipated. This was partly due to external factors such as housing, but was also in response to the level of anxiety and frustration that Billy exhibited on returning to the

community. This required additional direct intervention, additional training for carers and a longer period of graded discharge than planned.

It is important to note that, early on in his acute rehabilitation, the medical complications associated with his difficult to control INR meant there was a question over whether he would be able to return to living independently. This was therefore incorporated into Billy's intervention and supported by the nursing team and GP on the Transitional Unit.

Once established in his new property, Billy developed a positive routine and was able to function very independently inside the flat. He continued to require support to access the community but achieved this with friends and support workers several times per week. At three months post intervention, he had maintained the gains made in rehabilitation and reported that he liked the flat and onsite staff.

7. Case study: Richard

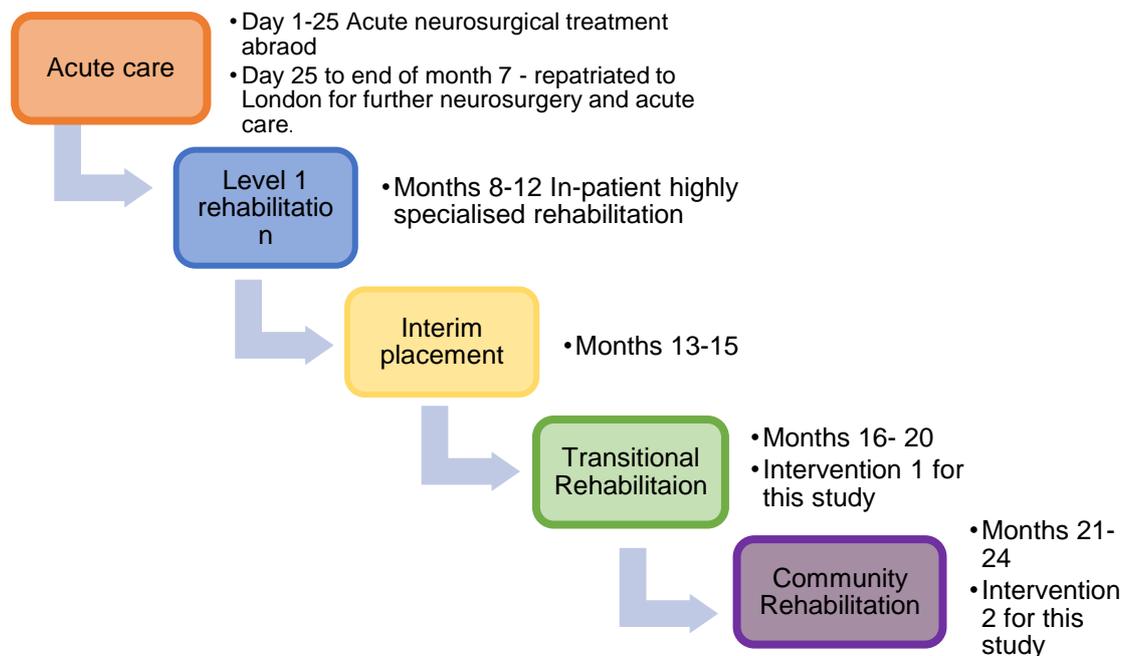
7.1. Background

Richard, a 33-year-old man, was travelling with friends, when he sustained a traumatic brain injury. Prior to this, he worked as a freelance events manager and travelled a lot with his work. He did not have a fixed address but stayed with or rented rooms from friends in London. He was close to both his parents who were separated and both lived out of London. He was also close to his sister who lived abroad and spoke to her regularly. Following his injury, Richard underwent craniectomy and evacuation of subdural haematoma in the country where the accident occurred. Richard was then repatriated to a specialist London Hospital where he underwent a cranioplasty.

Richard's diagnosis was:

- Frontal, parietal and temporal haemorrhage
- subdural haematoma

Figure 6: Richard rehabilitation pathway



7.2. Acute care and rehabilitation prior to the study intervention

Richard remained on a neurosurgical ward for two months following his repatriation and then transferred to an acute rehabilitation ward within the same hospital. He started to make a physical recovery and was able to mobilise. However, he had a significant cognitive impairment and was not able to manage his personal or domestic care as a result of this. He demonstrated reduced tolerance for frustration and associated verbal and physical aggression towards others. He was placed on a waiting list for highly specialised neurorehabilitation (Level 1) due to the severity of his cognitive and behavioural needs.

Richard received a four-month period of specialist neurorehabilitation (Level 1). This was primarily aimed at addressing his cognitive, behavioural and social communication needs.

Richard made good progress in rehabilitation in terms of his ability to carry out personal tasks, but continued to exhibit global lack of insight into his cognitive difficulties and high levels of frustration and anger. At the point of discharge, he still required daily support to manage his distress and there was concern from the Level 1 rehabilitation team about whether he could manage without 24-hour care in the future.

The Level 1 team recommended a period of transitional rehabilitation so that a detailed risk assessment could be completed prior to identifying a suitable long-term placement. The transitional service in this study was due to reopen after a period of closure whilst the pilot was evaluated, and therefore Richard moved to an interim placement for 12 weeks. The interim placement was a nursing home specialising in care for younger adults with ABI. It had access to some therapy intervention but was not an active rehabilitation service.

7.3. Entering the research study and gaining consent

The AHP Consultant from the Transitional Unit visited Richard in the interim placement regularly and worked with the team there to assess capacity to make a decision about long term placement. Richard required consistent feedback and support to understand the risks presented by his behaviour. However, when provided with this support he was able to demonstrate the capacity to decide that he wanted to return to live in the community. He was able to demonstrate understanding that a key goal for the transitional service would be to complete a risk assessment to define the level of care he would need.

The principal researcher met with Richard three times to discuss the research project following discharge planning meetings. He was also provided with written information (see Appendix 2). Richard was assessed by the principal researcher as having capacity to consent to the research and he consented prior to his transfer to the transitional service. Richard's mother was present for all the sessions discussing the research and was also provided with written information. She consented to participate in the interview verbally at this stage and in writing after Intervention 2.

7.4. Initial assessment

On entry to Intervention 1, Richard received a full multidisciplinary assessment which revealed the following:

- Mobility and physical ability: Richard was able to mobilise independently but he had poor balance and reduced exercise tolerance. He had reduced range of movement and strength in his left shoulder
- Activities of daily living (ADLs): Richard was able to complete his personal care and demonstrated reasonably good procedural memory in these familiar

practical tasks. He required close supervision for domestic tasks such as cooking due to reduced attention and safety awareness.

- **Communication:** Richard presented with moderate dysarthria characterised by reduced articulation (particularly with multi-syllabic words and consonant clusters), excessive use of stress, reduced pitch and volume range impacting on naturalness of speech and intelligibility. This was exacerbated by fatigue as well as periods of anxiety or frustration. Richard had a moderate cognitive communication impairment, characterised by poor understanding of social inference and non-verbal cues.
- **Cognition:** Richard presented with global cognitive difficulties affecting memory, organisation and planning skills. He had strengths in initiation of social and leisure activities and had good preserved procedural memory as demonstrated in personal ADLs. Richard demonstrated reduced insight into the cognitive, emotional and behavioural changes following his brain injury
- **Mood:** Richard presented with anxiety symptoms understood in the context of a trauma reaction to his brain injury. When anxious, Richard became very irritable with staff and asked for repeated reassurance about details such as confirmation of when family were visiting or his benefits would be paid.
- **Behaviour:** Richard presented with difficulty managing frustration and anger, resulting in verbal and occasionally physical altercations with staff and family members. These reactions were understood in the context of his brain injury, impaired problem solving, poor understanding of social inference and low frustration tolerance.

7.5. Intervention 1

As stated previously, Richard's admission to the transitional service was primarily to assess whether he would be able to return to living independently and safely in the

community. Prior to admission Richard's engagement was variable and he was negative about specific members of staff, reporting that he would find it difficult to engage with them. However, following a short settling in period, he engaged well with the team.

Richard had clearly stated his wish to return to living in London independently but due to his level of cognitive impairment, he was not able to reflect on the challenges he would have without consistent support. His rehabilitation programme addressed the risk areas for living in the community and replicated levels of supervision Richard would be able to access at home. He also worked within an allocated budget and was responsible for maintenance of his room and cooking his own meals in preparation for discharge. His goals included key personal achievements that were important to him, such as delivering a best man speech at his friend's wedding. His mother and father were both very involved in his rehabilitation and worked with Richard and the team to set and review goals.

Richard's Intervention 1 goals were set for a period of 16 weeks and were as follows:

- I will rehearse my best man's speech to an unfamiliar crowd for 5 minutes using clear speech strategies.
- I will be able to manage my weekly finances independently with an understanding of income and evidence of planning for a month.
- I will have contacted volunteering agencies, submitted an application and attended an introductory session with OT support
- I will use memory aids 75% of the time independently to recall appointments.
- I will improve intelligibility of my speech over the phone when speaking to unfamiliar listeners using strategies independently, as measured by a self-rating scale following phone calls.

- I will develop a long-term exercise routine through accessing regular (weekly) services in the community over a 6-week period.
- I will understand the ways my brain injury has affected me – including my thinking, feelings and behaviour – and learn about strategies that can help, evidenced by explaining my symptoms and strategies to family members.
- I will understand symptoms of anxiety that I get when near busy roads, and be able to reduce the frequency, intensity and level of distress caused by these symptoms, measured by a diary of symptoms.

Following the initial settling-in period, Richard worked well with the Intervention 1 team and was motivated by his goals. He continued to demonstrate a low frustration threshold and this had an impact on his interactions with other patients as well as staff. Early on in his admission there were several incidents such as slamming doors and shouting, but no physical aggression towards others. Richard went out from the unit once with friends and returned having drunk alcohol and was disruptive to the unit routine. A clear and consistent programme was established to respond to behavioural incidents and Richard engaged with one-to-one neuropsychology sessions to support understanding of his injury and the impact that it had on his emotions, behaviour and social interaction.

The key components of Intervention 1 (taken from the standard list defined in 3.2.3) for Richard, were as follows:

- Specific impairment-based therapy targeting areas identified in the goals
- Support to maximise access to the community, including addressing physical and cognitive barriers. This included a regularly reviewed community risk assessment

- Support to maximise access to chosen activities. including addressing cognitive challenges of accessing activities
- Support to plan a daily routine, taking into account the care available on discharge, the need for periods of activity and rest as well as the priority activities identified.
- Support for the patient and family members to understand the brain injury and the support required, as well as emotional support during the transition.

Richard's detailed goals and interventions are presented in Table 7 below.

Richard made considerable progress in terms of his ability to manage his frustration and anger. Episodes of verbal aggression towards others reduced significantly and Richard developed positive relationships with staff and other residents. The risk assessment carried out during Intervention 1 concluded that Richard would be able to live independently with appropriate support, but seeking housing was very challenging due to his inconsistent housing history. His admission was therefore extended beyond the optimum length. Supported housing was not made available to Richard because he could not demonstrate a consistent history of living in the area, and so his family found a flat on the open rental market.

Richard was discharged to a small studio flat on the ground floor of a converted house. He had access to a small garden. Richard had started to work with a brain injury support worker prior to discharge, and during a period of graded discharge, the transitional team provided support and training to the support worker to help Richard to maintain his routine on discharge.

Table 7: Richard Intervention 1 goals

Functional Therapy Goal	Goal Specific Intervention	Outcome
I will rehearse my best man's speech to an unfamiliar crowd for 5 minutes using clear speech strategies.	<ul style="list-style-type: none"> • SLT exercises focussing on articulation, varying use of pitch and altering stress. • Verbal and written education about compensatory strategies and opportunities to practice strategies (both one to one and to a crowd). 	Achieved
I will be able to manage my weekly finances independently with an understanding of income and evidence of planning for a month.	<ul style="list-style-type: none"> • Shopping and budgeting sessions with OT • Discussion of budgeting and need to provide evidence of ability to manage finances independently with OT • Worksheets provided requiring Richard to breakdown weekly and monthly income and spending. 	Partially achieved. Richard was able to manage a weekly stipend but was unable to provide evidence of planning expenditure for a month.
I will have contacted volunteering agencies, submitted an application and attended an introductory session with OT support	<ul style="list-style-type: none"> • Support from OT to contact Volunteer Service and set up meetings with relevant staff. • Support from OT to shortlist volunteering opportunities available considering role requirements and prioritisation • Joint session with OT at brain injury support centre, for volunteering interview. • Support to organise information using written notes and phone reminders 	Achieved
I will use memory aids 75% of the time independently to recall appointments.	<ul style="list-style-type: none"> • Cognitive rehab programme with Neuropsychologist and OT input explaining nature of injury and reason for memory difficulty. • Exploration of various strategies to assist including list checking/paper/diary/phone calendar. • Regular sessions with OT and brain injury support worker to reinforce successful strategies of phone calendar and list checking. 	Partially achieved Able to use all strategies independently but did not achieve 75%.

Functional Therapy Goal	Goal Specific Intervention	Outcome
I will improve the intelligibility of my speech over the phone when speaking to unfamiliar listeners using strategies independently, as measured by a self-rating scale following phone calls.	<ul style="list-style-type: none"> • Support from SLT to prepare content of phone calls • Opportunities to role play phone calls beforehand. • Reflection and feedback after phone calls. 	Achieved.
I will develop a long-term exercise routine through accessing regular(weekly) services in the community over a 6 week period.	<ul style="list-style-type: none"> • Independent exercise programme to improve the range of movement and strength in left shoulder provided by PT • PT sessions in the local gym to develop an exercise programme • Support from RAs to develop a five-a-side football match with friends 	Achieved
I will understand the ways my brain injury has affected me – including my thinking, feelings and behaviour – and learn about strategies that can help, evidenced by explaining my symptoms and strategies to family members.	<ul style="list-style-type: none"> • One-to-one sessions with Neuropsychologist to explore the impact of brain injury on cognition, emotions and behaviour, and to raise insight into the need to use strategies to manage difficulties • Support Richard to interview his Consultant Neurologist, and to see his brain scans, in order to understand where his brain was injured and the impact of factors such as drinking alcohol • Develop and practice strategies that successfully manage frustration/anger • Identify escalation patterns when becoming frustrated, and identify the most effective point to use strategies 	Achieved
I will understand symptoms of anxiety that I get when near busy roads, and be able to reduce the frequency, intensity and level of distress caused by these symptoms, as measured by a diary of symptoms	<ul style="list-style-type: none"> • One-to-one sessions with Neuropsychologist to develop a piece of narrative work with Richard and his family to compensate for the significant memory loss for the year preceding his accident and several months post-accident. Information was gathered about his accident, time in hospital, and his injuries. • Develop a piece of exposure based work with Richard, grading time spent near busy roads and supporting him to manage his anxiety reactions in context. 	Partially achieved Richard did not report a reduction in frequency of anxiety symptoms when near busy roads. But no longer felt upset by these symptoms

7.6. Intervention 2

Richard's care package was a brain injury support worker three times per week, funded by the Local Authority.

On discharge to his new property, Richard was supported by the Community Team who had been involved in the graded discharge period. Richard's intervention in the community was predominantly focussed on embedding successful strategies to manage his cognitive and social communication impairment into his new routine and establishing a routine of regular activity and volunteering. He engaged well with the team and was highly motivated. Richard's goals for Intervention 2 were set for a period of 12 weeks and were as follows:

- I will be able to manage my diary with minimum (weekly) support
- I will attend voluntary work two days a week independently with prompts in my diary
- I will attend an exercise classes once per week independently with prompts in my diary
- I will attend two social activities per week in the community independently using my diary
- I will engage in a regular (weekly) independent exercise programme

Richard worked with the Community Team and his brain injury support worker to facilitate transfer of strategies into his routine. Richard worked very successfully with his brain injury support worker, so the Community Team focussed some of the intervention on training for the support worker to embed Richard's positive routine.

Through regular community practice and feedback sessions, he started to demonstrate a greater insight into the risks associated with his cognitive impairment. For example, he was able to reflect on his vulnerability to be led by people (e.g. sales call), his tendency to misinterpret social and nonverbal communication and to recognise some of

his memory and attention difficulties. He successfully adopted strategies to manage these and built up a reasonably full routine with structured activity on most days.

The key components of Intervention 2 (taken from the standard list defined in 3.2.4) were as follows:

- Support to maximise access to the local community building on gains made in Intervention 1
- Support to plan a sustainable routine in the community
- Support to access identified leisure activities
- Support to consider vocational options through volunteering opportunities
- Ongoing support for the patient and family members to understand the brain injury and the support required, as well as emotional support at this stage in the pathway

On review by the Local Authority towards the end of Intervention 2, Richard was assessed as no longer eligible for his brain injury support worker due to the progress he had made. This resulted in the support worker time being first reduced and then stopped altogether. At this point, Richard had built up to a routine consisting of leisure activities, training courses and volunteering. He maintained this on a reduced level of support but when the support worker was withdrawn, he did not maintain his routine consistently and a number of significant risk areas were identified by family and the Community Team. Despite the identification of these risk areas, the support package was not reinstated. Most of the risks related to Richard not maintaining strategies successfully established with the support worker. Richard's family spent more time in London to support him but this placed a strain on relationships as both parents lived outside London and had limited capacity to stay for long-periods. The Community Team presented the risks but the funding for the support worker was not extended.

Table 8: Richard Intervention 2 goals

Functional Therapy Goal	Goal specific Intervention	Outcome
I will be able to manage my diary with minimum (weekly) support	<ul style="list-style-type: none"> • Support from OT and RA to assist organise and plan diary and voluntary work. • Recommendations of ongoing use of external memory aids, such as a calendar to improve organisation skills. 	Achieved
I will attend voluntary work two days a week independently with diary prompts	<ul style="list-style-type: none"> • Support from OT with contacting the voluntary service and establishing a regular point of contact • Training for brain injury support worker to reinforce Richard's routine and commitments 	Partially achieved Richard identified 3 volunteering opportunities but this did not progress to a regular 2-day routine.
I will be able to attend exercise classes once per week independently with diary prompts	<ul style="list-style-type: none"> • Support from PT to find sport/exercise he likes. • Support with attending the exercise weekly by ensuring that the Richard has created an appointment in his diary. 	Achieved
I will attend two social activities per week in the community independently using my diary	<ul style="list-style-type: none"> • Investigate different classes and courses in the community with support from OT • Support and advice to contact the different classes in the community and to investigate theme, time, date and frequency. 	Achieved
I will engage in a regular (weekly) independent exercise programme	<ul style="list-style-type: none"> • One-to-one PT sessions to review home exercise programme • Suggested schedule completed to introduce an exercise programme in to daily routine • Referral to specialist gym for on-going support with exercise engagement 	Partly achieved Richard was not independently engaging in a programme therefore disability specialist gym referral made for on-going support with exercise

The risks identified included:

- Risk of exploitation from others
- Risk of missing appointments and failing to maintain a routine or regular commitment
- Risk of not engaging in appropriate social activity
- Risk of deterioration in health and well being
- Risk of breakdown in family relationships
- Risk of non-maintenance of the flat/ environment.

The team felt that the impact of losing the support worker may have been reflected in the goals that were only partially achieved, such as establishing a regular volunteering routine. At this point, Richard was functioning very well, given the severity of his injury, and had demonstrated an ability to commit to volunteering. However, without the level of external structure provided by the support worker on a regular (weekly) basis, he was not able to reliably maintain strategies or organise his time to maintain a regular routine in these areas. The Community Team worked with Richard and his mother to agree strategies that he could use, with support from his mother via phone, email or video calls to minimise the risk. At the point of discharge from Intervention 2, Richard and his mother felt positive that these additional strategies were successful. There was a concern from the team and family that this arrangement would place strain on family relationships and therefore Richard and his mother were reassured that they could refer back to the service during the non-intervention period if required. Neither Richard nor his mother self-referred during the non-intervention period. The team also discussed the possible option of a formal vocational rehabilitation programme but Richard did not want to pursue this.

7.7. Outcome summary

Richard made considerable progress in his rehabilitation and was able to return to living independently, which was his priority goal. He reported reasonably high levels of satisfaction with his situation and was motivated to attend activities and socialise. Based on the progress that he made, it may be possible for him to establish a regular routine of volunteering or other vocational activity. However, it was not possible to identify the appropriate resource, either a support worker or vocational rehabilitation service, that he was eligible for.

At three months' post-intervention he remained positive about his situation and was seeing friends and family regularly. He was continuing to attend various activities on a somewhat sporadic basis. At the post-intervention visit the flat was in an untidy state and Richard's mother reported that she had to provide additional support to help him to maintain his tenancy and manage his routine since the support worker sessions stopped. Richard had missed a number of appointments and was not using his diary reliably. His mother was also keen for him to access more SLT.

A further period of intervention with the Community Team was triggered to support Richard to try to access more community supports to maintain his level of function.

Reasons for a further period of intervention were identified as:

- SLT review to provide additional advice and reinforce strategies. Potential to identify a community group to attend.
- OT review to trial further strategies to support maintenance of routine and domestic responsibilities
- AHP Consultant input to revisit social care support package.

8. Case study: Nathan

8.1. Background:

Nathan, a 36-year-old man, was living and working in London prior to his injury. He owned his flat in a central London location and worked full time in the fashion industry. Nathan had a large group of friends, an active social life and attended the gym regularly. He had interests in fashion, design and eating out.

Nathan had two brothers living in London whom he saw regularly. His parents lived outside London but they were close to Nathan and during his rehabilitation they stayed in his flat to support him.

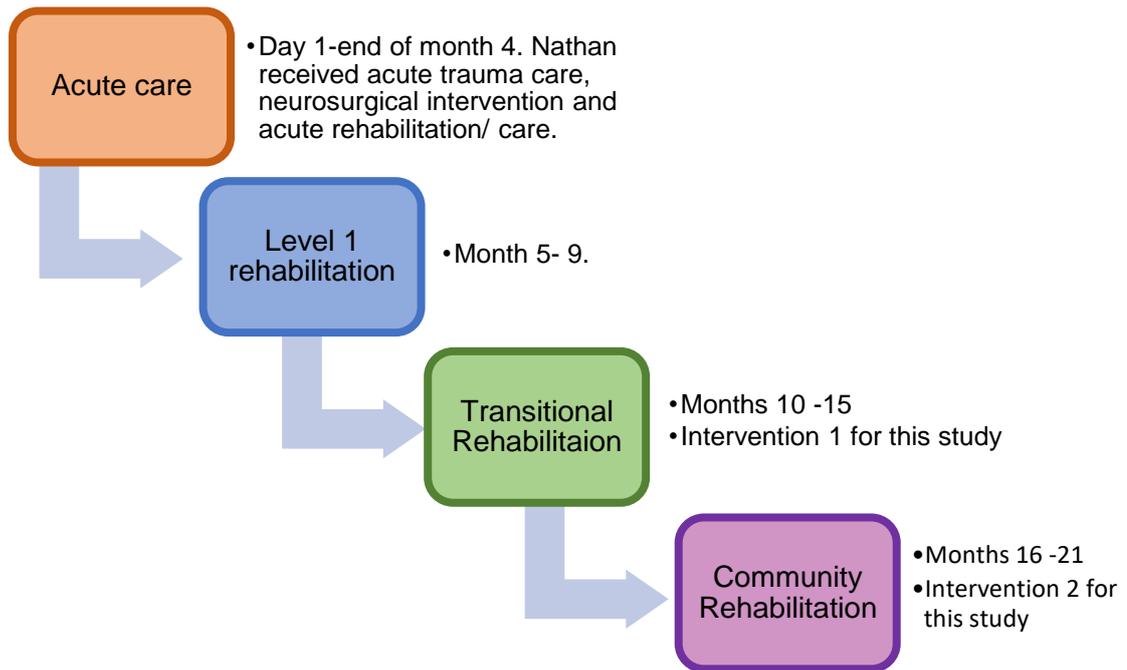
Nathan sustained his brain injury when he fell down a flight of stairs in the communal area of his block of flats. He was admitted to the locality major trauma centre and was found to have sustained a sub-arachnoid haemorrhage, bifrontal contusions and a subdural haemorrhage. He underwent a bi-frontal craniectomy and was initially intubated following surgery. He acquired pneumonia during his acute surgical admission and required ventilation. Six weeks after his injury he had a ventriculoperitoneal (VP) shunt inserted and a month later he had a bi-frontal cranioplasty.

His diagnosis was:

- Subarachnoid haemorrhage
- Subdural haemorrhage

Nathan's rehabilitation pathway is summarised in Figure 7.

Figure 7: Nathan rehabilitation pathway



8.2. Acute care and rehabilitation prior to the study intervention:

Nathan underwent neurosurgery as detailed above and then remained at the same hospital whilst awaiting rehabilitation. For the early part of this stay he was medically unwell as noted above and underwent further surgery. Following his cranioplasty he gradually stabilised medically and was decannulated. He did not receive co-ordinated multidisciplinary rehabilitation in this setting as it is not available but as he demonstrated good medical recovery a Level 1 placement was recommended. He was supported by the acute therapy team as his mobility and physical ability improved. In total, he remained at this hospital for four months before he was transferred to a specialist (Level 1) neurorehabilitation unit.

On admission to the Level 1 unit he had made a good physical recovery. He continued to demonstrate slow movements and impaired balance but was mobilising independently. He was impulsive in his movement and therefore was at risk of falls. He had a global cognitive impairment which had a significant impact on his functioning. He demonstrated impaired orientation to time, place and less familiar people, impaired information processing, reduced initiation and motivation. On the unit, he was unable to

use a timetable or follow the unit routine. He was incontinent in bed over-night and in the morning and did not initiate getting up or changing his clothes despite encouragement and prompting from staff.

During his Level 1 admission, he had a neurosurgical review and head CT scan that revealed enlarged ventricles but no acute concerns. He remained under the neurosurgical team for follow up.

During his admission, Nathan demonstrated improved mobility and safety indoors, but remained impulsive and demonstrated poor safety awareness outside, including a risk of walking into traffic or obstacles. His ability to carry out personal care routines improved once the activity had been initiated by someone else, but he did not initiate such activities and continued to stay in soiled clothes or bed.

Nathan presented with a cognitive communication impairment. His spoken expression was fluent but lacked content and was characterised by vague statements, impaired word retrieval and circumlocutory output. Receptive language was impaired for abstract or complex information.

Nathan had severely impaired insight into his needs and felt ready to return home and to work throughout his stay. His physical ability and general fluency masked the significance of his cognitive impairment and caused people to overestimate his abilities.

8.3. Entering the research study and gaining consent:

It was not clear at this stage whether Nathan would be able to return to living in the community due to his level of cognitive impairment and particularly lack of initiation in personal care tasks and impaired safety awareness. He required 24-hour supervision and the Level 1 rehabilitation team recommended a period of transitional assessment to see if he could return home safely. This decision was challenging for Nathan and his family as they were initially keen to access specialist vocational rehabilitation because Nathan was very preoccupied by a wish to return to work. It was the view of the Level 1

rehabilitation team that this reflected his impaired insight into his needs. The team instead recommended that it would be appropriate for Nathan to access a structured transitional rehabilitation programme close to home to enable community risk assessment in a familiar context. Nathan and his parents were given the opportunity to view both options before stating their preference. Nathan and his family choose to access the transitional rehabilitation (the research Intervention 1). Assessment by the Level 1 team during discharge planning concluded that Nathan did not have the capacity to reflect on his detailed care and support needs. A Best Interest Meeting¹² was therefore held to confirm the decision to access transitional rehabilitation.

Nathan's capacity to consent to the research study was assessed by the principal researcher during the discharge planning process and by the treating Neuropsychologist. The assessment concluded that he could consent to the research, despite not being able to reflect on his need for rehabilitation, as he could demonstrate understanding of the specific demands of the research project.

Nathan's parents consented at this point to also participate in the research interview.

8.4. Initial assessment:

Nathan transferred to the transitional rehabilitation service (for Intervention 1) nine months after his injury. On entry to the research project Nathan received a full multidisciplinary assessment which revealed the following:

- Communication: Nathan presented with moderate cognitive communication disorder characterised by verbose and tangential speech impacting on turn taking and topic maintenance. Responses often contained 'empty speech' with a verbal output of limited content and at times use of inappropriate

¹² The Mental Capacity Act (2005) provides detailed guidance on assessment of capacity for specific decisions. If a person does not have capacity to make a specified decision then a Best Interest process should be followed where the clinical team and family contribute to a decision making process with the values and beliefs of the patient at the centre of the discussion. Full guidance can be found in the Act.

words. Receptive language was affected by reduced attention and delayed processing, resulting in difficulties comprehending complex information. Nathan had a susceptibility to suggestion and tendency to acquiesce related to his communication impairment.

- Cognition: Nathan's assessment showed a cognitive profile characterised by relatively intact intellectual functioning, but marked memory and executive deficits as follows:
 - Dysexecutive memory profile characterised by inefficient and disorganised encoding (affected by perseverations and intrusions) in addition to a marked retrieval deficit. Tendency to confabulate when experiencing difficulties recalling information from memory, and difficulties accurately recalling the temporal sequence of events (e.g. often reporting events that happened several weeks ago as occurring the day before).
 - Executive dysfunction characterised by difficulties with initiation and task persistence, self-monitoring, concept generation, problem solving and strategy generation, and higher level attentional impairments (e.g. poor divided, sustained and selective attention). Significantly impaired insight.
 - Unable to independently generate ideas relating to choices about activities or when planning tasks (e.g. unable to plan, organise, cook or serve regular meals for self). This was considered to be due to combination of low motivation, impaired sustained attention, difficulties with decision making and no pre-morbid habit of cooking for self or others
- Activities of daily living (ADLs): Nathan required excessive time to complete personal care tasks secondary to cognitive impairment described above and characterised by reduced initiation and problems sustaining attention. He required prompts every 10 minutes over a two to three-hour timeframe to

complete morning personal care. Nathan was incontinent of urine overnight and unable to initiate alerting staff or completing his own personal care in this area.

8.5. Intervention 1:

On admission to the Transitional Unit (for Intervention 1), Nathan was able to express a clear desire to return home but, because of the severity of his cognitive impairment, he was not able to reflect on the challenges he would have living independently. The focus of his admission was therefore to continue to support independence in function, but also to complete comprehensive risk assessment for living in the community and explore potential leisure and vocational goals.

Nathan was consistently pleasant to all unit staff and always appeared to agree to sessions and activities, however he often, in fact, could not initiate coming to join sessions. He found it difficult to engage meaningfully in goal setting due to his impaired insight and executive function. He was able to state an over-arching wish to return to living at home, socialising with friends and working. Specific goals were largely set by the team and family, therefore, but with reference to Nathan's overall wish to return home and his previous beliefs and values. This is reflected in the presentation of Nathan's goals, which are written in the third person. The goals for Intervention 1 were set for a period of 16 weeks and were as follows:

- To be independent within a daily routine as demonstrated by:
 - To be able to get up, washed and dressed and have breakfast by 10.00 independently
 - To be able to arrive on time to 90% of sessions and appointments using an electronic reminder system
- To manage continence independently without requiring prompts from others to use the bathroom. Measured by a period of 3 weeks with no episodes of incontinence day or night without the aid of pads or medication.

- For the MDT to be able to present a clear understanding of the risks associated with Nathan accessing the community independently. Measured by Nathan accessing the community independently and safely by leaving the unit, attending a planned activity and returning within an agreed timescale.
- For Nathan to demonstrate understanding of the impact of his brain injury by consistently accepting assistance to help him to complete certain tasks (e.g. programming his phone with appointments on a weekly basis)
- To reduce instances of 'empty speech' with a skilled conversation partner by responding to a structure and prompts to indicate when he does not know the answer to a question and to present short factual answers to questions within an agreed structure.

The key components of Intervention 1 (taken from the standard list defined in 3.2.3) for Nathan were:

- Personal care support provided to maximise independence
- Support to maximise access to the community, including addressing physical and cognitive barriers. This included a regularly reviewed community risk assessment.
- Support to maximise access to chosen activities
- Support to plan a daily routine, taking into account the care available on discharge, the need for periods of activity and rest as well as the priority activities identified.
- Support to identify both specialist and mainstream services that will be helpful on discharge.
- Support for the patient and family members to understand the brain injury and the support required, as well as emotional support during the transition.

For Intervention 1, the team designed a highly-structured morning routine for Nathan to support him to overcome the difficulties he had relating to poor initiation and motivation.

On a practical basis, Nathan was not able to progress in his rehabilitation whilst his problems with initiation were preventing him from engaging in the most basic of daily tasks or routines such as getting out of bed or managing continence. It was essential that the team worked in a consistent manner to support Nathan to develop an appropriate routine and that all staff understood the cognitive basis for Nathan's difficulties. The programme involved members of staff going into Nathan's room to wake him at a set time every morning and prompting him to get out of bed and complete personal care. At the start of Intervention 1, Nathan was not able to respond to initial prompts to get up. Staff therefore followed a consistent pattern of remaining in the room, and continuing prompts at regular intervals to support initiation. The OT and Neuropsychologist modelled the programme and trained all staff to deliver it consistently. Staff reported that delivering this programme was very uncomfortable because the interaction was unnatural and it felt inappropriate to remain in the room delivering the prompts when Nathan was unable to respond appropriately for an extended period. Additional support was therefore provided to the unit staff delivering this intervention to help them to understand the rationale. When out of bed, Nathan was prompted to complete personal care following a consistent structured routine. Over the first four weeks of Intervention 1, with this consistent prompting, he started to respond and over a further four weeks, his continence improved and he initiated getting out of bed in response to an alarm clock.

This structured approach was applied to Nathan's entire day routine and a number of key prompts such as telephone alarms, written timetables and a timer for his television were used with consistent reinforcement from the staff team to embed these into his routine.

As Nathan's ability to engage with a regular routine improved, the team started a community risk assessment to establish whether Nathan could return to living safely in the community. This assessment comprised structured observations of key community

activity, trials of feedback and structured prompts and the development of a structured programme to gradually reduce community supervision. Nathan's family also received support to understand strategies to help Nathan to plan and carryout activities safely and to provide feedback.

When Nathan had received eight weeks of Intervention 1, he was demonstrating improved engagement in a structured personal care and daytime routine and had started to access the community with support. However, his family remained concerned that he was not demonstrating his previous high-levels of interest and pride in his clothes and appearance. At this point, Nathan's rehabilitation team and family also observed that he seemed more tired in the morning and was a little less responsive to prompting. The team triggered a review by the Consultant Neurologist who referred for a brain scan and review with the original neurosurgeons. This review concluded that his VP shunt was not working effectively and it was surgically revised. Following this surgical intervention Nathan continued to improve along the trajectory that he started in terms of embedding a routine and improved initiation. However, he also started to demonstrate a pride in his appearance and improved motivation.

Throughout Intervention 1, Nathan received structured feedback sessions to support him to recognise when he did not understand information or could not recall accurately the information requested. This element of Nathan's programme was led by his SLT but again required a consistent approach from all staff to feedback to Nathan when he used 'empty phrases' and to provide key information. He also received an ongoing brain injury education programme from the unit Neuropsychologist.

Nathan's detailed goals for Intervention 1 are summarised in the Table 9.

Table 9: Nathan Intervention 1 goals

Functional Therapy Goal	Goal Specific Intervention	Outcome
<p>To be independent within a daily routine as demonstrated by:</p> <p>(1) To be able to get up, washed and dressed and have breakfast by 10.00am independently</p> <p>(2) To be able to arrive on time to 90% of sessions and appointments using an electronic reminder system</p>	<ul style="list-style-type: none"> • Structured OT assessment sessions to determine most effective approach for morning support. • Trial use of goal directed checklists. • Trial Electronic Alarm assistance and implementation of timer plug for TV to reduce distraction • Identifying and establishing regular routine of motivating activities to help develop internal drive for independence. • Providing advance orientation to next day activities. • Routine sessions with OT/RA/Neuropsychologist and Brain Injury support worker • 1:1 Neuropsychology sessions focussed on raising insight to cognitive impairments and need to use external aids to compensate • Graded reduction of external support as routine established 	<p>Achieved</p>
<p>To manage continence independently without requiring prompts from others to use the bathroom. Measured by a period of 3 weeks with no episodes of incontinence day or night without the aid of pads or medication.</p>	<ul style="list-style-type: none"> • Continence Record Sheet completed by MDT. • Rehabilitation nursing record of timings of incidents to better understand continence routine. • Trial of electronic reminders • Direct Neuropsychology interventions to aid awareness with immediate explicit feedback when incontinence noted to highlight that it is inappropriate to remain in soiled clothes and to support a change in behaviour • Positive reinforcement of successful management of continence 	<p>Achieved</p>

Functional Therapy Goal	Goal Specific Intervention	Outcome
<p>For the MDT to be able to present a clear understanding of the risks associated with Nathan accessing the community independently</p> <p>Measured by Nathan accessing the community independently and safely by leaving the unit, attending a planned activity and returning within an agreed timescale.</p>	<ul style="list-style-type: none"> • MDT risk assessment for community access including review of road safety and vulnerability of harm from others • Management plan agreed for any identified risks • Graded programme progressing from supervised access to distant supervision and community meetings • Family meetings to support understanding of supervision and support needs and outcome of risk assessment 	Achieved
<p>For Nathan to demonstrate understanding of the impact of his brain injury by consistently accepting assistance to help him to complete certain tasks (e.g. programming his phone with appointments on a weekly basis)</p>	<ul style="list-style-type: none"> • 1:1 weekly sessions with a Neuropsychologist focussing on insight raising (especially for memory impairment) • Development of explanations/techniques/rationale (e.g. use of video) in order to support Nathan's insight/ability to make informed decisions about the assistance he requires in the moment • Techniques handed over to family and support worker with training provided by Neuropsychologist 	Achieved
<p>To reduce instances of 'empty speech' with a skilled conversation partner by responding to a structure and prompts to indicate when he does not know the answer to a question and to present short factual answers to questions within an agreed structure.</p>	<ul style="list-style-type: none"> • Regular 1:1 sessions with SLT to embed conversation strategies. • Use of prompt practised in structured SLT sessions. • Set of communication guidelines established with Nathan and SLT. • Guidelines jointly handed over to brain injury support workers and family. 	Achieved

The risk assessment completed throughout Intervention 1 concluded that Nathan would be able to return to live in his previous property. This decision was based on the considerable progress he had made in terms of his personal care routine and demonstration of insight into some of the risks and challenges that existed. However, he remained vulnerable because of his cognitive impairment and needed a care

package with skilled support workers to safely transition home. In order to apply for funding for this support package, the team had to provide a comprehensive report outlining the risks if Nathan was not supported. By presenting the risks very clearly in this way, a specialist brain injury support package was agreed that enabled Nathan to return to his own flat.

The key points of the risk assessment on discharge from Intervention 1 were as follows:

- Vulnerability to financial abuse when accessing the community: Nathan was susceptible to suggestion and had offered to give people money on occasion when in the community. This risk was mitigated as Nathan had agreed that his parents would continue to support him to manage his finances. Training was provided to the brain injury support worker to provide feedback to Nathan when in the community.
- Risk of self-neglect: Nathan presented with impaired motivation and initiation. He had established a positive personal care routine during Intervention 1 but there was a risk his routine would deteriorate again in the community with a reduction in structured support. This risk was mitigated by developing a daily routine with Nathan supported by his brain injury support worker.
- Risk of unsuccessful return to work: Nathan was keen to return to work but demonstrated a lack of insight into the areas he would find challenging or the support he would need. Mitigating factors were the level of support and understanding that his employer had demonstrated as well as the ongoing support from the Community Team to provide vocational rehabilitation in conjunction with the brain injury support workers.
- Risk of social isolation: Nathan was at risk of neglecting social relationships secondary to his impaired motivation and initiation. As described, he was

supported to establish a routine in his flat and received ongoing support from the brain injury support workers to engage in this routine.

Nathan's discharge from the Transitional Unit was graded to continue the risk assessment in his home environment and to trial initial short periods of time on his own. This grading built confidence in the team and in Nathan's family that he would be able to manage with the package arranged on discharge.

Nathan remained in Intervention 1 for a period of six months. This was longer than the planned intervention due mainly to the VP shunt revision, as Nathan's ability to engage in the programme improved after this point and it was deemed appropriate to extend the programme to ensure he received the full benefit.

8.6. Intervention 2

Nathan's care package on discharge was a brain injury support worker for three hours, five days per week. This was funded by the Local Authority with a financial contribution from Nathan.

On discharge to his flat, Nathan received support from the Intervention 2 Community Team to continue his rehabilitation. Nathan's presentation is a very good example of the hidden consequences of brain injury, because his strong physical abilities and intact verbal fluency masked the severity of his cognitive impairment. Identifying the risks associated with his impairment and building a support package with sufficient skill and specialism to support these needs were key to Nathan returning home successfully.

Nathan was very motivated by his return home and engaged well with the Community Team. At this stage, he was able to engage more fully in detailed goal setting and clearly identified return to work and independence as key areas he wished to focus on. However, he continued to require significant support from his family and the MDT to reflect on the challenges he would have achieving his goals and to identify measurable

steps. This is reflected in the goals summarised below where Nathan's goal is written in the first person and detailed achievement criteria have been added with support from the Community Team. His goals were set for a period of 16 weeks and were as follows:

- I will live independently
 - This will be demonstrated by Nathan living in his flat with input from support workers and his parents without readmission for 3 months.
- I will return to my previous employment
 - This will be demonstrated by Nathan attending his previous work place on a fixed frequency (e.g. one day per week) with clear tasks.

The Community Team focussed on these two key areas of intervention that Nathan had identified of independent living and return to work. Nathan established a positive relationship with his brain injury support workers and therefore Intervention 2 was largely delivered via these support workers so that it was embedded in Nathan's routine.

The Community Team intervention was delivered by three key members of the team (OT, SLT and Neuropsychologist) working in collaboration with Nathan's brain injury support workers. The support package initially provided brain injury support workers for three hours per day to support Nathan to maintain his daily routine and start to engage in more activity. He also attended a specialist Day Centre once a week. The Transitional Unit team had provided some initial training to the brain injury support workers but this was continued by the Community Team to ensure that they felt confident supporting Nathan in the community and were able to identify when he had not understood an interaction or may need support. Several joint sessions were carried out between the Community Team OT and the support workers in Nathan's flat or community locations to embed these strategies. Education and support sessions were also provided by the SLT and Neuropsychologist to help the brain injury support

workers to continue to use the brain injury awareness and communication strategies introduced in the Transitional Unit.

Nathan's detailed goal interventions are provided in Table 10. The key components of Intervention 2 for Nathan, taken from the standard set defined in section 3.2.4. are as follows:

- Support to maximise independence in the home, building on gains made in Intervention1.
- Support to maximise access to the local community building on gains made in Intervention 1
- Support to use public transport or access appropriate community transport services
- Support to plan a sustainable routine in the community
- Support to access identified leisure activities
- Support to consider vocational options and access rehabilitation in this area
- Ongoing support for the patient and family members to understand the brain injury and the support required, as well as emotional support at this stage in the pathway

The Community Team OT acted as a key worker link to Nathan's parents and supported them to understand that the programme was designed to enable a gradual increase in Nathan's safe independence in the community. Nathan's parents were initially still living in his flat at the start of Intervention 2, but, as part of the intervention, they were supported to reduce their time in the flat as Nathan gained more independence.

Table 10: Nathan Intervention 2 goals

Functional Therapy Goal	Goals Specific Intervention	Outcome
<p>I will live independently</p> <p>This will be demonstrated by Nathan living in his flat with input from support workers and his parents without readmission for 3 months.</p>	<ul style="list-style-type: none"> • Support from OT to identify tasks that need to be completed daily / weekly • Meeting with family and support workers to plan and discuss any risks • Graded plan of withdrawal of support from parents with input from support workers • OT and Neuropsychologist training for support workers • Trials of independent community access • Monitoring of maintenance of ADLs by brain injury support workers with regular feedback and support from the Community Team OT 	<p>Achieved</p>
<p>I will return to my previous employment</p> <p>This will be demonstrated by Nathan attending his previous work place on a fixed frequency (e.g. one day per week) with clear tasks.</p>	<ul style="list-style-type: none"> • Nathan was keen to manage return to work independently and therefore the Community Team worked to support the brain injury support workers who accompanied him and attended meetings. • Establishment of a regular pattern of attendance once per week with brain injury support worker • OT Liaison with workplace re likely level of support required • Support plan designed and agreed with OT, support worker and Nathan 	<p>Partially achieved</p> <p>Nathan attended work weekly but the content of his role remained vague with tasks allocated on weekly basis. This remained an ongoing focus of the brain injury support following Community Team discharge</p>

Nathan was able to return to living in his flat successfully and maintained his personal care and domestic independence. Over a period of five months he gradually reduced his reliance on support from his family and established a routine with his brain injury support workers. Within this support programme, he was able to establish a routine of going into work regularly and was allocated some tasks to carry out. However, his insight into the challenges he would have returning to work remained significantly impaired and, because of this, he was reluctant to accept a more structured vocational programme with the Community Team and his work place. It was therefore agreed that he would continue to build on regular attendance at work as part of his support

package and access to more formal vocational rehabilitation could be reviewed in the future.

At this point Nathan's brain injury support worker was reduced to twice per week by the Local Authority, the Community Team was happy with this reduction.

8.7. Outcome summary:

Nathan made considerable progress through Intervention 1 and was able to overcome a number of challenges, such as morning incontinence and reduced community and road safety, that might have prevented him from returning to live at home. During Intervention 2 he went on to demonstrate an ability to maintain his routine in the community with support. He also re-established an active social life. Nathan's parents were able to gradually reduce the level of support that they provided and the brain injury support worker package was also gradually reduced without adverse impact on Nathan's routine.

Nathan retained a relationship with his employer, who was very supportive, and he started to attend work during Intervention 2. At the follow-up visit after his period of no intervention, he had agreed with his employer that he would resign from his post. At this point he did not want to explore formal vocational rehabilitation, but he and his family have been advised that they can contact the Intervention 2 service if they wish to pursue this option in the future. Both Nathan and his parents reported that the regular visits to his workplace had lacked structure and that Nathan did not feel he had a useful role. He had maintained a very positive relationship with his work colleagues and the decision for him to stop work was mutually agreed. Nathan was maintaining a regular social routine within a reduced support package and was maintaining a number of regular leisure activities he had been supported to access, such as attendance at a gym, as part of his routine. He demonstrated a high level of pride in his appearance and the presentation of his flat, which was consistent with his behaviour prior to his injury and his family reported that he seemed happy.

A formal vocational programme might have enabled Nathan to return to work more successfully, but at the point he had reached in his rehabilitation it was important to respect Nathan's own priorities and choices. In the same way, a number of additional goals, for example relating to leisure activities, domestic tasks and ongoing brain injury education, could have been identified by the MDT, as part of Intervention 2, but outside the structure of the Transitional Unit, Nathan did not want to engage with these areas and instead focussed on his priority of re-establishing his social network.

9. Case study: Louise

9.1. Background

Louise, a 48-year-old woman, was living in a flat in London when she had a stroke. She presented to a hyper-acute stroke unit with sudden onset left sided weakness, Magnetic resonance imaging (MRI) of her brain revealed an acute right-sided segmental middle cerebral artery (MCA) infarct as well as an area of non-acute ischaemia in the left corona radiata. She was malnourished, weighing 33kgs on admission, with a Body Mass Index of 12.5¹³.

Prior to her stroke, Louise had a 10-year history of non-specific pain and fatigue and required 24-hour care. There was no medical cause identified for her pain and fatigue. There was thought to be a psychiatric or functional overlay to her pre-stroke presentation, although this had not been fully explored due to inconsistent engagement with community mental health services. There is no record of any brain imaging being done prior to her stroke, and the non-acute ischaemic changes on her MRI may have been significant in her premorbid presentation. She had last walked two to three years before her stroke and had been largely bed bound since that time. Louise found it difficult to tolerate high-levels of noise or light, which had an impact on her engagement with services and her social contact. Louise had an adult son who visited regularly and she was also close to her mother and cousin. Louise's religious beliefs were very important to her, but in the period prior to her stroke she had lost contact with friends and members of her church community.

Louise's diagnoses were as follows:

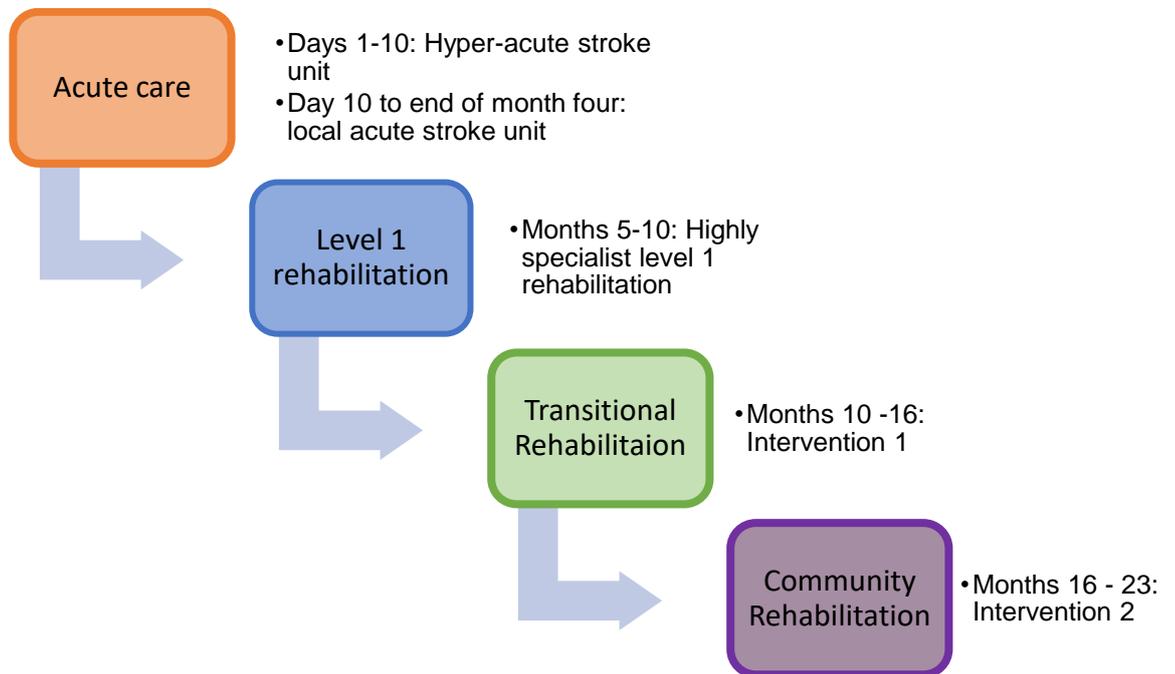
- Right hemispheric ischaemic stroke (MCA region)
- Chronic fatigue syndrome

¹³ Body Mass Index (BMI) is a measure of body fat based on weight in relation to height. The healthy range is 18.5 – 25.

- 10-year history of fatigue and non-specific pain with associated profound deconditioning
- Malnourishment
- Hypertension
- Osteoporosis

Figure 8 Summaries the stages of Louise’s rehabilitation pathway:

Figure 8: Louise rehabilitation pathway



9.2. Acute care and rehabilitation prior to the study intervention

Louise was transferred from the hyper acute unit to her local acute stroke unit for full young stroke assessment and acute rehabilitation after 10 days.

Louise had a percutaneous endoscopic gastrostomy (PEG) inserted for all nutrition and hydration due to moderate oropharyngeal dysphagia.

Louise experienced episodes of vasovagal syncope and during these episodes she would lose consciousness for a few seconds with no chest pain or palpitations. She was investigated by the cardiology team but no obvious cause was identified. She continued to be monitored by the cardiology team throughout her rehabilitation.

Louise was transferred to specialist neurorehabilitation (Level 1), four months after her stroke and received a period of five months' rehabilitation. On admission to the unit she had a dense left hemiplegia and required assistance from two people for all personal and domestic care. She could transfer into a tilt-in-space wheelchair with assistance of two. She had good language comprehension and expression but her intelligibility was reduced due to moderate dysarthria. Louise worked towards goals to increase independence in mobility, transfers, grooming, and meal preparation.

During her rehabilitation Louise remained highly anxious and required significant support to work with the team therapeutically due to a severe fear of falling. She engaged well with neuropsychology, attending regular one-to-one sessions and starting to open up about the period prior to her stroke. This engagement provided support for Louise to engage in the rehabilitation programme and she also started to explore some of the historic causes for her anxiety and fatigue.

On discharge from Level 1 rehabilitation, Louise could sit on the edge of the bed and stand with assistance of one person. She could sit in a standard wheelchair and complete transfers with the aid of a Sara Steady (mechanical standing transfer aid) and one person. She had made significant gains in her personal care but continued to need assistance from one person. Louise was taking most nutrition and hydration orally (eating a soft diet) and had fluid supplements and medication only via the PEG.

Louise's speech intelligibility improved and she was intelligible to most familiar listeners with strategies and extra time.

During her rehabilitation, she had an episode of heel pain on standing which was thought to be due to a possible fracture. An X-ray and CT scan showed there was no fracture and the pain reduced, but it was identified that she was at high risk of fractures due to osteoporosis and deconditioning.

9.3. Entering the research study and gaining consent

During her Level 1 rehabilitation, Louise had reported that she did not want to return to her previous flat as it had negative associations with the time she had lived there and was cared for in bed. Her family supported this position and the flat was also deemed unsuitable by the Level 1 rehabilitation team as wheelchair access was limited. Louise expressed a wish to return to living as independently as possible in her own property, but was keen to explore supported living options so that she would have assistance available if required. She also wanted to re-engage with her religious community.

The Level 1 rehabilitation team therefore initiated a rehousing application with a view to referral to a supported living scheme (SLS). This is an independent flat in a block with an onsite warden and care team. In discussion between Louise, her family, the Level 1 rehabilitation team and the AHP Consultant, it was agreed that Louise would benefit from further transitional rehabilitation prior to moving to a flat so that she could maximise her physical ability prior to moving to her own property. Transitional rehabilitation would also enable ongoing access to support for her anxiety.

Louise was assessed by the Level 1 rehabilitation team as having capacity to make the decision to return to living in a new property in the community and to consent to admission to the Transitional Unit. The principal researcher met with Louise twice following discharge planning meetings and explained the research verbally as well as providing the participant information sheet (see Appendix 2). The principal researcher assessed that Louise had the capacity to make the decision to consent to the research and this assessment was supported by the Level 1 team. Louise indicated that she would like to be involved in the research but remained anxious about the move to the transitional rehabilitation unit and opted to wait until she had transferred before making a final decision about participating in the research. On admission to the Transitional Unit, the researcher met with Louise again and reiterated the information about the study. Louise consented at this point. Louise identified a relative who might consent to

participating in the research and the researcher provided verbal information about the study to the relative at the start of Intervention 1. Louise's relative did not want written information at this stage and opted to wait to decide on consent due to other family commitments. Louise's relative discussed this on two further occasions with the principal researcher and opted not to participate in the interview, due to caring commitments to another member of her family.

9.4. Initial assessment

Louise completed an initial assessment with the Intervention 1 team which revealed the following:

- **Communication:** Louise had a mild- moderate dysarthria characterised by hyper nasality with nasal emissions, reduced articulation accuracy, reduced pitch range and volume. Her intelligibility to familiar people in quiet environments was good but reduced with background noise, on the telephone or when tired.
- **Dysphagia:** Louise continued to present with mild-moderate oropharyngeal dysphagia, characterised by difficulties chewing secondary to reduced range and strength of movement. On assessment, she demonstrated anterior loss of fluid on her left (hemiplegic) side and had slightly reduced range of laryngeal elevation. At this point she could eat a soft mashed diet but her dysphagia was exaggerated by anxiety and fatigue; therefore she required close supervision during meals and monitoring of intake. She continued to have some fluid and medications via her PEG.
- **Mobility:** Louise had a left sided sensory-motor impairment. She was able to weight bear through her left leg when standing still but was unable to then mobilise with this leg. She had no active movement in her left arm and had developed tonal changes. As noted above, she could transfer with a Sara Steady aid and one person assisting.

- Activities of daily living (ADLs): Louise required assistance from one person for all ADLs, in particular, she required help to use a wash-cloth, to wash areas hard to reach with her right arm and to dress/ undress. Louise was fully dependent for all domestic activities such as shopping and cooking. Assessment demonstrated that, as well as physical assistance, Louise required support secondary to cognitive impairments with planning, sequencing and problem solving. Fatigue and anxiety had an impact in all areas.
- Mood: Louise presented with high levels of anxiety which were exaggerated by the move to the Transitional Unit. Her anxiety was characterised by excessive worry about small things and the need for regular reassurance. She also exhibited some behaviours consistent with a panic disorder. Her psychological presentation was understood in the context of her longstanding anxiety. A referral for a psychiatric assessment was discussed with specialist mental health service but not pursued further.
- Emotional lability: Louise presented with emotional lability, with difficulty controlling both crying and laughing. She could reflect that her emotional reaction did not necessarily accurately represent her feeling during these moments.
- Cognition: Assessment demonstrated that Louise had cognitive strengths in orientation, verbal memory and attention. She demonstrated impaired speed of processing, working memory, visual memory, abstract thinking and problem solving, in addition to the practical difficulties with planning and sequencing observed in function.

9.5. Intervention 1

Louise was admitted to the Transitional Unit when she was ten months post stroke and had a six-month admission in total, including a period of graded discharge. She required intervention from all members of the transitional MDT.

Louise's goals for admission, set for a period of 18-20 weeks, were as follows:

- I will be able to wash and dress with assistance to set up and verbal prompts only
- I will be able to manage a soft diet, swallow all medication in tablet form and drink an adequate level of fluids for a consistent period of 4 weeks to enable PEG removal.
- I will increase my intelligibility when speaking over the phone to my mother and friend, measured on conversation partner feedback of intelligibility of 80%.
- I will be able to participate in eating a daily meal in shared space with support to set up.
- I will feel confident enough to explore transfers from bed to wheelchair without an aid and with assistance of one
- I will be able to self-propel my wheelchair from my bedroom to dining room without assistance.
- I will attend all relevant groups at the Transitional Unit and identify two relevant groups on discharge.
- I will understand the impact of anxiety on behaviour and recognise my response to anxiety with assistance of one
- I will increase my understanding of how stroke has affected my cognition and be able to summarise this to others.
- I will transition to a suitable home environment (supported living scheme) with an appropriate support package

The detailed interventions associated with each goal are given in Table 11 Louise presented with an increase in her anxiety on admission and required high-levels of reassurance during the first two weeks of the admission. One of the ways that this manifested was that Louise had a lack of confidence in her ability to return to living in the community. This had an impact on goal-setting because it was very difficult for

Louise to identify the steps that might help her to move towards her overall goal of moving to a new flat. The team worked closely with Louise to set her goals; these were as practical as possible to support her understanding of how the goal steps would contribute to building the abilities needed to live on her own.

To support Louise to maintain momentum towards her goals, the team had to provide very consistent reinforcement of what the goals were and how they supported the plan for discharge.

Louise made steady progress toward her goals, but when she had been on the Transitional Unit for three months she had two significant setbacks. The first was a fall from her wheelchair resulting in a fracture of her left tibia. Before the fall she had reached a point where she could secure the lap belt on her wheelchair and then reach for things on her table or shelf. The fall occurred whilst doing this but Louise had forgotten to secure her lap belt. She required a short admission to an orthopaedic ward in an acute hospital before returning to the unit with a full leg cast and reduced weight-bearing status. The fall and resulting cast had an impact on her physical ability; however, the more significant impact, was in terms of increased anxiety. Louise and the team had been aware that she was at high-risk of fracture due to her osteoporosis. To provide reassurance to Louise that the risk of another fall was minimised, the team reviewed the risk assessment and provided increased supervision and prompts whilst she built her confidence and ability back to her pre-fall level. At the same point in her rehabilitation, Louise experienced several episodes of dizziness and reduced consciousness with associated low blood pressure. She was also diagnosed with anaemia. Review of her hypertensive medication was arranged with the unit GP and, following alteration to her medication and the addition of iron supplements, both problems resolved. As with the fracture, this increased Louise's anxiety about discharge.

The admission length of six months was the revised timescale set after the fracture; prior to that a four to five-month admission had been anticipated. Louise's new flat in a SLS was identified two months prior to discharge, and from this point the team worked consistently with Louise to replicate the level of support she would receive in the scheme. This involved a very structured programme of gradually increasing periods unsupervised in her room. Louise was naturally highly anxious at the start of this programme, but the time increments were increased very slowly and Louise was provided with one-to-one neuropsychology support through this process to reinforce success and to use the evidence from the programme to challenge her levels of anxiety within a structured framework.

The key components of Intervention 1 (taken from the standard list defined in section 3.2.3) for Louise for were:

- Personal care support provided to maximise independence. The care support to be provided in the community was replicated as soon as possible and facilities used matched those that would be available.
- Specific impairment-based therapy targeting areas identified in the goals
- Support to plan a daily routine, taking into account the care available on discharge, the need for periods of activity and rest, as well as the priority activities identified.
- Support for the patient and family members to understand the brain injury and the support required, as well as emotional support during the transition.

For Louise, there was less of a focus on access to the community and identification of activities than for other patients in the programme, but this reflected the need to support Louise to build confidence in her abilities in core activities prior to discharge.

The detailed interventions delivered as for each goal and the outcomes are summarised in Table 11.

Table 11: Louise Intervention 1 goals

Functional Therapy Goal	Goal Specific Intervention	Outcome
I will be able to wash and dress with assistance to set up and verbal prompts only	<ul style="list-style-type: none"> • Regular 1:1 wash and dress sessions with RAs, Nurse and OT input. A formal routine was consistently followed to demonstrate the progress through the specific steps that Louise was making. 	<p>Partially achieved</p> <p>Louise required some physical assistance to wash her legs.</p>
I will be able to manage a soft diet, swallow all medication in tablet form and drink an adequate level of fluids for a consistent period of 4 weeks to enable PEG removal.	<p>Regular review with Nurse, SLT and RAs, including:</p> <ul style="list-style-type: none"> • Self-documentation of fluid intake. • Supported to transition from medication administered via the PEG to taking orally. This was supported by introducing oral medication one at a time and using strategies such as placing in a soft food or puree to help swallowing. • Regular dysphagia rehabilitation exercises to improve mastication and prevent anterior loss. 	<p>Achieved</p>
I will increase my intelligibility when speaking over the phone to my mother and friend, measured on conversation partner feedback of intelligibility of 80%.	<p>Regular one-to-one sessions with the SLT focussing on:</p> <ul style="list-style-type: none"> • exercises for articulation and to reduce nasal emissions. • Building confidence using the phone with use of role plays and phone calls to SLT and unfamiliar people. • Self-management programme set up to have key card of prompts next to the phone. 	<p>Achieved</p>
I will be able to participate in eating a daily meal in shared space with support to set up.	<ul style="list-style-type: none"> • Graded exposure to shared dining space with a consistent mealtime routine • Support from MDT to ensure that Louise feels comfortable in the communal areas of the unit. • Dysphagia rehabilitation to increase confidence when eating 	<p>Exceeded Louise was eating 2 meals per day in shared space by discharge.</p>
I will feel confident enough to explore transfers from bed to wheelchair without an aid and assistance of one	<ul style="list-style-type: none"> • One to one therapy sessions with PT and RA led exercise sessions • Regular feedback of objective measures of progress to build confidence 	<p>Achieved</p>
I will be able to self-propel my wheelchair from my bedroom to dining room without assistance.	<ul style="list-style-type: none"> • Referral to Wheelchair service • Practice self-propelling with RA and OT • Graded increase in demands of task (e.g. turning corners, negotiating doorways) to build confidence 	<p>Achieved</p>

Functional Therapy Goal	Goal Specific Intervention	Outcome
I will attend all relevant groups at the Transitional Unit and identify two relevant groups on discharge.	Regular support from the Neuropsychologist, SLT and OT: <ul style="list-style-type: none"> • Behavioural intervention (e.g. reinforcement of independence behaviours) • Extensive training of carers and support staff at the SLS. • Review of communal activities available at the SLS and trials of these 	Achieved
I will understand the impact of anxiety on behaviour and recognise my response to anxiety with assistance of one	Regular one-one sessions with the Neuropsychologist for: <ul style="list-style-type: none"> • Psycho-education relating to anxiety symptoms • Cognitive Behavioural Therapy focussed anxiety intervention • Regular mindfulness and relaxation • Consultation to MDT regarding anxiety management and training to SLS staff 	Achieved
I will increase my understanding of how stroke has affected my cognition and be able to summarise this to others.	Planned education sessions from the Neuropsychologist cancelled as Louise decided that this goal was not a priority and wanted to focus on anxiety management.	Not achieved/ discontinued
I will transition to a suitable home environment (SLS) with an appropriate support package	<ul style="list-style-type: none"> • A structured programme to gradually increase the length of time Louise could spend between care calls. This was supported by one-to-one neuropsychology sessions to help manage Louise's anxiety about this process. • When the SLS scheme was identified, the OT and Neuropsychologist handover/ in-reach programme including graded exposure visits to the SLS with Louise, shadowing of Transitional Unit team by the care staff from the SLS and drop in sessions for the SLS staff. • A four-week graded discharge to the SLS including Transitional Unit RAs attending daily to complete joint morning routine care calls with SLS carers for the first seven days • Training sessions and written guidelines for SLS staff regarding psychological and cognitive presentation and strategies. • Multiple training sessions from OT regarding support needed to transfer safely, carry out a stretching programme, apply splints and carry out personal care. • Training video provided to SLS staff for stretch and splint regime 	Achieved

The graded discharge period for Louise was very resource-intensive, but the Transitional Unit team deemed it necessary to avoid the increase in anxiety that had been noted on transfer from the Level 1 to the transitional service. In total, the graded discharge was a period of 4 weeks. In the first week, the RAs doubled up on all personal care sessions at the SLS, which was a total of approximately two hours a day, reducing to one hour a day for the second week and three hours a week after that. The rest of the MDT (OT, PT, Neuropsychologist and SLT) all provided specific training and handover as specified in Table 11, amounting to an average of three hours per therapist per week. The Intervention 2/ Community Team were also involved in this graded discharge period.

9.6. Intervention 2

Louise's care package consisted of four calls per day from the SLS team to support personal care. The SLS team also provided assistance with domestic tasks and provided a one-to-one support worker to facilitate exercises, application of splints and access to group activities. Louise's care package was provided by the Local Authority.

Louise was discharged from the transitional service at 16 months post-stroke. She had a seven-month Intervention 2. This intervention was not intensive, but continued the focus on increased independence and supporting the team at the SLS to facilitate ongoing gains that would be sustainable.

In light of Louise's pre-stroke history, the team felt it was important to provide support over this long period to ensure that robust support strategies were in place to continue to increase independence. The SLS that Louise moved to was attached to a residential service and the culture within the service was to provide care rather than necessarily facilitate independence. However, the SLS staff understood how important it was to Louise to gain independence and were very supportive of this. Intervention 2 was provided by the community SLT, OT, PT and Neuropsychologist.

The goals for Intervention 2 were as follows:

- I will be able to transfer from bed to chair using a banana board (transfer aid that supports a sliding transfer in sitting position) and assistance of one. I will be able to transfer to the commode independently.
- I will be able to make simple snacks (e.g. sandwiches) in my kitchen.
- I will rate my speech as clear on audio recordings 90% of the time.
- I will use a tablet computer for video calls and email to contact friends and family independently.
- I will have a splinting routine that staff can support me with.
- I will engage in a daily social activity within the SLS environment.

Louise engaged well with the Community Team and did not demonstrate the same spike in anxiety levels that had been observed at the start of Intervention 1. With support from her son and mother, Louise had re-established contact with her friends and wider religious community, and the SLS where she was living was within this community. As a result, she received very regular visitors when she moved to the SLS. With support from the Community Team, SLS team and her family, she established a routine of social activity in her flat and in the communal areas of the SLS, as well as periods of rest and time for exercises as part of her rehabilitation programme.

During Intervention 2 Louise frequently requested more intensive intervention from the Community Team and wished to continue to focus on one-to-one sessions targeting her impairments (e.g. speech intelligibility and mobility). Louise remained motivated in these areas and had clear goals, therefore this element was part of her Intervention 2. The Community Team also reinforced the need to establish a sustainable routine within the SLS.

The key components of Louise's Intervention 2 (taken from the standard list defined in 3.2.4) were as follows:

- Support to maximise independence in the home, building on gains made in Intervention1.
- Support to plan a sustainable routine in the community
- Support to access identified leisure activities
- Ongoing support for the client and family members to understand the brain injury and the support required, as well as emotional support at this stage in the pathway

As per Intervention 1, there was not a focus for Louise on access to the community as this was not an area she identified as important. To her it was important that she did not lose the contact with friends, family and the religious community that she had re-established, but she was happy for this activity to take place in her flat or in the communal areas of the SLS. When she wanted or needed to go out to appointments or particular events, she was driven by her son.

The detailed interventions for Louise's goals are shown in Table 12.

Towards the end of Intervention 2, Louise expressed some concern about being discharged from the Intervention 2 team. Over a period of six weeks, frequency of contact with the team was gradually reduced. During this time, Louise was able to reflect that the support from the SLS staff remained consistent and was able to accept the discharge plan. Between sessions she did demonstrate a spike in anxiety levels about certain activities and required reassurance from the SLS team. At the outcome visit after the non-intervention period, the SLS team were still supporting Louise to increase her independence and she had not reverted to asking for more care.

Table 12: Louise Intervention 2 goals

Functional Therapy Goal	Goals Specific Intervention	Outcome
I will be able to transfer from bed to chair using a banana board and assistance of one. I will be able to transfer to the commode independently.	<ul style="list-style-type: none"> • PT sessions for transfer practice • Equipment provision including ankle splint and shoulder brace • Exercises and balance training 	Exceeded Louise could transfer with minimal assistance from one person and no equipment.
I will be able to make simple snacks (e.g. sandwiches) in my kitchen.	<ul style="list-style-type: none"> • OT assessment of the environment to establish if Louise could prepare food from her wheelchair and preparation practice sessions. • OT sessions to support graded activity levels in kitchen tasks 	Not achieved Louise was not able to achieve this due to fatigue.
I will rate my speech as clear on audio recordings 90% of the time.	<ul style="list-style-type: none"> • SLT sessions to identify and use clear speech strategies. • Regular role play recordings and self-rating. 	Partially achieved Louise achieved 80% on self-rating.
I will use a tablet computer for video calls and email to contact friends and family independently.	<ul style="list-style-type: none"> • OT sessions and training for staff to support Louise to set up and use tablet computer • Errorless learning approach to task 	Partially achieved Able to use with ongoing staff set up.
I will have a splinting routine that staff can support me with.	<ul style="list-style-type: none"> • OT review of splints and training for SLS staff: • Assessment of upper limb and review of stretches • Handover to SLS staff 	Achieved
I will engage in a daily social activity within the SLS environment.	<ul style="list-style-type: none"> • Review following settling in period to ensure activities maintained. • Regular diary of activities established • Training provided to staff to facilitate Louise in activities 	Achieved

9.7. Outcome summary

Louise was successful in returning to live in her own flat within an SLS environment following the research intervention. She continued to receive a support package from the SLS team to assist her with both personal and domestic tasks, but the SLS team

was committed to supporting her to continue to increase her independence. This was maintained during her non-intervention period.

The design of Louise's intervention was heavily influenced by her level of anxiety and her pre-stroke history of pain, fatigue and deconditioning. The teams involved in both Interventions 1 and 2 felt it was important to build Louise's confidence and establish a strong routine that would enable her to maintain social contact and activity. At the end of Intervention 2, Louise had a routine that included regular socialising with family and friends in her flat and was engaged with the communal programme of activities in the SLS. She was not accessing the wider community very much and did not identify this as a priority.

The design of Louise's intervention prioritised handover and management of anxiety. The transition between Interventions 1 and 2 was the first transition in her rehabilitation pathway when she did not demonstrate an increase in anxiety, which may be, in part, attributable to the graded period. Louise's pre-injury history was highly significant in the team's intervention, as a return to very low levels of activity was seen as a significant risk. The impact of these considerations is reflected in the length of both intervention stages.

10. Case study: Simon

10.1. Background

Simon, a 48-year-old man, was cycling on holiday when he sustained his traumatic brain injury. Prior to his injury he lived in a flat in London. His parents lived outside London and he spoke to them or saw them infrequently. He also had a sister living outside London. Simon worked intermittently as an electrical contractor and often worked nights or unusual shifts.

Simon was a very keen cyclist before his injury and was an active member of a local club. He had a large circle of friends, mainly through cycling and an active social life. As well as riding, Simon was very interested in bicycle maintenance, and often built bespoke elements of his bicycles or fixed parts for friends in his spare time.

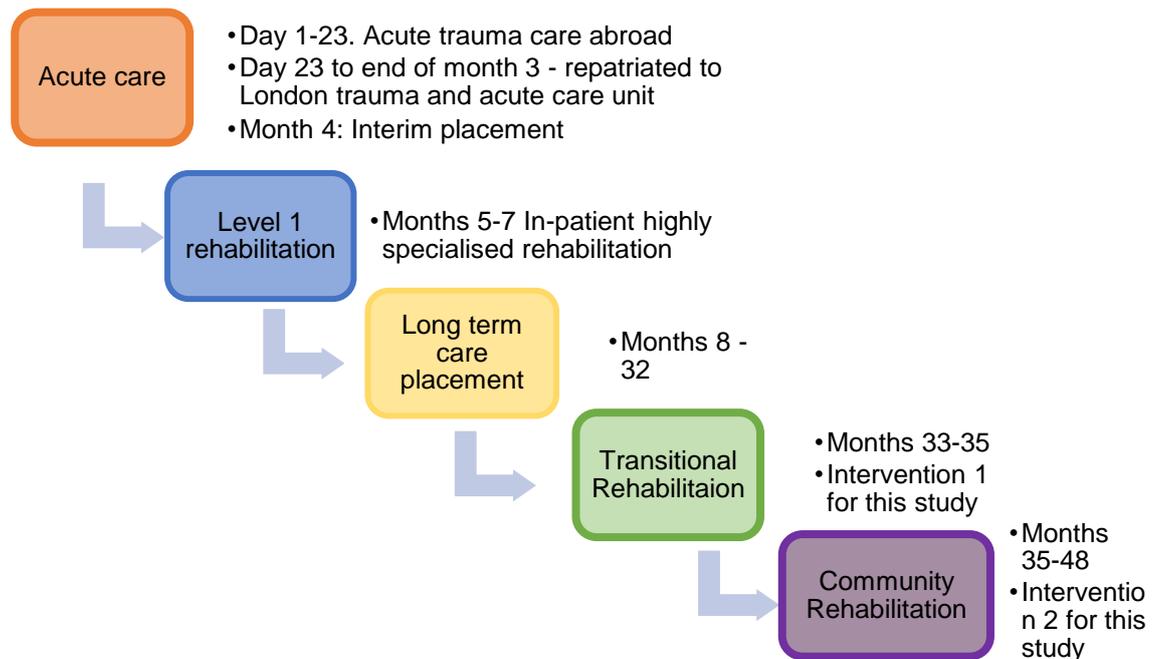
Simon was leading a charity club ride abroad when he was injured. He was treated initially in the country where the injury occurred. A CT scan revealed a left occipital and left temporal fracture associated with underlying contusions and subdural haemorrhage. Simon presented with uncontrolled agitation and was sedated and intubated. A further CT scan showed additional frontal contusions and some midline shift. His recovery was complicated by staphylococcal pneumonia. He remained in hospital to allow this infection to be treated and was then repatriated to his local trauma unit in the UK. He was diagnosed with post traumatic amnesia on admission to the UK trauma unit.

His diagnosis was as follows:

- Left occipital and left temporal fractures
- Traumatic subdural haemorrhage with occipital, temporal and frontal contusions and midline shift.
- Post traumatic amnesia.

Simon's rehabilitation pathway is summarised in Figure 9. Simon did not follow the standard pathway following his acute and Level 1 rehabilitation because his presentation at the end of his Level 1 rehabilitation placement did not indicate community placement would be possible. More detail is given in section 10.2 below.

Figure 9: Simon rehabilitation pathway



10.2. Acute care and rehabilitation prior to the study

Simon was highly agitated on the acute trauma ward, which was deemed to be secondary to his post traumatic amnesia. He exhibited paranoid behaviours which resulted in verbal and physical aggression towards staff and patients. He was able to mobilise independently at this point and therefore his behaviour was highly disruptive to the acute ward environment as he approached other patients and initiated conflict. He was referred to a Level 1 rehabilitation unit specialising in behavioural management. Due to the waiting list for this service and his level of agitation, he was transferred to an interim placement where his behaviour could be managed appropriately. The interim placement was a specialist nursing home for people with ABI. They were able to

provide Simon with his own room and one-to-one staff support so that his aggressive behaviour did not present a risk to himself to others. Simon spent four weeks in this placement.

Simon was transferred to a Level 1 specialist behavioural unit five months post injury. At this point he was still in PTA. He presented as highly agitated, anxious and paranoid. Simon's ability to interpret other people's communication was severely impaired and this contributed to his anxious and paranoid presentation as he interpreted other people as aggressive towards him. He had no memory of his injury or acute hospital admission and demonstrated no insight into his impairments. He worked predominantly with the Level 1 Clinical Psychologist and SLT through this admission. He received brain injury education and a structured behavioural programme. The team assessed that he emerged from PTA during this admission when a reduction in agitation was noted. He demonstrated inconsistent ability to use simple aids such as a memory book to orientate himself to the facts of his accident. However, his insight into his presentation remained severely impaired. He responded to the behavioural programme and was able to use simple strategies and feedback to reduce incidents of aggressive behaviour. He became fixated with a wish to return home and was not able to demonstrate any insight into the challenges he would have living alone. At this stage, he no longer required 24-hour one-to-one care but remained dependent on a highly structured environment, with staff support for most of the day, to maintain the reduction in behavioural incidents. The Level 1 team assessed Simon to not have capacity to make a decision about discharge destination as he was unable to understand, retain or accept the level of care support he would require, even with skilled support to facilitate the discussion. The team recommended that Simon would need a residential placement with staff with expertise in brain injury and behavioural programmes. At this stage, he was only eight months post injury but was deemed to have emerged from PTA. It was the opinion of the Level 1 treating team that this type

of placement might need to be long term but with a recommendation for regular review to ensure that the option of returning to living in the community or more independently was explored if appropriate in the future.

A specialist nursing home placement with expertise in brain injury and management of behaviour was identified, that was also geographically close to Simon's parents. The placement was able to continue to provide a non-intensive level of rehabilitation support to ensure that the behavioural programme established in the Level 1 unit was maintained, and to offer opportunities for Simon to increase his participation and activity as appropriate.

To understand Simon's pathway, it is important to understand the process in place at this stage for funding and monitoring his placement. On discharge from the Level 1 unit, Simon was assessed as meeting the eligibility for Continuing Healthcare (CHC) funding (see section 1.3). This was because his primary need for care related to his behavioural and cognitive impairment secondary to his traumatic brain injury. As part of the provision of this placement in the specialist nursing home, Simon was reviewed regularly by the AHP Consultant to ensure that the placement remained safe and appropriate. In Simon's situation, because he was only eight months post injury at the start of his placement and the Level 1 team had expressed a need to monitor whether he could in the future live more independently, his placement was reviewed regularly (every three months).

Simon settled well in this placement and his level of agitation decreased. He continued to exhibit paranoid behaviour and incidents of verbal and threatened physical aggression towards other residents continued. The staff were able to manage these incidents to prevent escalation. Simon demonstrated a reluctance to participate in personal care. He was able to shower independently but did not initiate washing and responded defensively to prompts. He was also reluctant to allow staff into his room to clean or tidy. Over a period of 9 months, Simon developed a structured routine in this

placement. He responded to prompts to shower approximately twice per week and agreed an acceptable level of support with cleaning his room. He attended mealtimes in the communal areas and started to attend a local gym and to cycle with staff support. He continued to need feedback and memory aids to recall that he had a brain injury and his insight remained severely impaired but he was reasonably content at this point (17 months post injury) and his review frequency was reduced to six months.

On review six months later (23 months post injury), Simon had increased his independence, he was maintaining his routine in the placement with less prompting and had started to access the community for short periods on his own (e.g. for a short cycle ride). However, he expressed high levels of frustration with the placement; he stated that he wished to return to living on his own in London and he felt trapped by the placement. The staff reported this was a message that he consistently expressed, although he was still not able to reflect on the challenges he might experience living alone or on the level of support he received in the placement. Simon's capacity to make a decision about where he should live was assessed by the Clinical Psychologist in the placement, who concluded that he did not have capacity to make this decision. A Best Interest Meeting¹⁴ was held and Simon was supported by an Independent Mental Capacity Advocate (IMCA).¹⁵ The Best Interests process sought input from Simon's parents and sister as well as his close friends. Simon's parents were very anxious about his vulnerability and concerned that if he returned to London they would not be able to visit him as regularly. Simon's sister and friends provided background that he had always been very independent, leaving home when he was 18, and had always

¹⁴ The Mental Capacity Act (2005) provides detailed guidance on assessment of capacity for specific decisions. If a person does not have capacity to make a specified decision then a Best Interest process should be followed where the clinical team and family contribute to a decision-making process with the values and beliefs of the patient at the centre of the discussion. Full guidance can be found in the Act.

¹⁵ The MCA (2005) makes provision for an independent person to support decision making if someone does not have the capacity to make that decision. The IMCA role is to ensure that the person's values and beliefs are taken into account during the Best Interest process, full guidance can be found in the Act.

identified the area of London where he settled as his home. They felt that living in the area of London he had chosen, having regular access to his friends and being able to access cycling activities, were core to his self-identity. The conclusion of the Best Interest's Meeting at this point was that Simon currently remained too vulnerable to return to living on his own in London but that, as it was so important to him and reflected his previously held beliefs and values, this option should be explored to establish whether sufficient support could be provided to facilitate this move.

Over the next 6 months, Simon was supported to visit the area of London where he used to live and to complete a number of risk assessments to establish how vulnerable he would be in areas such as safety with domestic appliances, road safety and harm from others. He also continued to receive support in the specialist nursing home placement to increase his independence in domestic tasks and community access. Simon received regular support sessions from the placement Clinical Psychologist to understand the likely challenges of living alone and the effects of his brain injury. Following this period of targeted intervention, Simon was able to reflect on the fact that he would need a package of care in the community and was therefore assessed by the placement Clinical Psychologist to have capacity to make a decision about his future placement. He remained very clear that he wished to return to living in London in a flat of his own and therefore he was offered a placement in the transitional service in the current study to facilitate this transfer from residential care to living in the community.

10.3. Entering the research study and gaining consent

As summarised in the previous paragraph, the treating Clinical Psychologist in the specialist nursing home placement assessed Simon to have the capacity to consent to the transfer to the Transitional Unit (Intervention 1) with a view to moving to a new flat in his chosen community area. As part of giving this consent, Simon demonstrated an understanding that he would require care support in the community. Due to Simon's complex history, the Transitional Unit team started to work with him four weeks prior to

transfer, visiting him at his nursing home placement and preparing him for the move. During this period, the transitional team focused on defining the planned goals of Intervention 1. Simon's goal was to return to living in a property of his own in the part London where he had previously lived and therefore this was the primary goal of his admission. The Intervention 1 team negotiated with Simon during this period that goals of his admission should also reflect the need to complete a risk assessment and train care staff to support Simon in his flat. Simon agreed to these negotiated goals and was able to demonstrate an understanding of the need for care support in the community.

The principal researcher met with Simon twice during the discharge planning period, explained the current study and provided the written information sheets. Simon indicated that he was happy to consent to the research but was unsure if he would want his outcome measures to be videoed. The principal researcher explained the purpose of the videos was to enable peer review of the research and Simon was then happy with this aspect of the consent. The researcher reinforced Simon's right to opt out of the research or individual videos at any point.

Simon consented to the research on admission to the Transitional Unit (Intervention 1). Simon nominated his parents to complete the relative interview. They were provided with information prior to Simon's transfer to the Transitional Unit and provided verbal consent at this stage. They were provided with the information again during Intervention 2 and provided signed consent at this point.

10.4. Initial assessment

On entry to Intervention 1, Simon received a full multidisciplinary assessment which revealed the following:

- Mobility and physical ability: Simon was independently mobile and physically able to complete activities of daily living; however, his cognitive impairment,

described below, had an impact on his functional ability. Simon had a low exercise tolerance and level of fitness.

- **Activities of Daily Living (ADLs):** Simon did not initiate personal care on a regular basis, as observed at the nursing home placement and this led to a risk of neglect of his personal care. During the assessment period, Simon responded inconsistently to prompts to use the shower and wear clean clothes. He showered twice per week during these initial assessment weeks. Simon did not initiate cooking during this initial period but attended communal mealtimes within the unit.
- **Communication:** Simon presented with impaired comprehension of non-verbal cues and social inference. This interacted with his cognitive impairment and manifested in a tendency to assume others were talking about him or being rude. He assumed a negative attitude towards him from others unless his conversation partner delivered information in an exaggerated positive manner.
- **Cognition:** Simon presented with a significant cognitive impairment characterised by impaired executive function, memory and a gross lack of insight. During his initial assessment period, he was not able to reflect on his need for the transitional placement or care support as he had in the period of preparation. This inability to reflect on his needs may have been a reaction to the move but Simon did not attempt to leave the Transitional Unit, or express a wish to do so.
- **Mood:** Simon's presentation remained anxious and, at times, paranoid during the assessment period. This was consistent with his presentation at the nursing home placement.
- **Behaviour:** Simon was quite withdrawn initially in Intervention 1. He tended to choose to stay in his room and responded with annoyance if people wanted to talk to him. If staff knocked, waited and introduced themselves from the

doorway, he was usually happy for them to come into the room but would sometimes not respond at all. In communal areas Simon was largely pleasant to other residents in the assessment period, but did respond with suspicion or was verbally rude or dismissive to others if he perceived them to be talking about him. There were no episodes of physical aggression in the assessment period.

- Additional history: During this assessment period, the Transitional Unit Neuropsychologist met with Simon's parents and close friends. They provided anecdotal reports that Simon had chosen to shower less than daily prior to his brain injury. They also confirmed that he had a tendency to hoard items such as bicycle parts and was particular about how these items were stored and arranged in his flat. Prior to his injury there were also examples of him misinterpreting communication and having some difficulties with social interaction and communication. This history was relevant as it helped the team to understand Simon's premorbid behaviours and values.

10.5. Intervention 1

Simon was highly anxious on the day of the move to the Transitional Unit and this manifested itself in suspicion of others and a wish to remain in his room for the first day. He was reluctant to unpack his belongings or to let staff assist him. This initial anxiety settled over the first few days but Simon remained protective of his belongings and reluctant to allow staff to help him to sort and unpack.

Simon engaged with goal discussion with the team in the early weeks of his admission. He remained very clear that his only goal was to return to living in his own property in his chosen part of London. He found more detailed conversations about what support he might require more difficult and required support from the team to reflect on the specific tasks that he might find challenging. His goals are written in the first person to reflect the key areas that he identified with support, but some of the detailed

achievement criteria were planned by the team and are written to reflect this input. His Intervention 1 goals were set for a period of 12 weeks and were:

- I will have a weekly routine of activities. This will include the following:
 - Simon will be able to manage his personal care independently with prompts to initiate
 - Simon will be able to wash his clothes with instructions to use the washing machine
 - Simon will be able to prepare simple meals and will prepare at least one meal per day for himself
 - Simon will clean his bathroom weekly or allow cleaners weekly access to his bathroom
 - Simon will go swimming and or cycling once per week
- I will be ready to move to my new flat. This will include the following points:
 - Simon will participate in three visits to explore local area and shops
 - Simon will participate in sessions to identify what furniture he requires, look in shops and order items online
 - Simon will work with the MDT and his parents to decide which items he wants from storage
- I will be able to move to my new flat safely. This will include the following areas of risk assessment:
 - Identify areas of risk related to Simon living alone
 - Devise a risk management plan
 - Determine the level of support required on discharge
- I will work with support workers to help me to move to my new flat.
 - Simon will be able to manage a weekly budget with help from his support worker

- Simon will be able to plan activities for sessions with his support worker with assistance on a daily basis
- Simon will be able to identify one social activity he would like to attend with his support worker.
- I will join in with social activities. This will include the following points:
 - Simon will attend a weekly coffee morning group on the Transitional Unit
 - Simon will be able to initiate conversation with another member of the group who he has met before within the structure of the group session.

Simon remained quite withdrawn from the Intervention 1 team over the first few weeks of the admission. The strategy used by the team to engage with him was to provide a very structured routine, offering engagement in the goal areas. The team identified a number of boundaries that were important to Simon in terms of his privacy and organisations of his possessions. This was built into the routine of the unit, for instance, staff always knocked on Simon's door and identified themselves from the doorway, they then waited for Simon to invite them in before entering further. The team also agreed with Simon that people would not enter and clean or tidy his room without his permission and that during cleaning, his possessions would not be moved. This agreement reinforced the normal levels of privacy and respect for possessions that was standard on the unit but Simon requested written agreement to reassure him that items would not be moved.

Simon's engagement remained variable within structured therapy sessions. He was most likely to engage in activities that he could see were related to moving to a new flat, such as visiting the local area. He engaged in some physical and leisure activity sessions; he completed a cycling risk assessment and three escorted cycling trips, he also completed two swimming sessions. Simon expressed frustration about the need for a cycling risk assessment as he had already started to cycle at the specialist nursing home placement. However, that was in a quiet residential and rural area,

whereas the Transitional Unit and planned new property were in central London. Simon participated in and reported he enjoyed a coffee morning group on the unit, where he made drinks for others and joined in with conversation based on materials such as the daily papers. He enjoyed talking about current events in the newspapers and his friends informed the team that he had previously been very politically active. Simon was supported to register and to vote in a general election, and these two activities seemed to improve engagement with the staff. With the exception of the group, Simon engaged more in the informal social opportunities on the unit than in structured sessions. He initiated coming out of his room in the evening when there were fewer staff on the unit and participated in communal evening meals, watching films and having general conversation with other residents.

The core components of Intervention 1 (taken from the standard list defined in 3.2.3) for Simon were:

- Support to maximise access to the community, including addressing physical and cognitive barriers.
- Support to maximise access to chosen activities. Including consideration of the physical and cognitive challenges of accessing an activity and strategies to overcome these.
- Support to plan a daily routine, taking into account the care available on discharge, the need for periods of activity and rest as well as the priority activities identified.
- Support to identify both specialist and mainstream services that will be helpful on discharge.

Following the initial assessment period, Simon became increasingly reluctant to engage in personal care. If prompted to wash, shower or change his clothes, Simon responded with suspicion and annoyance that he was being told to do things that he was able to plan himself. The team trialled a number of approaches, such as

negotiating a personal care routine, using structured, consistent prompting and using timetabled, motivating activities to prompt personal care. Simon agreed to a weekly personal care routine with the team, but on most days, did not respond to prompts. The most effective strategy was to use timetabled activities that motivated Simon to encourage him to complete personal care, for example if he had a visit to a new flat planned or a friend visiting, this would be entered on his timetable and staff would refer to it, conversationally the day before and on the morning of the activity. Simon would often then initiate personal care before the event and appeared to take some pride in his appearance, especially for friends.

Simon was reluctant to let staff enter and clean his room and was particularly upset if staff moved items that belonged to him, even just very small adjustments to clean around items on the table. He did agree to a weekly routine for room cleaning and this was maintained through the intervention with support from the clinical team. The best time for cleaning was during the coffee morning group that Simon had engaged in. After six weeks, Simon also started to collect items in his room such as empty food packets that he did not want to be thrown away. Simon responded inconsistently to negotiations to allow items to be thrown away if they presented a health risk (e.g. packets containing food debris).

Simon continued to demonstrate high levels of anxiety and agitation, which seemed to be related to times of particular stress such as moving into the unit or the day of a planned visit to a potential new property. The most challenging of these episodes culminated in an incident where Simon was alleged to have hit another patient. The episode was not observed by staff but Simon reported that he thought the other patient was laughing at him but denied striking him. The police attended the unit and spoke to Simon and the other patient, but decided no further formal action was indicated. Simon's risk assessment was reviewed and an urgent application was made for a

Deprivation of Liberty Safeguards (DoLS) authorisation.¹⁶ The DoLS authorisation was required because the risk assessment concluded that Simon should have distant one-to-one supervision on the unit for a period following the incident, but Simon was not able to demonstrate the capacity to understand the need for this supervision and therefore consent. Observations in the weeks following suggested that this had been a one-off incident and the level of supervision was reduced, although it was noted that this type of reaction based on Simon's level of anxiety and perception of other people's behaviours remained a risk area.

The transitional team were concerned about Simon's levels of anxiety and particularly about the episode of alleged violence, as it represented a risk to himself and others. This incident had occurred at a time when Simon was being supported to achieve his goal of return to the community after a long period of residential care, so the team felt it was sensible to explore Simon's presentation further to help understand the behaviour. The team sought advice about Simon's presentation from the Neurologist who supported the unit and also made a referral for a neuropsychiatry opinion. Based on these opinions and neuropsychological testing carried out on the unit, it was concluded that his behavioural difficulties were not consistent with a diagnosable mental health condition, but that his anger and agitation were the result of an acquired emotional lability and executive dysfunction secondary to his brain injury. The team concluded that his brain injury had exacerbated a premorbid history of difficulties understanding social inference. The timing of the incident was felt to be secondary to frustration that it was taking time to complete the risk assessment to move to a new property, but also underlying anxiety about the planned move.

¹⁶ DoLS: Deprivation of Liberty Safeguards are an amendment to the Mental Capacity Act (2005) that sets out the conditions under which a person's freedom can be restricted to ensure their safety if they do not have the capacity to maintain that safety independently. Provision of one to one supervision without consent is an example of a restriction of freedom that requires authorisation. Restrictions of this type should be minimised.

The team met with Simon, his parents and his close friends to review the Intervention 1 goals and discharge plan. The team recommended that Simon should live in a flat with a 24-hour care team on site so that he had access to staff when required and so the risk of him becoming aggressive to others could be safely managed. The team also recommended that Simon's move to the flat be bought forward and that his risk assessment and rehabilitation be continued in the home environment. The rationale for this was that Simon was finding the Transitional Unit process frustrating and so, rather than engaging in the community risk assessment, he was withdrawing from the process. The team felt that moving to his own property would potentially motivate him to engage with the rehabilitation process again. The team also hypothesised that a supported move, with sufficient care in place to ensure it was successful, would help to manage Simon's anxiety about living in his own again. The choice of property was very important for Simon because he required support from staff who would have the skills to support his behaviour but would also respect his wish for privacy. A flat was identified within a small SLS of 18 flats specialising in providing support for people with ABI or mental health diagnosis, at risk of challenging or aggressive behaviour.

Simon was supported to visit the property and work with the staff team to agree what furniture he required and how he would like the flat to be arranged and decorated. He was supported to visit the local area which was within his chosen area of London.

Simon had engaged with his brain injury support worker during Intervention 1 and therefore the team recommended that this arrangement continue in addition to the SLS team to ensure consistency of support and to facilitate access to the community. This support was funded as part of Simon's CHC package of care in the community.

Simon's motivation and engagement improved with this short period of discharge planning. The Community Team (for Intervention 2) met with Simon during this period and also met with the support workers as the consistent link between the two stages.

Simon's goal-based interventions are summarised in Table 13.

Table 13: Simon Intervention 1 goals

Functional Therapy Goal	Goals Specific Intervention	Outcome
<p>I will have a weekly routine of activities.</p> <ul style="list-style-type: none"> • Simon will be able to manage his personal care independently with prompts to initiate • Simon will be able to wash his clothes with instructions to use the washing machine • Simon will be able to prepare simple meals and will prepare at least one meal per day for himself • Simon will clean his bathroom weekly or allow cleaners weekly access to his bathroom • Simon will go swimming and /or cycling once per week 	<ul style="list-style-type: none"> • Neuropsychologist supported discussion with Simon to identify acceptable weekly routine • Provision of timetable to reflect weekly routine • Regular discussion and provision of written information to support following routine (e.g. contract of agreement re: personal care) • Supported cycling, swimming and grocery shopping sessions with OT and PT. Graded support to plan and carry out cognitive and physical aspects of the task/activity. • Supported Meal preparation activities with OT. 	<p>Not achieved</p> <p>Simon did not consistently engage in a routine.</p> <p>Engagement in personal care was intermittent, he did not respond well to use of prompts but responded more positively to use of motivating activities to encourage personal care.</p> <p>Simon participated in cycling on 3 occasions with support of 2 staff. He also participated in swimming with support of 2 to navigate and manage communal areas. He declined all other offered swimming and cycling sessions.</p>
<p>I will be ready to move to my new flat.</p> <ul style="list-style-type: none"> • Simon will participate in three visits to explore the local area and shops • Simon will participate in sessions to identify what furniture he requires, look in shops and order items on line • Simon will work with the MDT and his parents to decide which items he wants from storage. 	<ul style="list-style-type: none"> • OT support to catalogue and review stored possessions. • OT and RA support to organise and manage possessions within the Transitional Unit, including unpacking, organising and maintaining an ordered room. • Supervised community access to local shops and cafes with OT. 	<p>Partially achieved</p> <p>Simon participated in community sessions when they were focused a motivating task such as going to the bank.</p> <p>Simon was not willing to participate in organising or reducing his possessions. His proposed flat was furnished</p>
<p>I will be able to move to my new flat safely, to include:</p> <ul style="list-style-type: none"> • Identify areas of risk related to Simon living alone • Devise a risk management plan • Determine the level of support required on discharge 	<ul style="list-style-type: none"> • MDT risk assessment of all aspects of community placement such as risk of self-neglect, risk related to community safety and risk related to behaviours and perceptions of other. 	<p>Achieved</p>

Functional Therapy Goal	Goals Specific Intervention	Outcome
<p>I will work with support workers to help me to move to my new flat.</p> <p>This will include the following:</p> <ul style="list-style-type: none"> • Simon will be able to manage a weekly budget with help from his support worker • Simon will be able to plan one regular activity he wants to do with assistance from his support worker • Simon will be able to identify one social activity he would like to attend with his support worker. 	<ul style="list-style-type: none"> • Financial assessment completed by Local Authority social worker with support from the Neuropsychologist. • Trials of Simon managing a budget for the week that his father transferred to his account for him to plan/ use for food and necessary personal items (not bills or rent) with the OT and his support worker. • Support provided to access social activities with his friends by the OT and support worker. • Support provided to identify activities that Simon would like to do with his support worker and building rapport prior to discharge 	<p>Partially achieved</p> <p>Simon did not participate in discussion or assessment of ability to manage his finances which therefore remained with his parents under arrangements made by the Court of Protection. ¹⁷</p> <p>He did demonstrate the ability to use a cashpoint, check his balance, withdraw money and calculate change in a shop.</p> <p>Simon met with his support worker and started to participate in some social activities.</p>
<p>I will join in with social activities.</p> <p>This will include:</p> <ul style="list-style-type: none"> • Simon will attend a weekly coffee morning group on the Transitional Unit • Simon will be able to initiate conversation with another member of the group who he has met before within the structure of the group session. 	<ul style="list-style-type: none"> • Attendance at a weekly coffee morning group facilitated by the SLT which involved sharing experiences and discussing newspaper articles. • Feedback was given regarding Simon's interaction and his interpretation of other people's communication. 	<p>Achieved</p> <p>Simon was engaged and motivated during the group and was willing to help set up and clear away.</p> <p>Simon began commenting and asking more questions to others within the group and an improvement in eye contact was also noticed.</p> <p>This type of social interaction was also noted at times outside of the group.</p>

Simon had a period of two weeks graded discharge. During this time, he was living in the new property but the Transitional Unit team (Intervention 1) remained involved to train and support the SLS staff team. The transitional team also handed over the risk assessment completed for Simon to the Intervention 2 Community Team who would

¹⁷ Court of Protection: Is a UK Court responsible for making decisions about finance or welfare for people who are unable to make these decisions independently.

need to continue to review and amend it in response to Simon's progress in the community. The key points of the risk assessment were as follows:

- **Cycling:** Simon was at risk of harm when cycling in London because his ability to divide his attention between multiple stimuli was impaired. He had retained good riding ability and his lack of initiation acted as a protective factor in this instance because he had not initiated riding alone when on the Transitional Unit. The recommendation in place on discharge was that he was accompanied by two friends or staff members and his friends were aware of this recommendation.
- **Self-neglect of personal care:** Simon was at risk of self-neglect due to his reluctance to shower or wash regularly. It was acknowledged that this had been a premorbid pattern in Simon's behaviour but had been exaggerated by his brain injury. A protective factor appeared to be that Simon was motivated to shower and improve his appearance for activities he valued or for friends visiting. The recommendation to the SLS team was to prompt Simon using reminders of planned activities as a motivating factor. The SLS were also advised to contact the Community Team if they were concerned that Simon was neglecting his personal hygiene.
- **Self-neglect of nutrition:** Simon had demonstrated limited motivation to plan and cook meals and therefore a risk was identified in this area. However, he had demonstrated an ability to shop, calculate money and heat simple meals when prompted and motivated. An associated risk was that he would opt to eat simple, instant food and would be at risk of weight gain. The SLS team were advised to offer to shop and cook for Simon and to monitor that he was eating regular meals.
- **Risk of not maintaining his flat or tenancy:** The SLS team offered support to maintain the flat and manage payment of bills. However, Simon had to commit

to maintaining the flat or allowing entry to let the staff clean. There was a risk that he would allow the flat to deteriorate to a poor level of hygiene and place his tenancy at risk. The SLS staff were supported to negotiate a good time to clean as this had been reasonably successful during Intervention 1.

During the graded discharge, Simon's parents were given support to understand the risk assessment and the recommendations in place. They reported to the team on a number of occasions that they felt very worried about Simon and would feel more reassured that he was safe if he was moved back to a nursing home. The Transitional Unit team spoke to Simon's parents very regularly during this period on the telephone and provided information about Simon's capacity assessment and the support that was available. It was recommended that very frequent contact be continued between the Community Team and Simon's parents so that they had a channel to feedback concerns and could also remain up to date about Simon's intervention.

10.6. Intervention 2

Simon's care support was funded by NHS Continuing Healthcare. He did not have set hours of care from the SLS staff but they were available 24 hours if required. An outline of the support they needed to provide was agreed on a care plan. Simon also had a brain injury support worker twice per week.

The risk assessment presented at the end of Intervention 1 was the basis for the two-week handover between the teams. Ongoing review of this risk assessment also formed the basis for the initial goals with Simon in the community. Simon's Intervention 2 was therefore delivered in two distinct sections, with a period of risk assessment followed by a period of more typical community rehabilitation. The Community Team were aware that Simon had disengaged from structured rehabilitation in the past and therefore worked with Simon via his support workers and the SLS where possible and set goals at his pace. This approach, combined with the need to review the risk

assessment to ensure Simon's community placement remained safe, meant that Simon's Intervention 2 was unusually long.

The core components of 'active ingredients' of Simon's Intervention 2 were:

- Support to maximise access to the local community, building on gains made in Intervention 1
- Support to plan a sustainable routine in the community
- Support to access identified leisure activities

Simon was pleased to be in his flat and reported satisfaction with the situation. His engagement remained variable with different members of staff. Whilst this is quite common, in Simon's case he would only speak to certain staff members and did not respond or acknowledge staff that he did not like. He responded most positively to consistent members of the team who had worked with him at the Transitional Unit and in the community, to his brain injury support worker and to a specific member of staff at the SLS. Simon indicated at this stage that he did not want any further rehabilitation intervention and that he felt he could manage most tasks. He reported that if he could not manage a task, he was able to go downstairs to the office to ask for help. In this way Simon indicated he had quickly understood the support available on site and was able to access it. However, based on the level of concerns expressed in the risk assessment, it was important to negotiate a period of ongoing training for SLS staff and support for Simon whilst he settled in the community. Simon had demonstrated that he had capacity to make the decision to move to his flat, to understand how to access on-site support and to accept input from a brain injury support worker and SLS staff. It would therefore not have been appropriate to continue to provide a rehabilitation intervention without his consent, even if this intervention was largely provision of indirect training to staff.

Goals were therefore negotiated with Simon that respected his expressed wish not to engage in active rehabilitation but also met the Community Team's responsibility to complete the community risk assessment and staff training. Simon was able to demonstrate that he understood the need for ongoing support to the SLS staff and support worker. He also consented to frequent (initially weekly) visits from a member of the Community Team to ensure that he was managing in his flat and did not require additional support.

This section of Simon's intervention was therefore unusual for the team, it was underpinned by goals which were negotiated as follows:

- Simon will engage with regular (weekly for six weeks, then reducing to fortnightly and monthly over a three-month period) support from the Community Team to ensure that he is living safely in his property, which will include participating in an acceptable level of personal care, maintaining nutritional intake and maintaining his tenancy.
- Simon will engage with SLS staff and his support worker to ensure that community access is supervised. Simon is aware that SLS staff and support workers will be provided with training from the Community Team to support this supervision.
- Simon will contact SLS staff if he feels another resident or member of public is behaving negatively towards him. Simon is aware that SLS staff and support workers will be provided with training from the Community Team to support him.

This first section of Intervention 2 therefore consisted of regular visits to Simon from consistent members of the Community Team which were presented in a positive social manner to ensure he was managing his personal care and maintaining his tenancy.

Training was provided to the SLS staff and support worker by the community OT and Neuropsychologist. Sessions moved on from formal provision of training, to supporting the SLS staff and support worker in a problem-solving approach, to trying strategies to

prompt Simon (e.g. with personal care) and identifying the best communication and prompting style.

During a period of four months with this support, Simon established a routine at the SLS. He used the SLS staff and his support worker appropriately to help him to access the bank, shop for food and use his washing machine and oven. There were some aspects of his routine that remained challenging; he had not unpacked all of his belongings and was resistant to accepting help with this. Simon did sometimes accept help from his support workers to unpack items but some items (e.g. old copies of bicycle magazines) remained in boxes in the flat. These boxes occupied the main part of the living room. He was showering approximately once per week.

Simon had engaged with his support worker to go to shops and cafes and demonstrated good road safety and route recall having settled into the area. Simon did not engage in leisure activities such as cycling and swimming that he had previously identified as important to him. He stated that he would start these activities again when he was ready.

Over the next four months, with only monthly monitoring, Simon had started to initiate spending time in the evening in the communal areas of the SLS, watching television with staff and making conversation. The improvement was noted by Simon's family as well as the staff at the SLS.

At this point Simon was assessed as no longer requiring the regular monitoring of his safety in the placement and he agreed to re-engage with Neuropsychology and OT to set some new goals around community access.

In discussion with the OT and Neuropsychologist, Simon agreed that he would like to work towards managing his own money. He also identified that he would like to return to cycling.

Simon's brain injury support worker changed at this point and his new support workers were very anxious about escorting him into the community. This anxiety was noted by Simon's parents to annoy him and increase his agitation. Therefore, a period of training and indirect work to enable the new support workers to engage with Simon was included in this intervention. The goals were a mixture of self-directed and negotiated as follows:

- I will manage a small weekly budget independently. I will plan what I need and use this money for food and items for the flat (e.g. washing powder).
- I will start cycling with supervision from friends.
- Simon's carers will have a positive support plan to help them to engage with him and enable him to access the community and leisure activities safely.

Simon's engagement with his self-directed goals was variable, as it had been at previous stages of his rehabilitation. He agreed to a weekly financial budget, suggested by his parents based on what income he received and what was required for essential bills. Simon agreed to this level and was able to take on simple strategies to check his balance via a cash point machine, record the amount in his mobile phone and monitor his spending against that. He did not engage with planning weekly expenses or meals. He continued to shop per meal but did demonstrate an ability to stay within the budget set. As he was content with this level of financial independence, the goal was discontinued at this stage.

In terms of cycling, Simon did not accept any further supervised sessions with Community Team staff. However, his friends were an experienced group of cyclists and were able to supervise him appropriately. His friends liaised with the Community Team to understand Simon's brain injury and supervision need. They then started to offer to take him for rides. Simon engaged with this offer and started to ride occasionally.

Simon's support workers received fortnightly training and supervision from the Neuropsychologist, consisting of brain injury education and positive support strategies.

The support plan was based on observations of Simon in the community and reports from his support workers, parents and SLS staff about times when he became agitated. As previously observed, Simon could misinterpret the intention of others. If this happened in the community and he perceived someone to be acting aggressively or negatively towards him, his anxiety quickly escalated and he became aggressive or intimidating, standing close to people and demanding an explanation for perceived negative behaviour.

In order to reduce Simon's anxiety and the risk of confrontation, the following strategies were introduced via the support workers;

- Building rapport with Simon and spending time getting to know him prior to going out in to the community
- Providing a clear and concise summary of the support worker role and positive suggestions of activities.
- Avoiding the need for Simon to split his attention (e.g. not asking a question when he is ordering a drink or eating).
- Checking in with Simon regularly about how he is sleeping as it had been noted that poor sleep had an impact on his levels of anxiety.
- Taking a newspaper when going out into the community, as Simon enjoyed talking about current affairs if prompted and the paper was useful as a joint focus of attention for the conversation in cafes.

The support workers were also provided with strategies to use if Simon did start to demonstrate increased anxiety, particularly when in the community. When Simon was becoming agitated there would usually be signs as he would start looking repeatedly at another person in the area, asking whether they were looking at him or talking about him or respond defensively in conversation. If these behaviours were observed, the support workers were advised to reinforce that there was no negative communication

or action towards Simon and if possible to change the topic of conversation and location.

Simon settled well over this second section of Intervention 2, building a good relationship with his support workers and continuing to integrate more with the SLS staff. He returned to cycling regularly with friends and asked his parents to bring more of his bicycles to London from storage. Simon also started to access the community on his own. He was initially provided with distant supervision from the SLS staff but demonstrated he was able to access the local shops and the bank independently. SLS staff monitored the length of time he was out and his level of agitation on return. As Simon did not go out for long periods and did not return agitated, the risk assessment was therefore revised to reflect this level of independence.

In total Simon's Intervention 2 was 13 months which is much longer than is usual for this programme. It was largely carried out via the support workers and SLS staff, it was also not an intensive intervention at any point because the Community Team did not feel Simon would respond well to an intensive programme as he had disengaged from structured rehabilitation in the past.

Simon's goal specific interventions are summarised in Table 14.

Table 14: Simon Intervention 2 goals

Functional Therapy Goal	Goals Specific Intervention	Outcome
<p>Simon will engage with regular (weekly for six weeks, then reducing to fortnightly and monthly over a three-month period) support from the Community Team to ensure that he is living safely in his property, this will include participating in an acceptable level of personal care, maintaining nutritional intake and maintaining his tenancy.</p>	<ul style="list-style-type: none"> • Social visits carried out at stated intervals from AHP Consultant and OT. Checks carried out via conversation and positive offers of assistance to ensure Simon had food and domestic items needed in the flat. • Training carried out for staff at SLS by OT based on risk assessment and recommendations from Intervention 1. • Regular feedback sessions carried out with SLS staff and support workers to ensure monitoring of personal care and domestic tasks. • Regular telephone calls to Simon's parents to seek and provide feedback. 	<p>Achieved</p>
<p>Simon will engage with SLS staff and his support worker to ensure that community access is supervised. Simon is aware that SLS staff and support workers will be provided with training from the Community Team to support this supervision.</p>	<ul style="list-style-type: none"> • Training provided to SLS staff and support workers by the Community OT to ensure that they were aware of the risk assessment recommendations. 	<p>Achieved</p>
<p>Simon will contact SLS staff if he feels another resident or member of public is behaving negatively towards him. Simon is aware that SLS staff and support workers will be provided with training from the Community Team to support him.</p>	<ul style="list-style-type: none"> • Simon was provided with regular reinforcement of the support available via the SLS team. • SLS team and support staff provided with training and support to understand Simon's communication and behaviour and to support him if he became agitated. 	<p>Partially achieved</p> <p>SLS staff and support workers provided effective monitoring and Simon usually approached staff if he was concerned about anything. However, there was a single incident of Simon confronting another resident in the SLS and becoming agitated and aggressive.</p>

Functional Therapy Goal	Goals Specific Intervention	Outcome
I will manage a small weekly budget independently. I will plan domestic expenditure within this budget and ensure I purchase food for a week and any domestic items (e.g. washing powder) within this amount.	<ul style="list-style-type: none"> • Weekly budget agreed with Simon's father by OT and explained to Simon. • Strategy developed with Simon, OT and support workers to check balance via cash machine, record this on mobile phone and spend within weekly budget. • OT sessions offered to support planning and budgeting on a weekly basis. 	Partially achieved Simon demonstrated a consistent ability to use the cash machine and mobile strategy and did not over spend on a weekly basis. He did not engage in planning/ budgeting sessions or shop on a weekly basis. He continued to need prompts from SLS staff to buy domestic products such as washing powder.
I will start cycling with supervision from friends.	<ul style="list-style-type: none"> • Neuropsychologist provided Simon's friends with information and recommendations based on his cognitive impairments and vulnerabilities when cycling. • Recommendations shared with Simon, the SLS staff and support workers about the need for supervision. 	Achieved
Simon's carers will have a positive support plan to help them to engage with him and enable him to access the community and leisure activities safely.	<ul style="list-style-type: none"> • Neuropsychologist provided training and fortnightly supervision to Simon's support workers for a period of three months. 	Achieved

10.7. Outcome summary

Simon was successful in his primary goal of returning to live in his own flat in his chosen part of London. He moved into an SLS property with access to 24-hour support and a support worker package to assist with community access. During Simon's non-intervention period, his support workers, the SLS staff and his family reported that he continued to settle into a positive routine, continuing the gains made in Intervention 2. For example, at the review following the non-intervention period he was reported to be cycling more regularly with friends and had continued to unpack his belongings.

The design of Simon's intervention was based on a principle of respecting his wish to return to live in the community. Simon had demonstrated a reluctance to engage in formal rehabilitation and therefore the intervention aimed to support him in ways he found acceptable to enable him to develop independence in the community. Simon's capacity to consent to rehabilitation and make decisions about his living arrangements and care had to be monitored and reviewed regularly and his intervention was based on the principles of the Mental Capacity Act (2005) of providing support to enable someone to have capacity to decide where possible.

Returning to his chosen part of London allowed him to re-establish friendships with people who helped him to cycle in London.

11. Results and analysis

The outcome measures for each participant are presented in this chapter. Within-participant analysis of the scores was carried out across the different measures and intervention points using Wilcoxon signed rank test, as described in section 5.9. The analysis was carried out using the following outcome measure points:

- Whole Intervention period (outcome points 2 to 4)
- Intervention 1: (outcome points 2 to 3)
- Intervention 2: (outcome points 3 to 4)
- Between baselines (outcome points 1 to 2)
- Non-intervention period (outcome points 4 to 5).

Correlation was analysed using Spearman Rho correlation coefficient as described in section 5.9. The goals were scored using the GAS methodology and combined to produce a single standardised t- score for the start and end of each intervention period as described in section 5.9.

Within this Chapter, the results and analysis for each participant will be presented and case specific issues will be identified. There will be further discussion of the issues identified in the context of the whole case series in Chapter 13, when the case series results will be considered against the research hypotheses.

11.1. Billy results

The total scores at each intervention point for Billy are summarised in Table 15 and Figure 10. The raw scores for Billy's outcome measures can be found in Appendix 6.

Table 15: Billy summary of outcome measures

	1 (baseline)	2 (repeated baseline)	3 (end of Intervention 1)	4 (end of Intervention 2)	5 (end of non-intervention)
CIM *	39	41	16	35	41
FIM/ FAM **	163	159	173	189	191
MPAI ***	60	58	49	41	44

* The CIM has a score range of 10- 50 and the score increases with higher subjective feeling of integration

** The UKFIMFAM has a score range of 36- 252 and the score increases with increased independence in functional activity

*** The MPAI has a score range of 0-111 and the score decreases as independence in tasks increases

Figure 10: Billy summary of outcome measures

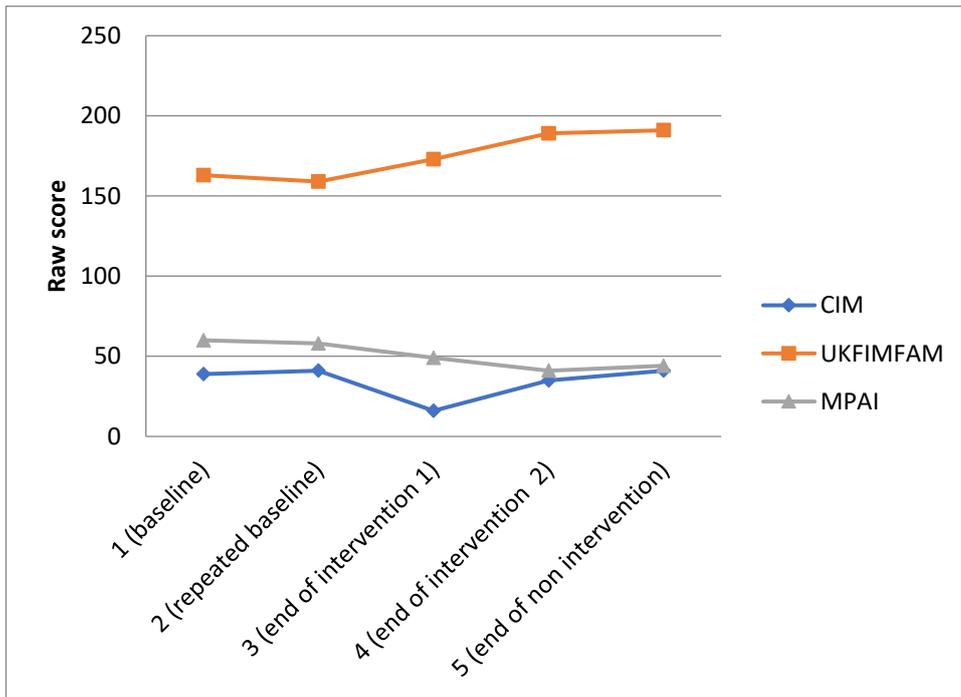


Figure 11 shows Billy's outcome measure results presented as a percentage of the score range available. This demonstrates how close to the floor or ceiling performance the scores are on each measure. The scores for the MPAI are presented as a percentage of the total available range, where 0 is the highest score achievable. The

graph shows increase in performance presented as a higher percentage on all three measures.¹⁸

Figure 11: Billy outcome scores presented as a percentage of the available score range

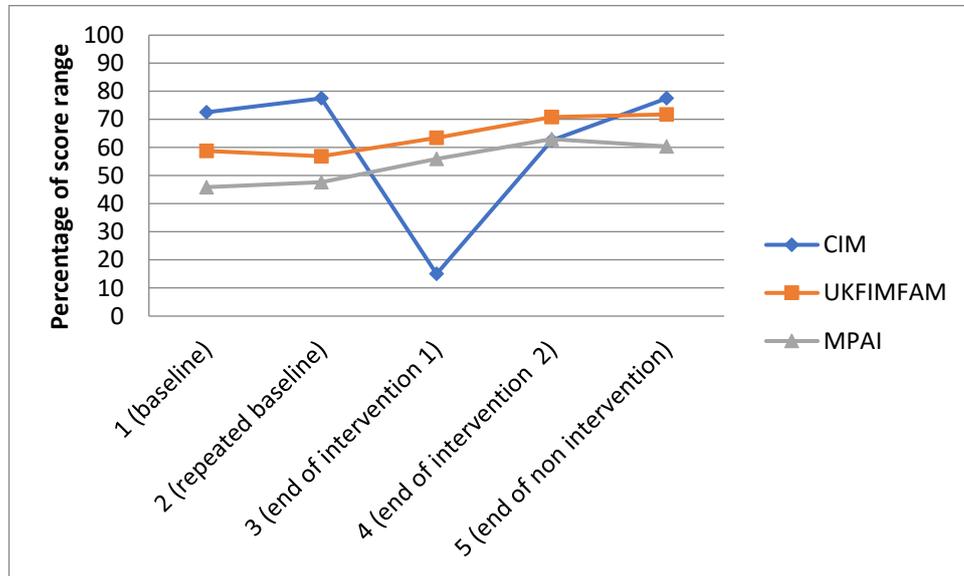


Figure 11 illustrates that Billy’s score on the primary outcome measure (CIM) was reasonably static throughout the study except for a dip at outcome point 3 (end of Intervention 1). The secondary outcome measures both demonstrate steady gain through the two intervention stages. There is an obvious gain on the primary measure during Intervention 2 but in the context of the very low score at outcome point 3. This will be discussed below in section 11.3.

11.2. Billy analysis

The results of the Wilcoxon signed rank analyses are summarised in Table 16.

¹⁸ Percentage scores for the CIM and UKFIMFAM were calculated using the following formula:
 $(\text{actual score} - \text{minimum score}) \div \text{total range}$
 Percentage scores for the MPAI were calculated using the following formula:
 $(\text{minimum score} - \text{actual score}) \div \text{total range}$

Table 16: Billy analysis of results

Outcome points	Measure	Z value	N (no. of paired observations)	P value	Comments
2-4 Whole Intervention	CIM	0.853	10	0.394	No significant change on the primary outcome measures. Significant positive change on both secondary measures.
	UKFIMFAM	4.049	36	<0.001**	
	MPAI	3.285	30	0.001**	
2-3 Intervention 1	CIM	2.694	10	0.007 (-)**	Significant negative change on primary measure and positive change on both secondary measures
	UKFIMFAM	2.144	36	0.032*	
	MPAI	2.828	30	0.005*	
3-4 Intervention 2	CIM	2.030	10	0.042*	Significant positive change on primary and both secondary measures
	UKFIMFAM	3.252	36	0.001**	
	MPAI	2.55	30	0.011*	
1-2 Baseline period	CIM	0.356	10	0.722	No significant change on the primary or secondary measures during the baseline period
	UKFIMFAM	0.894	36	0.371	
	MPAI	1.508	30	0.132	
4-5 Non- intervention period	CIM	1.029	10	0.304	No significant change on the primary or secondary measures during the non-intervention period
	UKFIMFAM	1.414	36	0.157	
	MPAI	1.633	30	0.102	

* Significant at $p \leq 0.05$

** Significant at $p \leq 0.01$

There was not a significant change on Billy's primary outcome measure across the whole intervention (outcome points 2 to 4). The significant change noted on the primary outcome measure over Intervention 1 (negative change from outcome point 2 to 3) and Intervention 2 (positive change from outcome points 3 to 4) are both related to the single low score at point three which was the end of Intervention 1.

Billy demonstrates a significant positive change on both secondary outcomes across the whole intervention (outcome points 2 to 4). For both secondary outcome measures, there is a statistically significant change during each intervention period (outcome points 2 to 3 and 3 to 4).

There was no significant change on either primary or secondary measures between outcome points 1 and 2, indicating a stable baseline period. There was no significant change on the primary or secondary outcome measures between outcome points 4 and 5, indicating a period of stability during the non-intervention period.

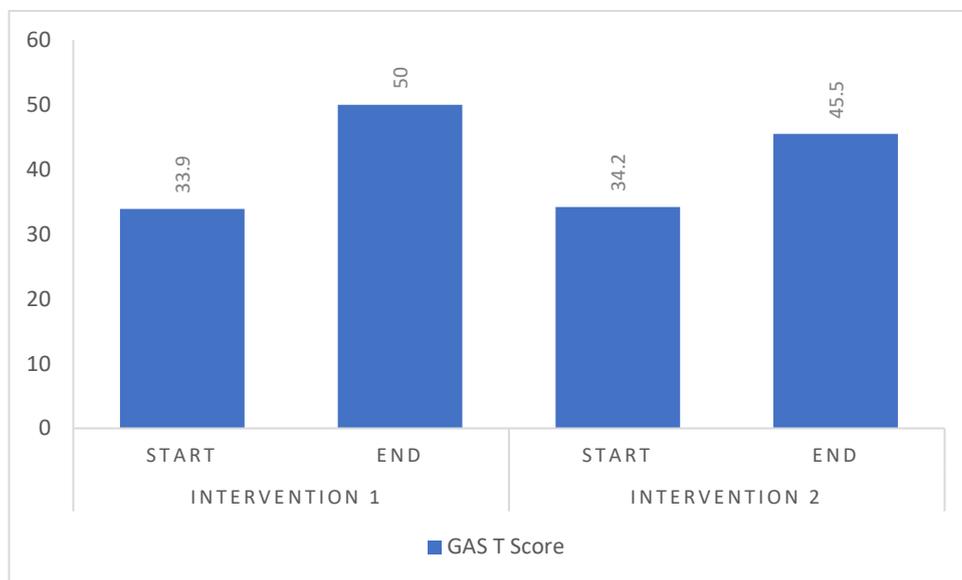
There was not a significant correlation between the MPAI and UKFIMFAM total scores at the five outcome measure points ($r = 0.800$, $p = 0.104$, $N = 5$) and no correlation between the CIM and the UKFIMFAM ($r = 0.103$, $p = 0.870$, $N = 5$) or the CIM and the MPAI ($r = 0.205$, $p = 0.741$, $N = 5$). Non-significant correlations should be interpreted carefully as there were only five outcome points. If these non-significant correlations are viewed in the context of the visual presentation/ distribution of scores in Figures 10 and 11 then that the CIM does follow a very different pattern across the five points and therefore a significant correlation would not be expected. The scores on the secondary measures on the other hand do appear to follow a very similar trajectory in terms of improvement through the intervention and therefore the non-significant correlation should be interpreted cautiously.

Billy's' goal attainment across the two intervention periods is summarised in Table 17. This translates to GAS t-scores as presented in Figure 12. A GAS t-score between 40 and 60 indicates overall goal attainment based on a normal distribution.

Table 17: Billy summary of goal attainment

Intervention stage	Total goals set	Exceeded	Achieved	Partially achieved	Not achieved
1	8	1	6	1	0
2	7	0	5	2	0

Figure 12: Billy summary of GAS t-scores



11.3. Billy discussion of results

The analysis reported above confirms that Billy made significant objective gains through his rehabilitation intervention as measured on the secondary outcome measures. This is supported by the fact that he was successful in moving to a new flat in the community and validated clinically by the high-level of goal achievement. However, he did not demonstrate any significant change on the primary outcome measure through the whole intervention, which needs exploring further. Billy did demonstrate a statistically significant change on the primary measure during the

individual intervention stages but these changes were both due to a single low score at outcome point 3 (end of Intervention 1). This coincided with Billy's move to his new flat and on the day of the point 3 assessment, Billy was agitated and expressed high levels of frustration with elements of his accommodation such as the communal areas. This may be what is reflected in the score at outcome point 3 rather than reflecting Billy's overall feelings of attainment over Intervention 1. For this reason, it is more appropriate to explore the overall lack of significant change across the whole intervention (outcome points 2 to 4) for Billy.

The primary outcome measure looks at subjective feelings of integration and so the simple interpretation of the outcomes would be that, despite having made significant objective gains, Billy did not feel any more integrated into the community at the end of the intervention than at the start. If this is the case, then it is important to try to understand this further. Due to his communication impairment, Billy did not provide a narrative to support his responses on the CIM that might indicate the reason for his scoring and therefore this discussion can consider potential reasons.

One consideration is whether Billy was able to fully understand and use the measure accurately due to his communication impairment. As per the guidance in the protocol described in section 4.2, additional support was provided to Billy to use the outcome measure. Prior to the initial baseline, the underlying concepts included in the measure were explained to Billy. Pictures were used to support his understanding and expression to explore what he thinks of as 'this community', for example was it the Transitional Unit, the area of London, the wider community or a virtual community of his family and friends? Pictures were also used to support his understanding of example activities that might form leisure or productive activity during his day. Finally, he was given visual analogue scales to support him to respond to the statements in the measure. Billy demonstrated he was able to use the visual analogue scales to express agreement or disagreement with a statement on a number of example statements

where his opinion was known. The peer reviewer concluded that in the example video reviewed, Billy was able to understand the concepts in the measure and respond appropriately using the materials provided. The available supports were reinforced at the beginning of each outcome point and example questions were used to check he was able to use the analogue scales. It is therefore difficult to conclude that he did not understand the measure or the concepts within it.

Assuming, for the purposes of this discussion, that Billy was able to use the outcome measure effectively, it is important to identify some of the areas where he did express frustration, to try to improve and develop the intervention further. Areas where he was able to express frustration were, *dissatisfaction with the communal living space* and *support workers not arriving on time for sessions*. It would be valuable to explore these two areas further as part of the development of the intervention. These elements both sit outside the research intervention but can be influenced with careful training and handover to care and support staff. It may be of note that Billy's period of graded discharge was curtailed and this coincided with a period of high frustration with his environment.

In summary therefore, the statistically significant change that Billy demonstrated on the secondary measures during both intervention stages supports the premise that he made objective improvements in function. His goal attainment was good in both intervention stages and his goals targeted areas identified by Billy, relating to access to the community and re-establishing previously enjoyed leisure activities. This supports the argument that the gains made were clinically significant and that the intervention may have been successful in targeting changes in community access. Billy did not express increased feeling of integration, as measured by the primary outcome measure, following the intervention and some of the potential reasons for this will be explored further in Chapter 13.

11.4. Richard results

The total scores at each intervention point are summarised in Table 18 and Figure 13.

The raw scores for Richard's outcome measures can be found in Appendix 7.

Table 18: Richard summary of outcome measures

	1 (baseline)	2 (repeated baseline)	3 (end of Intervention 1)	4 (end of Intervention 2)	5 (end of non- intervention.)
CIM *	41	42	40	41	39
UKFIMFAM **	201	200	220	227	225
MPAI ***	58	59	48	34	37

* The CIM has a score range of 10- 50 and the score increases with higher subjective feeling of integration

** The UKFIMFAM has a score range of 36- 252 and the score increases with increased independence in functional activity

*** The MPAI has a score range of 0-111 and the score decreases as independence in tasks increases

Figure 13: Richard summary of outcome measures

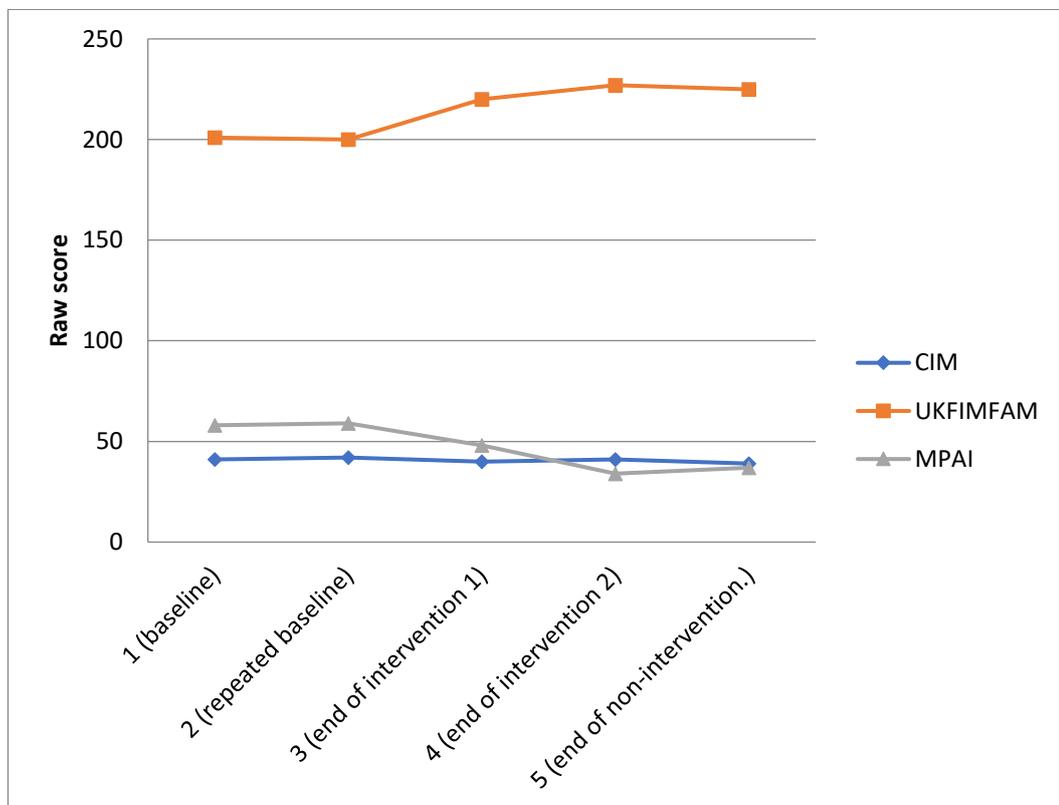


Figure 14 shows Richard's outcome measure results presented as a percentage of the score range available. This demonstrates how close to the floor or ceiling performance the scores are on each measure. The scores for the MPAI are presented as a percentage of the total available range, where 0 is the highest score achievable. The graph shows increase in performance presented as a higher percentage on all three measures.¹⁹

Figure 14: Richard outcome scores presented as a percentage of the available score range

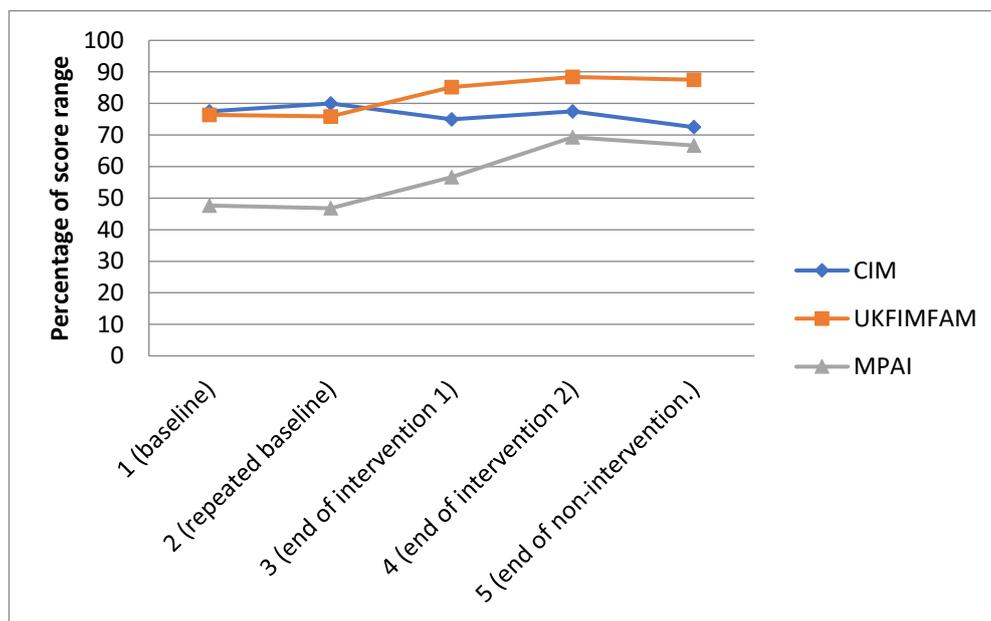


Figure 14 illustrates that Richard's score on the primary outcome measure shows very little change throughout the study. The scores on both the secondary measures increase steadily through both intervention stages. The graph illustrates a slight reduction in performance on both secondary measures during the non-intervention period.

11.5. Richard analysis

The results of the Wilcoxon signed rank analyses are summarised in Table 19

¹⁹ Percentage scores for the CIM and UKFIMFAM were calculated using the following formula:
 $(\text{actual score} - \text{minimum score}) \div \text{total range}$
 Percentage scores for the MPAI were calculated using the following formula:
 $(\text{minimum score} - \text{actual score}) \div \text{total range}$

Table 19: Richard analysis of results

Outcome points	Measure	Z value	N (no. of paired observations)	P value	Comments
2-4 Whole intervention	CIM	0.108	10	0.914	No significant change on the primary measure. Significant positive gains on both secondary measures.
	UKFIMFAM	3.345	36	0.001**	
	MPAI	4.354	30	<0.001**	
2-3 Intervention 1	CIM	0.575	10	0.565	No significant change on the primary measure. Significant positive gains on both secondary measures.
	UKFIMFAM	3.573	36	<0.001**	
	MPAI	3.00	30	0.003**	
3-4 Intervention 2	CIM	0.431	10	0.666	No significant gain on the primary measure or the UKFIMFAM. Significant positive change on the MPAI
	UKFIMFAM	1.512	36	0.131	
	MPAI	2.976	30	0.003**	
1-2 Baseline period	CIM	0.171	10	0.864	No significant change on the primary or either secondary outcome measures.
	UKFIMFAM	0.333	36	0.739	
	MPAI	0 ²⁰	30	1	
4-5 Non- intervention period	CIM	0.408	10	0.683	No significant change on the primary measure or UKFIMFAM. Significant negative change on the MPAI.
	UKFIMFAM	1.414	36	0.157	
	MPAI	2.00	30	0.046 (-)*	

* Significant at $p \leq 0.05$

** Significant at $p \leq 0.01$

²⁰ The Z score of 0 and corresponding p value of 1 indicates that the sum of the negative ranks equals the sum of the positive ranks between the two outcome points.

There was not a significant change on the primary outcome measure across the whole intervention (outcome points 2 to 4) or during either intervention stage for Richard.

Richard's secondary outcomes both demonstrate significant change across the whole intervention (outcome points 2 to 4). Both secondary measures demonstrate significant change during Intervention 1 (outcome points 2 to 3) when independence in functional tasks was being targeted by the intervention. In Intervention 2 (outcome points 3 to 4) there is significant change only on the MPAI. Referring to the raw scores in Appendix 7, these changes occur across all three subscales, suggesting ongoing improvement in abilities, adjustment and participation during Intervention 2. It is relevant to note that Richard's UKFIMFAM score was at ceiling for a number of items at the end of Intervention 1 and therefore would be unlikely to demonstrate further significant change during Intervention 2.

There is no change on the primary or secondary measures between outcome points 1 and 2, indicating a stable baseline period.

There is a negative significant change in Richard's MPAI during the non-intervention period (outcome points 4 to 5). Referring to the raw scores in Appendix 7, the change in scores at this point are on the adjustment and participation subscales. The abilities subscale remains stable which is consistent with the stable UKFIMFAM score as the abilities subscales measures similar items. The possible reasons for this negative change on the MPAI will be discussed in section 11.6.

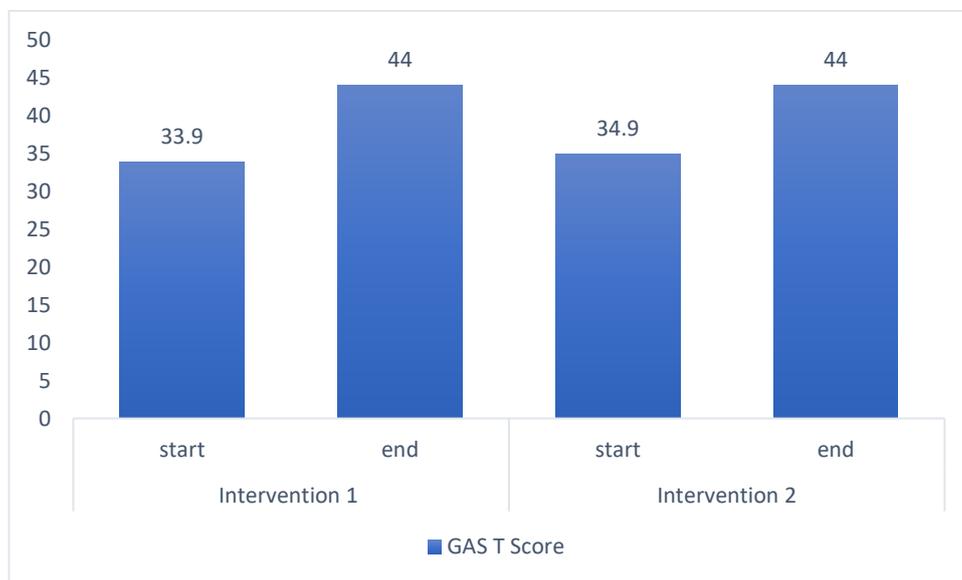
There was a correlation between the UKFIMFAM and the MPAI across the five measurement points using Spearman Rho correlation co-efficient ($r = 1.00$, $p < 0.001$, $N = 5$). There is no correlation between the CIM and the UKFIMFAM ($r = 0.564$, $p = 0.322$, $N = 5$) or the CIM and the MPAI ($r = 0.564$, $p = 0.322$, $N = 5$). The visual distribution of scores presented in Figures 13 and 14 supports this analysis of correlations.

Richard's goals attainment is summarised in Table 20. This translates to GAS t-scores as presented in Figure 15. A GAS t-score between 40 and 60 indicates overall goal attainment based on a normal distribution.

Table 20: Richard summary of goal attainment

Intervention stage	Total goals set	Exceeded	Achieved	Partially achieved	Not achieved
1	8	0	5	3	0
2	5	0	3	2	0

Figure 15: Richard summary of GAS t-scores



11.6. Richard discussion of results

Based on the analysis, it is clear that Richard made significant objective gains over the two-part intervention. He also achieved the majority of his goals and successfully transitioned to the community. However, the lack of change on the primary outcome measure (CIM) is concerning as it suggests that Richard's subjective feelings of integration have not improved.

There are a number of factors that need to be taken into account in this case in relation to the CIM. The measure is designed to be entirely subjective to enable the person with a brain injury to identify their own priorities and concept of integration. However, this

does make it challenging for people with impaired insight as they may not be able to reflect accurately on their level of integration. When completing the baseline measures (outcome points 1 and 2), Richard presented with globally impaired cognition, including a lack of insight into his own impairments and particularly his social communication. Prior to completing each CIM, the concepts within the statements were discussed with Richard to ensure that he understood them. He was provided with potential options for defining concepts such as *community* and *productive activity*, with specific examples. He was also asked to describe what he understood by these terms. Richard demonstrated an understanding of the concepts, but whilst completing the measure, the narrative that he provided suggested that he was not able to reflect accurately on his level of function within the community. During the administration of the measure, it was not possible to provide him with feedback about his interactions without compromising the subjectivity of the assessment. It is therefore worth considering whether this is a suitable measure for people with very impaired insight.

Another point to consider is that the time-lapse between outcome measure points was long; there was 11 months between outcome point 1 and 5. During this time, Richard's presentation had changed and his living situation was very different. This was the case for all participants in the study, but in Richard's case, the narrative that he provided indicated that his concepts of independence and integration were very concrete and specific to his current environment. When completing the primary outcome measure, Richard provided a narrative that explained his thinking when rating the statements. During outcome measures 1 and 2, he expressed his relief at being back in London and also that he liked the privacy he had at the Transitional Unit compared to the interim placement. He referred to specific factors, such as being able to choose when visitors came and being able to close his bedroom door if he wanted privacy, as reasons he felt settled and happy living at the unit. In contrast, completing the later measures (outcome points 4, and 5) when he was in his flat, he referred to a broader

community in the local areas and reflected on positive and negative interactions he had with his immediate neighbours and friends in the area. This would suggest a very different frame of reference for '*this community*' at the different outcome measures points, as well as a difference in Richard's ability to reflect on his situation.

Richard's statistically significant gains on both secondary measures through the whole intervention (outcome points 2 to 4) demonstrates increased independence in function and increased levels of activity. This corresponds to his high level of goal attainment and supports the argument that the goal interventions supported this improvement in function. The UKFIMFAM did not show significant improvement during Intervention 2 (outcome points 3 to 4) but this measure focusses predominantly on personal and domestic care tasks, while Richard's goals for Intervention 2 centred on community access and establishing a routine. These elements are captured by the MPAI which did show significant gains in Intervention 2.

The statistically significant negative change on the MPAI during the non- intervention period reflects changes on the adjustment and participation subscales. Specifically, the change in score reflects the fact that, at this point, Richard was attending volunteering and leisure activities less regularly and failing to maintain some of his organisational strategies. This coincided with the removal of his brain injury support worker who had previously provided input to help Richard structure his week and maintain commitments. The withdrawal of the support worker at this point may therefore have had an impact on Richards functioning and performance on the MPAI.

In summary, therefore Richard made significant gains in his abilities, moved successfully to a new flat and has a routine of attending leisure and volunteering activities. This far exceeds the expected level of outcome at the beginning of the Intervention but it remains concerning that he does not self-report feeling more integrated. The themes raised here will be discussed in more detail in Chapter 13.

11.7. Nathan results

Nathan's outcome measures are summarised in Table 21 and Figure 16. The raw score can be found in Appendix 8.

Table 21: Nathan summary of outcome measures

	1 (baseline)	2 (repeated baseline)	3 (end of Intervention 1)	4 (end of Intervention 2)	5 (end of non- intervention period)
CIM *	49	48	50	49	49
UKFIMFAM **	165	167	224	241	237
MPAI ***	68	66	40	32	33

* The CIM has a score range of 10- 50 and the score increases with higher subjective feeling of integration

** The UKFIMFAM has a score range of 36- 252 and the score increases with increased independence in functional activity

*** The MPAI has a score range of 0-111 and the score decreases as independence in tasks increases

Figure 16: Nathan summary of outcome measures

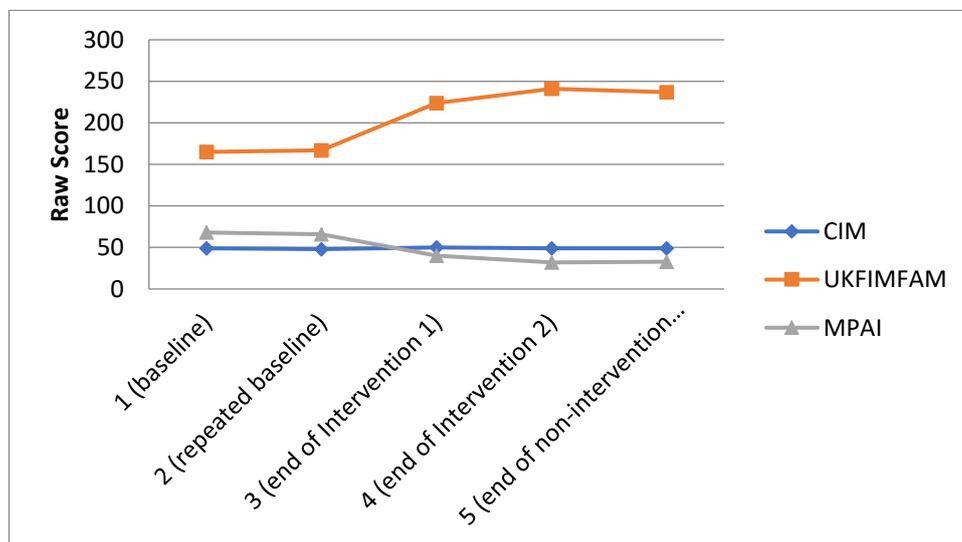
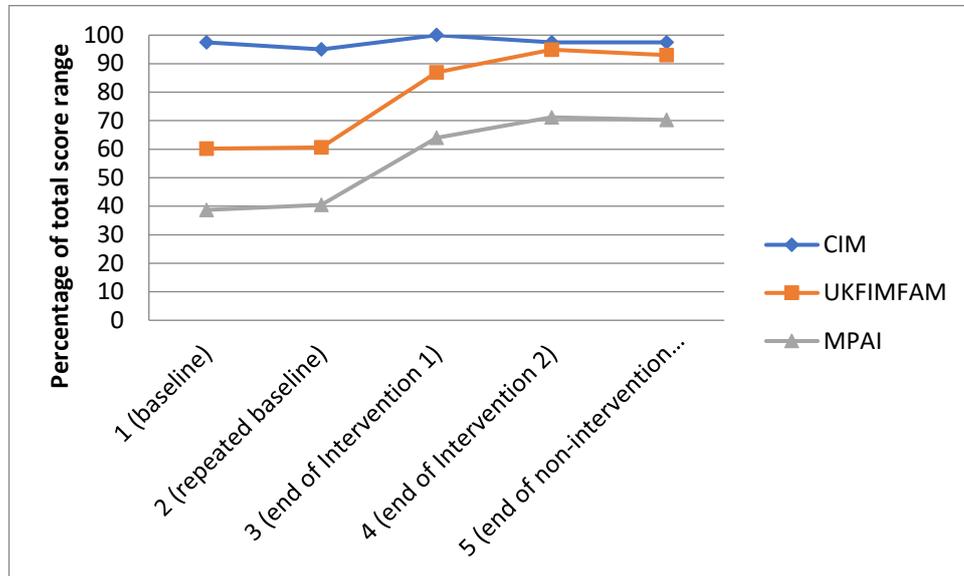


Figure 17 shows Nathan's outcome measure results presented as a percentage of the score range available. This demonstrates how close to the floor or ceiling performance the scores are on each measure. The scores for the MPAI are presented as a percentage of the total available range, where 0 is the highest score achievable. The

graph shows increase in performance presented as a higher percentage on all three measures.²¹

Figure 17: Nathan outcome scores presented as a percentage of the available score range



Nathan’s CIM score remains at a ceiling level throughout. Nathan’s UKFIMFAM score increased through both interventions but most notably through Intervention 1. Nathan’s MPAI scores also improved through both intervention stages with most change in Intervention 1.

11.8. Nathan analysis

The results of the Wilcoxon signed rank analyses are summarised in Table 22.

²¹ Percentage scores for the CIM and UKFIMFAM were calculated using the following formula:
 $(\text{actual score} - \text{minimum score}) \div \text{total range}$
 Percentage scores for the MPAI were calculated using the following formula:
 $(\text{minimum score} - \text{actual score}) \div \text{total range}$

Table 22: Nathan analysis of results

Outcome points	Measure	Z value	N (no. of paired observations)	P value	Comments
2-4 Whole intervention	CIM	1.00	10	0.317	No significant change on primary measure. Significant positive change on both secondary measures
	UKFIMFAM	4.423	36	p<0.001**	
	MPAI	4.216	30	p<0.001**	
2-3 Intervention 1	CIM	1.414	10	0.157	No significant change on primary measure. Significant positive change on both secondary measures
	UKFIMFAM	4.427	36	p<0.001**	
	MPAI	4.349	30	p<0.001**	
3-4 Intervention 2	CIM	1.00	10	0.317	No significant change on the primary measure. Significant positive change on the UKFIMFAM but not the MPAI.
	UKFIMFAM	2.709	36	0.007**	
	MPAI	1.811	30	0.070	
1-2 Baseline period	CIM	0.577	10	0.564	No significant change on primary or secondary measures.
	UKFIMFAM	0.486	36	0.627	
	MPAI	0.816	30	0.414	
4-5 Non- intervention period	CIM	0 ²²	10	1	No significant change on primary or secondary measures.
	UKFIMFAM	1.683	36	0.102	
	MPAI	0.577	30	0.564	

* Significant at p ≤ 0.05

** Significant at p ≤ 0.01

The analysis demonstrated no significant change on the primary outcome measure, either over the whole intervention (outcome points 2 to 4) or in either Intervention 1 (outcome points 2 to 3) or Intervention 2 (outcome points 3 to 4).

²² The Z score of 0 and corresponding p value of 1 indicates that the sum of the negative ranks equals the sum of the positive ranks between the two outcome points.

Analysis of the secondary measures shows significant change in both the UKFIMFAM and the MPAI over the course of the whole intervention (outcome points 2 to 4). If broken down into the separate interventions, the change remains significant for the UKFIMFAM for Intervention 1 (outcome points 2 to 3) and Intervention 2 (points 3 to 4). For the MPAI the change is only significant during Intervention 1.

There were no significant changes on the primary or secondary measures between outcome points 1 and 2, indicating a stable baseline period. There were no significant changes on the primary or secondary measures during the non-intervention period (outcome points 4 to 5) indicating Nathan maintained gains in function during this period.

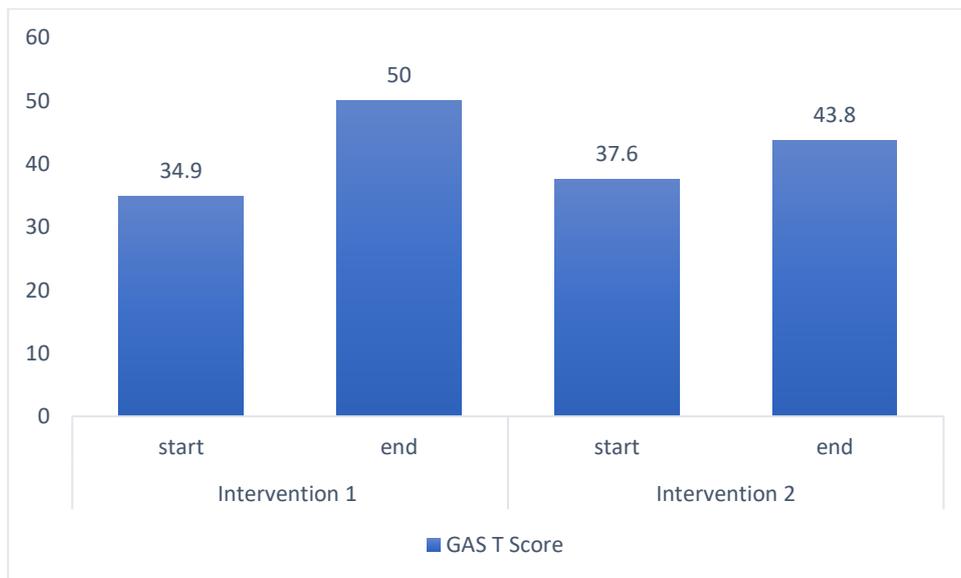
There was a correlation between the total scores on the UKFIMFAM and the MPAI across the five outcome points using Spearman's Rho correlation co-efficient ($r = 1.00$, $p < 0.001$, $N = 5$). There was no correlation between the CIM and the UKFIMFAM ($r = 0.224$, $p = 0.718$, $N = 5$) or the CIM and the MPAI ($r = 0.224$, $p = 0.718$, $N = 5$). The visual distribution of scores presented in Figures 16 and 17 supports this analysis of correlation.

Nathan's goal attainment is summarised in Table 23. This translates to GAS t-scores as presented in Figure 17. A GAS t-score between 40 and 60 indicates overall goal attainment based on a normal distribution.

Table 23: Nathan summary of goal attainment

Intervention stage	Total goals set	Exceeded	Achieved	Partially achieved	Not achieved
1	5	0	5	0	0
2	2	0	1	1	0

Figure 18: Nathan summary of GAS t-scores



11.9. Nathan discussion of results

Nathan's progress through the research intervention was very positive and his secondary outcomes show an objective increase in his independence across a broad range of personal care and domestic tasks as well as an increase in social interaction and activity. His primary outcome measure does not show change in his subjective reports of community integration, with his CIM scores remaining at or near the maximum score throughout. This may reflect the fact that Nathan feels genuinely well integrated at each stage of the intervention. Certainly, within his narrative during the CIM administration at each stage he is very positive about the Transitional Unit, the return to his flat and the wider geographical area. However, it is important to consider both his impaired insight and his tendency to use vague language and give positive verbal responses that may not be reflected in his behaviour. Based on this cognitive and communication presentation, it is reasonable to consider whether his reduced insight into his level of support needs may be reflected in his responses and whether he presents a positive verbal presentation masking this. This theory is supported by the narrative that Nathan provided when completing the CIM. Nathan demonstrates that he understands the concepts within the statements by providing examples of

factors he is considering when providing his answers. For example, at outcome point three, when responding to an item about knowing the area, he explains that he has lived locally for some years, walks to most places and is very familiar with the local transport options. However, the narrative that he provides to support his ratings against these concepts demonstrates his impaired insight. For example, at the same outcome measure point, when referring to productive activity, Nathan does equate this with work but then goes on to say he does not anticipate any challenges with returning to his previous role full time despite that fact that at this stage he had only completed informal/ social visits to his workplace. In other contexts, such as goal setting, the intervention teams were able to feedback to Nathan on these points and he was able to reflect on some of the support he was receiving or would need. However, it was not possible to provide this feedback during the outcome measure without compromising the subjectivity of the scale. The general issue of use of this outcome measure with people with impaired insight will be discussed in Chapter 13.

The statistically significant changes on the secondary measures, particularly in Intervention 1 (outcome points 2 to 3), reflects the level of change in Nathan's ability to carry out personal and domestic tasks independently, as well as to access the community. During Intervention 1, when Nathan was in the structured environment of the Transitional Unit, it was possible to ensure a consistent approach to his rehabilitation to support him to develop a healthy routine. The statistically significant gains on both secondary measures at this stage, taken with the high level of goal attainment supports the premise that the intervention and structured environment helped Nathan to achieve these gains.

During Intervention 2, Nathan continued to make statistically significant gains on the UKFIMFAM but not on the MPAI, he also achieved his goals within the parameters set (outcome t-score 40 - 60). Nathan did make gains on all three subscales of the MPAI during Intervention 2 but these were relatively small compared to Intervention 1 and

therefore do not reach a point of statistical significance. There is potential that Nathan could have worked towards a broader range of goals during Intervention 2, however when he returned home and had developed sufficient insight to direct and influence his rehabilitation more, he chose to focus on a narrower range of goals. This raises an interesting point for discussion about the balance between using the assessment of a professional team and personal preference to guide a rehabilitation programme. The professionals within the Community Team would have liked to have set a number of structured goals focussing on vocational activity to support a structured return to employment; however, Nathan did not want to engage in this, preferring to rely on his strong personal relationships with work colleagues and his knowledge of the job. Nathan's return to work was not successful where it might otherwise have been. Whilst this may relate in part to Nathan's ongoing reduced insight into his needs, having made the decision to support him to return to living independently, the Community Team made the assessment that it was appropriate for Nathan to make this choice. If a risk assessment had demonstrated that his decision would put him at risk in the community, this would have changed that decision but in these circumstances where the work colleagues were so supportive of Nathan returning in this informal way, no real risk to him was identified. This balance of when to intervene based on professional judgement and when to respect personal choice is key to community programmes with this client group and will be discussed further in Chapter 13.

The third key point to emerge from Nathan's case study is the potential benefits of working through skilled support workers to ensure that strategies and feedback continue as the level of formal rehabilitation reduces. This was very successful in Nathan's case and allowed him to return home safely, the rehabilitation team to discharge and his parents to reduce their support, without him losing the independence he had developed. This is a key part of the 'active ingredients' of the intervention described in this study, but it is also one of the hardest to maintain as it requires

collaboration across different elements of health and social care provision and is vulnerable to funding cuts and changes in eligibility. Again, this point will be discussed further in Chapter 13.

11.10. Louise results

The raw scores for Louise's outcome measures can be found in Appendix 9. The total scores at each intervention point are summarised in Table 24 and Figure 19.

Table 24: Louise summary of outcome measures

	1 (baseline)	2 (repeated baseline)	3 (end of Intervention 1)	4 (end of Intervention 2)	5 (end of non-intervention period)
CIM	25	37	37	44	42
UKFIMFAM	115	113	121	122	130
MPAI	70	72	59	56	52

* The CIM has a score range of 10- 50 and the score increases with higher subjective feeling of integration

** The UKFIMFAM has a score range of 36- 252 and the score increases with increased independence in functional activity

*** The MPAI has a score range of 0-111 and the score decreases as independence in tasks increases

Figure 19: Louise summary of outcome measures

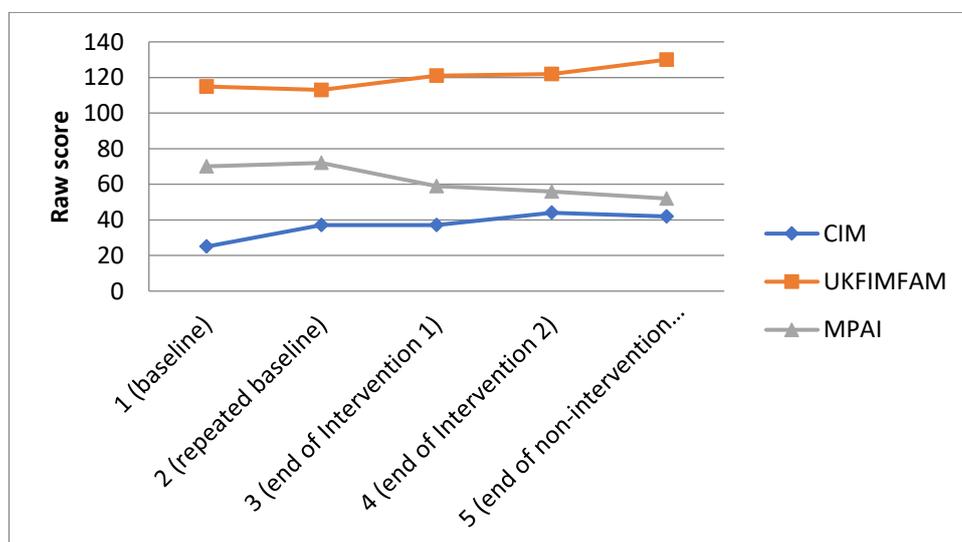
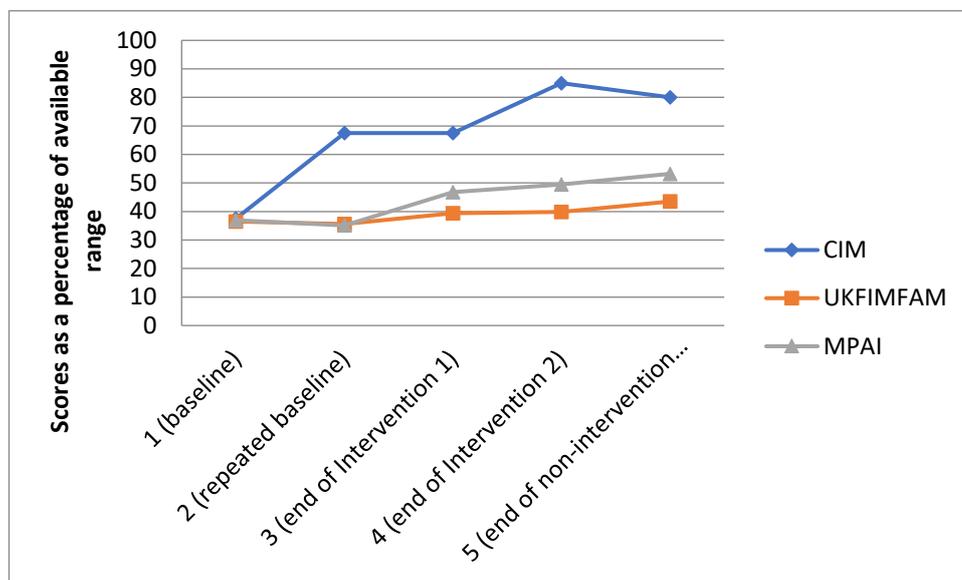


Figure 20 shows Louise’s outcome measure results presented as a percentage of the score range available. This demonstrates how close to the floor or ceiling performance the scores are on each measure. The scores for the MPAI are presented as a percentage of the total available range, where 0 is the highest score achievable. The graph shows increase in performance presented as a higher percentage on all three measures.²³

Figure 20: Louise outcome measures scores presented as a percentage of the score range available



The graph in Figure 20 illustrates that Louise made gains on all measures through the whole intervention period, although the gains on the secondary measures are small. The most notable gains on the secondary outcomes are made during Intervention 1 (outcome points 2 to 3) and the largest gains are made on the primary outcome measure during Intervention 2 (outcome points 3 to 4). There is also an increase in score on the CIM during the baseline phase (outcome points 1 to 2) which will be explored in sections 11.11 and 11.12. Louise’s score on the primary outcome measure

²³ Percentage scores for the CIM and UKFIMFAM were calculated using the following formula:
 $(\text{actual score} - \text{minimum score}) \div \text{total range}$
 Percentage scores for the MPAI were calculated using the following formula:
 $(\text{minimum score} - \text{actual score}) \div \text{total range}$

decreases during the non-intervention stage (outcome points 4 to 5) and this will be explored in section 11.11.

11.11. Louise analysis

The results of the Wilcoxon signed rank analyses are summarised in Table 25.

Table 25: Louise analysis of results

Outcome points	Measure	Z Value	N (no. of paired observations)	P value	Comments
2-4 Whole intervention	CIM	1.196	10	0.232	No significant change on primary measure or UKFIMFAM. Significant positive change on the MPAI
	UKFIMFAM	0.974	36	0.330	
	MPAI	2.640	30	0.008**	
2-3 Intervention 1	CIM	0.71	10	0.944	No significant change on primary measure or UKFIMFAM. Significant positive change on the MPAI
	UKFIMFAM	1.498	36	0.134	
	MPAI	2.360	30	0.018*	
3-4 Intervention 2	CIM	1.282	10	0.2	No significant change on primary or secondary measures
	UKFIMFAM	0.158	36	0.874	
	MPAI	0.073	30	0.941	
1-2 Baseline period	CIM	2.585	10	0.010**	Significant positive change on the primary measure. No significant change on the secondary measures.
	UKFIMFAM	0.816	36	0.414	
	MPAI	1.414	30	0.157	
4-5 Non- intervention period	CIM	0.552	10	0.581	No significant change on the primary measure. Significant positive change on both secondary measures.
	UKFIMFAM	1.994	36	0.046*	
	MPAI	2.236	30	0.025*	

* Significant at $p \leq 0.05$

** Significant at $p \leq 0.01$

The analysis demonstrated there was no significant change on the primary outcome measure across the whole intervention (outcome points 2 to 4) or during separate intervention stages (outcome points 2 to 3 and 3 to 4). Over the whole intervention, Louise's self-rating increased by 7 points, all during Intervention 2, which when viewed as a percentage of the score range available (see Figure 19) appears large, however the analysis demonstrates it is not statistically significant. As described in section 5.9, when choosing an analysis method, artificial analysis was carried out to see what level of gain was required to show statistically significant outcome. This revealed that an increase of 1 point per item was needed on 4 items to demonstrate statistical significance. In Louise's case, her gains are greater than this but there are two items of the CIM where her score decreases between points 2 and 4. As Wilcoxon signed rank test is based on ranking the scores, a decrease on one or two items reduces the impact of increases on other items as the negative ranks balance out the positive ranks. This will be discussed in relation to Louise's outcomes in section 11.12.

The analysis demonstrates that there was no significant change on the UKFIMFAM across the whole intervention (outcome points 2 to 4) or in either Intervention 1 (outcome points 2 to 3) or Intervention 2 (outcome points 3 to 4). This indicates that although Louise made gains on the UKFIMFAM, they were not sufficient to be statistically significant. There was significant change on the MPAI during the whole intervention (outcome points 2 to 4) and during Intervention 1 (outcome points 2-3), but there was not significant change in Intervention 2 (outcome points 3 to 4).

The analysis does demonstrate a significant change on Louise's primary outcome measure between the two baselines (outcome points 1 to 2). There is no change on the secondary outcome measures in this time indicating that Louise had a stable baseline period in terms of the objective measure of her abilities, but not in terms of her subjective report of community integration. This will be discussed in section 11.12.

There is also a significant change in the secondary measures for Louise during the non-intervention period (outcome points 4 to 5). There is no change on the primary measure during this period.

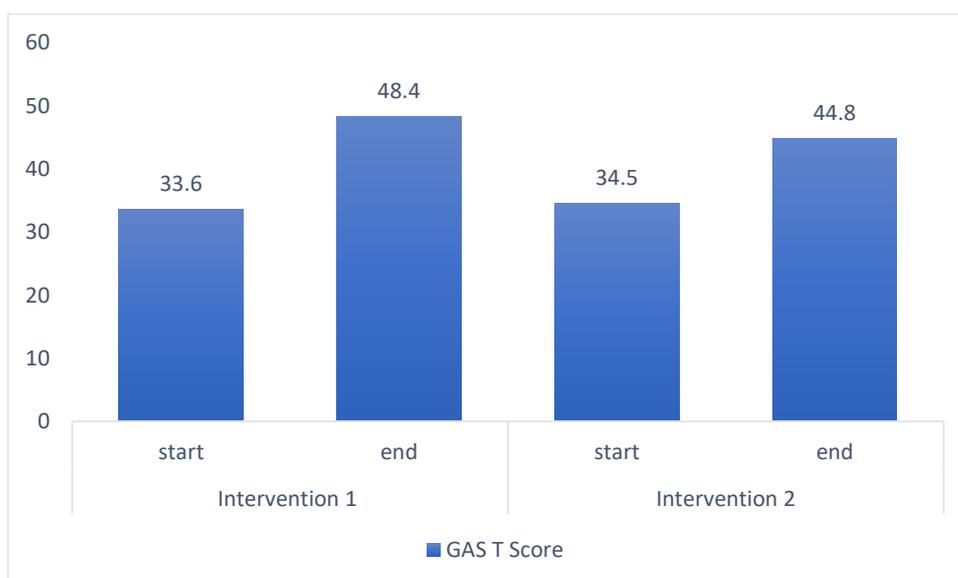
Correlation was measured on the total scores on each measure at the five outcome points using Spearman's Rho correlation co-efficient. This showed the secondary outcome measures (UKFIMFAM and MPAI) were significantly correlated ($r = 1.00$, $p < 0.001$, $N = 5$). There was not a significant correlation between the CIM and the UKFIMFAM ($r = 0.718$, $p = 0.172$, $N = 5$), or the CIM and the MPAI ($r = 0.718$, $p = 0.172$, $N = 5$). The visual distribution of score presented in Figures 19 and 20 support the analysis that the secondary measures are correlated. The pattern of change on the primary measure (CIM) also appears to be reasonably similar but with such a small sample ($N = 5$) the correlation needs to be very strong to indicate statistical significance.

Louise's goal attainment is summarised in Table 26. This translates to GAS t-scores as presented in Figure 21. A GAS t-score between 40 and 60 indicates overall goal attainment based on a normal distribution.

Table 26: Louise summary of goal attainment

Intervention stage	Total goals set	Exceeded	Achieved	Partially achieved	Not achieved
1	10	1	7	1	1
2	6	1	2	2	1

Figure 21: Louise summary of GAS t-scores



11.12. Louise discussion of results

The analysis reported above indicates that the changes that Louise made on the primary outcome measure during the intervention period were not statistically significant. However, there are a number of factors that need to be considered in relation to this.

The decision for Louise to access the transitional rehabilitation service (Intervention 1) was made on the basis of her level of anxiety and pre-injury history of pain, fatigue and subsequent deconditioning. The Level 1 team, Louise, her family and the AHP Consultant all agreed that, without a further period of structured rehabilitation, she would be at risk of losing gains made so far in her pathway.

Louise was not a typical patient for the transitional programme; although she was on a trajectory to return to living in the community, she was starting from a very low level of pre-morbid function in terms of integration. This is reflected in her goals, as they tended to focus on independence in the home and engaging with social activities within her environment rather than in the wider community. The primary outcome measure therefore may not have been as sensitive to change on Louise's goals as for other people in the programme.

The test used for analysis in this case, Wilcoxon signed rank test, sets quite a high level for statistical significance. Louise's total score on the CIM increased by 7 points which is an increase of 17.5% of the available score range (range 10-50). Between outcome points 2 and 4 her responses on three items increased from 'sometimes disagree (score of 2/5) to always agree (score of 5/5), these items were:

- I like where I am living now
- There are things I can do in this community for fun in my spare time
- I have something to do in this community in the main part of my day that is both useful and productive.

Given that pre-morbidly, Louise and her family reported that she did not like her flat and had disengaged from all activities, the changes on these self-ratings appear clinically significant. They do not meet the standard for statistical significance because there were two items where Louise's self-rating decreased between outcome points 2 and 4, as follows:

- I feel that I am accepted in this community (score 5/5/ reduced to 3/5)
- I can be independent in this community (score 4/5 reduced to 2/5)

These two scores also need to be considered carefully as they indicate areas where Louise appears to feel she has become less independent or less accepted. During the administration of the CIM at outcome point 4, Louise did express anxiety at being discharged from the community service which may be a factor but does not fully explain the change in scores. In Louise's case, therefore, there is an argument for looking in more detail at the items and how she rated them to understand her subjective feelings of integration and tailor her intervention.

The analysis also showed no significant change on the UKFIMFAM. Again, Louise made gains, but these were small. The UKFIMFAM measures change in ability on a number of functional tasks. Louise's complex pre-morbid presentation had an impact

on the level of goals she was likely to achieve, both physically and emotionally. This was reflected in the level of goals set and is likely to be a contributing factor to the statistically non-significant change on the UKFIMFAM. Louise did demonstrate significant change on the MPAI over the whole intervention and during Intervention 1. The MPAI has some overlap with the UKFIMFAM, mainly within the abilities subscale. As might be expected, Louise's score did not show very much change on the abilities subscale which is consistent with the small gains on the UKFIMFAM. She demonstrated larger gains on the adjustment and participation subscales which reflect the areas where she had goals in both Intervention 1 and 2. This supports the premise that the intervention may have been successful in targeting these areas via goal-based interventions, despite the mixed level of statistical significance.

The significant change in Louise's score on the CIM between the two baseline measures (outcome points 1 to 2) is a concern because it introduces a question about whether Louise had a stable baseline. As noted above, the secondary measures are stable during this period indicating a stable baseline in terms of functional ability. The initial baseline (outcome point 1) was completed when Louise had just moved from the Level 1 unit and she was reporting high levels of anxiety about the move and the unit. During the administration of the measure she reported high levels of concern about whether she would be able to transition to living in the community and it is therefore possible that this level of anxiety was reflected in her self-ratings. The repeated baseline (outcome point 2) was carried out within 2 weeks as per the protocol. Although formal goal-based interventions had not started at this point, Louise was reporting feeling more settled and comfortable with the unit and staff, again her narrative suggested that this feeling of having settled-in was reflected in her self-rating.

The use of goals as a validity indicator also supports the premise that the gains made were clinically significant as Louise achieved the majority of her goals and

demonstrated a large increase in pre-and post- intervention t-score. This issue will be discussed in more detail in Chapter 13.

Finally, there were a number of complicating factors in Louise’s presentation which affected her outcomes, such as her comorbid diagnoses of osteoporosis, hypertension, chronic fatigue and anxiety. The most obvious impact of this was the fall resulting in a fracture which set Louise’s progress back in Intervention 1. It is not possible to provide evidence of what point she would have reached on the outcome measures if this fall had not occurred, but it is possible that this would have had an impact on the significance of the gains made.

In summary therefore, Louise made small gains throughout her rehabilitation in her ability in functional tasks and her self-report of community integration but these gains were largely not statistically significant. Louise required a long and, at times, intensive programme to achieve these gains but the context of her pre-stroke history and the achievement of her personalised goals provide a rationale for the programme in this instance, and support the argument that gains made were clinically significant.

11.13. Simon results

The total scores at each intervention point are summarised in Table 27 and Figure 22.

The raw scores for Simon’s outcome measures can be found in Appendix 10.

Table 27: Simon summary of outcome measures

	1 (baseline)	2 (repeated baseline)	3 (end of Intervention 1)	4 (end of Intervention 2)	5 (end of non- intervention period)
CIM	37	32	12	43	41
UKFIMFAM	172	172	162	188	195
MPAI	66	65	64	50	44

* The CIM has a score range of 10- 50 and the score increases with higher subjective feeling of integration

** The UKFIMFAM has a score range of 36- 252 and the score increases with increased independence in functional activity

*** The MPAI has a score range of 0-111 and the score decreases as independence in tasks increases

Figure 22: Simon summary of outcome measures

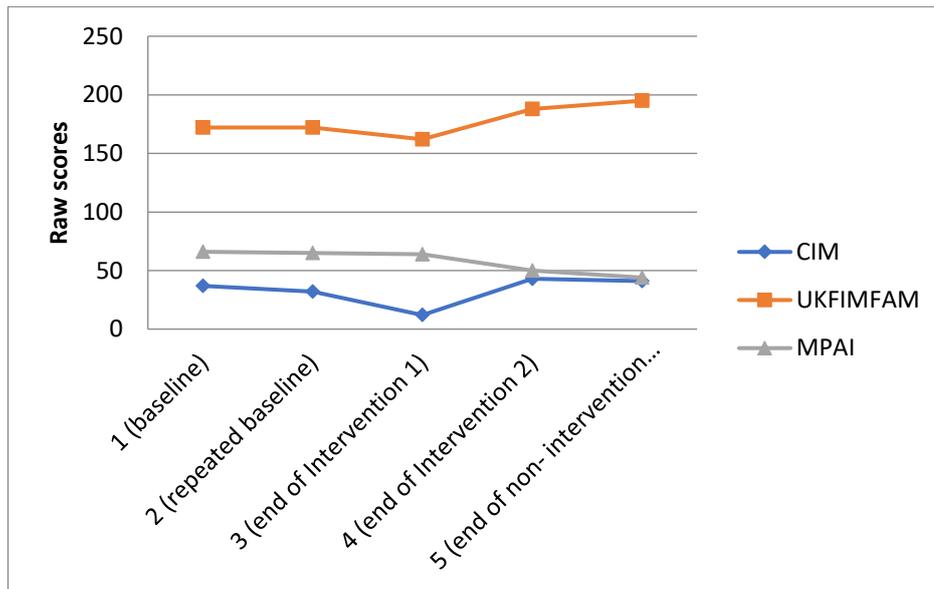


Figure 22 shows Simon's outcome measure results presented as a percentage of the score range available. This demonstrates how close to the floor or ceiling performance the scores are on each measure. The scores for the MPAI are presented as a percentage of the total available range, where 0 is the highest score achievable. The graph shows increase in performance presented as a higher percentage on all three measures.²⁴

²⁴ Percentage scores for the CIM and UKFIMFAM were calculated using the following formula:
 $(\text{actual score} - \text{minimum score}) \div \text{total range}$
 Percentage scores for the MPAI were calculated using the following formula:
 $(\text{minimum score} - \text{actual score}) \div \text{total range}$

Figure 23: Simon outcome scores presented as a percentage of the available score range

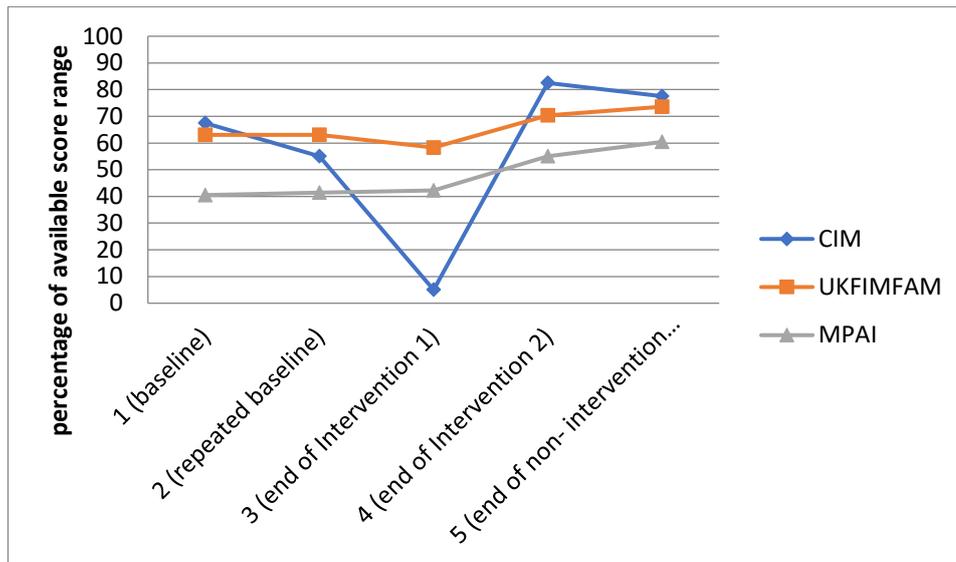


Figure 23 illustrates that Simon’s scores on the primary outcome measure do go up over the course of the whole intervention (outcome points 2 to 4) but with a very notable low score at the end of Intervention 1 (outcome point 3). The UKFIMFAM score decreases slightly during Intervention 1 (outcome points 2 to 3) but gains steadily through Intervention 2 and the non-intervention period (outcome points 3 to 5). The MPAI scores show gains throughout both interventions and the non-intervention period (outcome points 2 to 5).

11.14. Simon analysis

The results of the Wilcoxon signed rank analyses are summarised in Table 28.

Table 28: Simon analysis of results

Outcome points	Measure	Z value	N (no. of paired observations)	P value	Comments
2-4 Whole intervention	CIM	2.598	10	0.009**	Significant change on the primary outcome measures and the MPAI but not the UKFIMFAM
	UKFIMFAM	1.390	36	0.165	
	MPAI	2.385	30	0.017*	
2-3 Intervention 1	CIM	2.701	10	0.007 (-)**	Significant (negative) change on the primary measure. No significant change on the secondary measures.
	UKFIMFAM	1.732	36	0.083	
	MPAI	0.632	30	0.527	
3-4 Intervention 2	CIM	2.836	10	0.005**	Significant change on primary and both secondary outcome measures
	UKFIMFAM	2.452	36	0.014*	
	MPAI	2.150	30	0.032*	
1-2 Baseline period	CIM	0.884	10	0.377	No significant change on primary or secondary measures
	UKFIMFAM	0 ²⁵	36	1	
	MPAI	0	30	1	
4-5 Non- intervention period	CIM	0.816	10	0.414	No significant change on the primary measure. Significant change on both secondary measures.
	UKFIMFAM	2.333	36	0.02*	
	MPAI	2.333	30	0.02*	

* Significant at $p \leq 0.05$

** Significant at $p \leq 0.01$

The analysis demonstrates a significant change on the primary outcome measure during the whole intervention (outcome points 2 to 4). During Intervention 1 (outcome points 2 to 3) there is a significant negative change on the CIM and during Intervention 2 (outcome points 3 to 4) there is a significant positive change. These significant

²⁵ The Z score of 0 and corresponding p value of 1 indicates that the sum of the negative ranks equals the sum of the positive ranks between the two outcome points.

changes are both related to a single very low score at the end of Intervention 1 (outcome point 3).

Analysis of the secondary measures does not show significant change on the UKFIMFAM across the whole intervention (outcome points 2 to 4), but does show significant change on the MPAI over the same period. If broken down to the separate intervention stages, there is not a significant gain on the UK FIM FAM during Intervention 1 (outcome points 2 to 3) but there is during Intervention 2 (outcome points 3 to 4). The same pattern is true for the MPAI with no significant gain during Intervention 1 (outcome points 2 to 3) but a significant gain during Intervention 2 (outcome points 3 to 4).

There is no significant change on any of the measures between the two baseline points (outcome points 1 to 2), indicating a stable baseline period. There is not a significant change on the primary measure during the non-intervention period (outcome points 4 to 5). There is a significant positive change on both the secondary measures during the non-intervention period (outcome points 4 to 5) indicating ongoing gains in function during this time.

Correlation was measured between the total scores on all measures at the five outcome points using Spearman's Rho correlation co-efficient. This showed that there was not a significant correlation between the secondary measures, the UKFIMFAM and MPAI ($r = 0.667$, $p = 0.219$, $N = 5$). There was also no correlation between the primary measure (CIM) and the UKFIMFAM ($r = 0.872$, $p = 0.054$, $N = 5$), or between the CIM and the MPAI ($r = 0.500$, $p = 0.392$, $N = 5$). As previously stated, five outcome points is a very small sample for looking at correlations and so it is useful to look at these in the context of the visual representation of the scores in Figures 22 and 23. From these graphs it is clear that the pattern of change on the primary measure (CIM) is very different from the pattern of the secondary measures which is consistent with the analysis of correlation reported. However, the pattern of change on the two secondary

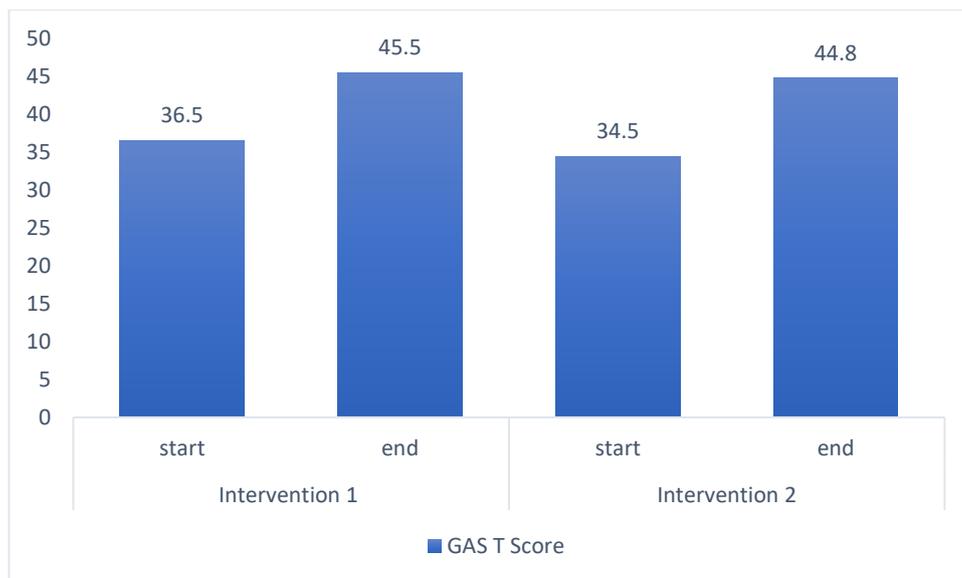
measures (UKFIMFAM and MPAI) looks similar and therefore the statistically non-significant result on the correlation analysis should be interpreted with caution.

Simon’s goal attainment is summarised in Table 29. This translates to GAS t-scores as presented in Figure 24. A GAS t-score between 40 and 60 indicates overall goal attainment based on a normal distribution.

Table 29: Simon summary of goal attainment

Intervention stage	Total goals set	Exceeded	Achieved	Partially achieved	Not achieved
1	5	0	2	2	1
2	6	0	4	2	0

Figure 24: Simon summary of GAS t-scores



11.15. Simon discussion of results

The outcome measures and analysis reported above demonstrate that Simon made significant gains on the primary outcome measure, indicating improved subjective feelings of integration, across the whole intervention period (outcome points 2 to 4). However, the pattern of scores on the primary measure is notable because of the significant low score at the end of Intervention 1. This score needs to be explored in more detail to understand the potential reasons for this. The first consideration is

whether Simon was able to understand the measure and provide responses that reflect his feelings. The measure was explained to Simon prior to each administration and the concepts contained in the measure were briefly explored to check that Simon understood them. He was able to provide comments that indicated he did understand the concepts, for example, at the end of Intervention 2, he explained that he considered the '*community*' to be the area immediately surrounding the supported living flat and provided a number of local points of reference such as the shops he used and a pub he went to with his parents. He also generated potential activities that could be considered leisure or productive activity. The peer reviewer commented on the fact that Simon made statements during administration that indicated he was reflecting appropriately on his level of activity to rate the statements and that he also made comments that indicated he understood the concept of the scale and ratings. It is therefore reasonable to assume that the low score at the end of Intervention 1 (outcome point 3) was an accurate reflection of his feelings at the time.

The end of Intervention 1 outcome measures were completed during Simon's graded discharge period when he was living in his new property but still receiving support from the Intervention 1 team. Simon was highly anxious at this point and this may be reflected in his CIM score. This was consistent with previous transitions when he has demonstrated increased anxiety for a period whilst settling in. As described in Chapter 10, Simon's engagement with the structured risk assessment and rehabilitation programme in Intervention 1 was variable and towards the end of Intervention 1 he became frustrated by the time it was taking to identify a property and complete risk assessment. The incident, of alleged physical assault of another patient, and the increased supervision following this is likely to have contributed to an increase in Simon's agitation. The low score on the CIM at the end of Intervention 1, may therefore reflect Simon's levels of anxiety and agitation at the time of his move to the new property, combined with his frustration with the structured Intervention 1 programme.

If it is assumed, for the purposes of this discussion, that the low score was a reflection of these factors then it is important to reflect on whether Intervention 1 could have been shorter for Simon or whether he could have been supported to move straight to the community to reduce the number of transitions. The issue of identifying which patients will most benefit from transitional rehabilitation, and the timing of this rehabilitation, is discussed further in Chapter 13.

Overall, through the whole intervention period and considering the primary and secondary measures, Simon's outcomes can be seen as very positive, particularly given that the recommendation following his Level 1 rehabilitation had been that he was likely to need long-term residential care. Providing the study intervention to Simon was very challenging and at repeated points during the intervention he did not engage with the team and required an innovative design to his intervention, utilising support workers. One of the complexities of Simon's case was the need to regularly review his capacity to make the decision to move to his own flat, in light of his poor engagement and level of risk. To an observer, Simon often made unwise or unsafe decisions (e.g. to neglect his personal care), but this did not necessarily reflect a lack of capacity in this area. Based on conversations with Simon, his family and friends, the teams delivering both Intervention 1 and 2 took into account Simon's previous strong feelings about where he lived and also his premorbid patterns of behaviour. This is important to do and emphasised in the Mental Capacity Act (2005) but introduces a level of complexity for a rehabilitation team who also have to take a view about the extent to which a newly acquired cognitive impairment is impacting on these underlying values and beliefs. This issue will be discussed in more detail in Chapters 13 and 14 but, in Simon's case, this was very difficult for his parents to understand and this highlighted the need to support families and provide clear information about the process and decision making.

Simon's intervention for this study was unusual as it took place when he was three years post injury. Transitional rehabilitation is usually made available during the first

12-18 months after an injury and, depending on the way services are organised, this type of rehabilitation would not always be available to someone placed in a long-term environment. Simon's two intervention stages in this study lasted a total of 15 months and whilst the programme was not intensive for this time, an intervention of this length does require a significant resource. Simon's case is a single example but his positive outcome raises questions about how long-term placements are reviewed and what resource there should be for people to re-access rehabilitation services further post injury. In this specific case, Simon received his Level 1 rehabilitation whilst he still had a diagnosis of Post Traumatic Amnesia (PTA) and therefore could not engage well with the programme. For Simon, therefore, there was an argument for keeping the option of further rehabilitation open. However, there are practical and resource implications to this and so the point will be discussed in more detail in Chapter 13.

In summary, therefore Simon's case presents a different perspective from the others as it demonstrates how the rehabilitation intervention described in this study can be delivered to someone further post injury and who has a variable level of engagement with formal rehabilitation. The more general implications of this case will be discussed in Chapter 13, taking into account the context of the whole case series and the views of relative participants summarised in the next chapter.

11.16. Peer review of primary outcome measure

A randomly selected video of the primary outcome measure for each participant was reviewed by an experienced SLT. The peer reviewer was provided with a copy of the summary protocol from Clay (2015) as presented in Appendix 4. The peer review forms are provided in Appendix 11. The peer reviewer was blind to the point in the intervention that each measure was completed, although there would have been contextual information in the videos (e.g. location) and information in the participants narratives, that would have provided some information about the time points.

The peer reviewer concluded that, where adaptations had been made, or additional materials used they were appropriate to the communication needs of the participant. The peer reviewer also concluded that the use of adapted materials did not impact on the validity of the measure.

The reviewer raised one point of query, relating to Richard's video. There was an item on the CIM that Richard scored across two responses (always agree and sometimes agree) as he was unsure how he wanted to rate the statement. The peer reviewer queried whether the scoring for the measure allowed for scoring between two points and whether this affected the validity. As previously stated, the measure does not have a manual and it is therefore unclear how this type of response should be scored. In the particular example, Richard revisited the item at the end of the measure and clarified his answer (to sometimes agree) and therefore the standard scoring was used. The general issues raised about the use and administration of the CIM are discussed in more detail in Chapter 14.

11.17. Summary

This chapter has summarised the outcomes for each participant and identified some of the key points for discussion that relate to the individual cases. Chapter 12 summarises the themes generated from the interviews with relative participants (RPs) and Chapter 13 reviews the whole case series, taking into account the case specific issues presented in this chapter and the themes presented in Chapter 12.

12. Analysis of the relative participant interviews

The semi-structured interviews with Relative Participants (RP) were thematically analysed as described in section 5.9. The themes presented here were extracted by a member of the research team not involved in the intervention. The analysis of the interviews is reported in a separate study (Dennis, 2017 Forthcoming). The principal researcher for the current study reviewed the themes and identified areas where the supporting quotes related to elements of the rehabilitation pathway that were not part of the research intervention (e.g. related to acute provision). When such quotes were identified, they were left in if they supported a broader point or had an impact on how the research intervention should be planned, but were removed if they related to a single issue that was specific to that element of the pathway. For example, comments about the communication and discharge planning in the acute sector were retained as they had an impact on the information RP's had received at the start of the research intervention; whereas a specific comment about the role of a social worker from another organisation was removed.

The themes presented below are those presented in Dennis (2017, Forthcoming) with the adjustments described above to focus on the research intervention in the current study.

12.1. Themes from relative participant interviews

Five themes, with accompanying sub-themes, were identified in relation to the research questions and are shown in Table 30.

Table 30: Themes from the relative participant interviews

Theme	Sub Themes
1.Perceptions of Intervention	1.1 Satisfaction 1.2 Amount 1.3 Staff skill 1.4 Managing participant behaviour 1.5 Welfare benefits
2.Perception of Support	2.1 Staff rapport 2.2 Staff availability and accessibility 2.3 Provision of RP support for participants 2.2 Communication
3.Perceptions of Organisation and Timing	3.1 Discharge 3.2 Reliability of outpatient appointments
4.Perceptions of Environment	4.1 Location 4.2 Atmosphere 4.3 Facilities
5. Perceptions of Transition	5.1 Independence 5.2 Community integration

Theme 1: Perceptions of intervention

Sub-theme 1.1: Satisfaction

A sense of general RP satisfaction with the rehabilitation programme provided is evident in the data (1), (2). Negative comments are generally restricted to: perceived paucity of provision (see sub-theme 1.2 Amount), individual staff members (see sub-theme 1.3 Staff skill) or services in the pathway outside the research intervention (3).

- 1) *The care was.... seemed to be thorough and all aspects of his problems were being considered. I really personally wouldn't have had any complaints [laughs].... I'm not just paying lip service. It was just genuinely it seemed to work you now, he went through the process and at the end of it he was looked after, given the services he needed, and housed. I mean, brilliant, yeah, back into the community so, good (RP1).*
- 2) *I mean there've been hiccups... but, but erm, as far as the rehab and being here [the Transitional Unit], we've been very, very happy with the way he's been treated, with such encouragement and respect and yeah. So we're very, very grateful to the NHS, I can't tell you how grateful, yeah. (RP2)*
- 3) *I had a lot of respect for [the specialist nursing home]. I think they did a significantly better job at rehabbing than [the Level 1 unit] did. (RP4)*

Sub-theme 1.2: Amount

A common perception is the insufficiency of particular interventions and services. For example, one RP reported feeling such consternation with the lack of speech and language provision that they resorted to investigating private services (4). Lack of continued intervention in the community is a prominent theme (5), (6).

- 4) *Erm the speech and language component of his daily living was erm you know intermittent... I can't say it was bad, it just didn't appear to happen very frequently... The reality is [Richard's sister] took the bull by the horns and started... talking to private practitioners in speech and language. And her attitude was well, "just as I have to buy my healthcare in [locations], you know maybe we've just got to, you know, bite the bullet and invest, you know, in Richard because this is his future"...(RP4)*
- 5) *I think the inpatient [Transitional Unit] was better. I think the community component of it is definitely needing reviewing. It was fairly thin, very thin on the ground. (RP4)*
- 6) *The assumption.... and we were led to believe that he'd get on-going psychology [in the community]. That didn't happen. That did not happen at all. (RP4)*

Negative experiences of the quality and availability of the Local Authority support are common (7). One participant is critical of the support offered by social services generally and particularly in relation to the withdrawal of her son's brain injury support worker (8).

- 7) *I mean [Locality] social service are, for want of a better word, as useful as a chocolate teapot. (RP4)*
- 8) *The social worker made, and has made a contact around Christmas time recently. Interviewer: And so that's over a year after the initial discharge from the [Transitional Unit]? RP4: Yeah. They are literally not available.... Because on one occasion Richard's key worker from [the brain injury charity] was clearly saying, "I am going to finish on Friday, that is it, I will not be here any more, and like you've... got to make representations". (RP4)*

Sub-theme 1.3: Staff skill

RPs are generally very complimentary of the skill and ability of staff encountered (9), (10), (11). Criticism of staff generally relates generally to perceived lack of rapport, communication style or irritation concerning discrete issues (see theme 2 Perceptions of Support). However, one RP reports concerns over rehabilitation being delivered by assistants due to perceived lack of skill (12).

- 9) *RP 2: The team [at the Transitional Unit] were really... great. RP3: No the team were great, really great. (RP 2 and RP3)*
- 10) *[neurologist]... I think he's quite intuitive and he's also skilful (RP4)*
- 11) *There were several staff here [The Transitional Unit], you know, and it was often some of the assistants who were really good, really really supportive. (RP4)*
- 12) *The delivery with a rehab assistant.... I don't think it worked in this for instance, and I don't think it worked because it was delivered by somebody who perhaps didn't have that rapport and skill and the communication ability you know? (RP4)*

Sub-theme 1.4: Managing participant behaviour

RPs are knowledgeable about the triggers for their relative or friends challenging behaviour. There is a perception in the interviews that newly encountered staff may not understand these triggers (13). One participant reflected on which types of response they considered to be the most effective (14).

- 13) *And I knew the transitional period going there [community] was going to be quite difficult for him because he was so determined to be independent that he, if people did things incorrectly, I knew he was quite aggressive (RP1)*
- 14) *He had several outbursts here [the Transitional Unit] you know that were not, that were managed.... That was the one issue, is that when he was here, when erm when Richard became assertive and aggressive and was losing it with [OT] or, erm you know because I think he did a few throwing the door into the door frame a few times. Erm, if there was every erm, come back. Because I think you know that sort of makes people a bit nervous, makes staff a bit nervous. (RP4)*

Sub-theme 1.5: Welfare benefits

Lack of understanding of, and subsequent inability to support participants in relation to, the welfare benefits system is also a recurring theme (15). In one case, this reportedly led to significant stress for both the participant and RP (16).

- 15) *Interviewer: So that was a challenge initially on the [The Transitional Unit], the delay supporting Simon to get benefits? RP6: Yeah. (RP6)*
- 16) *Now that was one thing that was really really irritating when he was in [the Transitional Unit] and it was extremely irritating for the simple reason that his key worker.... Because he kept saying, "I want to know what my benefits are. I want to do my benefits". Now I'd explained to [his key worker], as I had at the team meetings, look from the word go when it was immediately almost after he had his injury, I had contact with DwP... I then said, "This is how it is, I'm his appointee.... He will be paid the employment support allowance but he won't get the PIP, he won't get it because he's in an institution". It was almost as if Richard had said, "Well if you don't help me do it". That's my only impression is that he must have*

made it difficult, or they thought that it was straightforward and he should have access to all that information. He had a file in his room with the benefits he was entitled to. They weren't being paid. A, I had explained it initially and B the information was available in his folders in a bookcase in his room. He didn't always remember where it was but [his key worker] should have known that.... Richard himself became more and more frustrated because he kept thinking that he was getting all of these benefits..... What I'm very carefully trying to sort of say look, maybe you didn't understand, maybe this wasn't something you did with any intention, but the effect is a lot of stress. It's a lot of stress to me because Richard questions it and when he questions it, he then gets himself in a state...

Theme 2: Perceptions of support

Generally, RPs report good levels of support, both for their relative and themselves (17) and report feeling listened to (18). RPs reported valuing support to help manage their own emotional response (19), (20). However once participants return home, lack of long term support is identified as a concern (21), (22).

17) *We really have been very, very happy and overwhelmed by the amount of encouragement and support that we've received throughout the whole journey. (RP1)*

18) *It was really the [The Transitional Unit] who contacted [The Neurologist] saying they really, the parents and the family really think there's something wrong there and [The neurologist] got him into the [Specialist Hospital]. (RP2)*

19) *The combination of having to process it intellectually and to try and understand it and to actually know what the feelings felt like, it was quite significant and I think, certainly, at [the specialist nursing home] the psychologist was, I think, slightly [observational] of myself...When he came here [The Transitional Unit], the psychologist here was also spending time with me as well as Richard. I think that was helpful, I think that was quite helpful. (RP4)*

20) *When I was being upset, when I was in the establishment [The Transitional Unit], I think there were certain people who could deal with that easily. (RP4)*

21) *Interviewer: And so he's home, so the on-going level of support that he has now? How are you finding that? RP4: I think I provide it. I think that's it. (RP4)*

22) *Most of the stuff has been up to yourself and [the AHP Consultant], that's sorted things out. But that's vanished, we've got nobody, this [social worker] we never hear hide nor hair from him. Whereas from [the AHP Consultant], I mean every two or three weeks we'd hear from her how things was going this that and t'other, but we don't hear nothing now. (RP5)*

Sub-theme 2.1: Staff rapport

There were many positive comments about the personal qualities of staff and staff rapport. Participants clearly value empathy (23), (24), patience and friendliness (25).

However, this was balanced by reports of occasional incidents of insensitivity that left a long-lasting impression (26).

- 23) *What I think what was more curious was the professional boundaries and remoteness that people, some of the professional staff here [The Transitional Unit] had. And I'm not saying the nursing staff were particularly different. In the main, I think they were more human for a want of a better.... I can't describe it any other way, I think they were more intuitive about their emotional involvement. (RP4)*
- 24) *There was a couple of professionals who I think probably they have their professional boundaries and often that doesn't allow them to be particularly empathetic. [Empathy was] highly variable. Very often it was totally fine. (RP4)*
- 25) *In the main the nursing staff [at the Transitional Unit] were really friendly. (RP4)*
- 26) *Now Richard's injury was massive and one of the things that you know at the time stood out like, I don't know, almost like a flashing beacon was the specialist nurse at the [Acute Hospital], took us all aside one day and just kept repeating, "He's had a massive head injury, a very severe head injury". Well, I think [that is] the last thing you need. (RP4)*

Sub -theme 2.2: Staff availability and accessibility

Reports of staff availability and accessibility are variable (27), (28), (29), (30). A strong theme is RPs reliance on the AHP Consultant as a consistent point of contact during their relative's time in the Transitional Unit and following discharge, which is valued (31).

- 27) *We liked the people [on the Transitional Unit], and they were always available when we have a question (RP 3)*
- 28) *In the main, the staffing here [the Transitional Unit], erm particularly in the office, always appeared to be accessible, I would say. (RP4)*
- 29) *The staffing erm the key worker [on the Transitional Unit] was easily identified but was not always available. (RP4)*
- 30) *The managers at [the specialist Nursing Home] were very accessible they were more accessible than they are here [the Transitional Unit]. (RP4)*
- 31) *If I felt that I hadn't had [the AHP Consultant] to go back to. Because [the AHP Consultant] was much more fundamentally important. (RP4)*

Sub-theme 2.3: Provision of RP support to participants

It is clear from the data that RPs felt responsible for supporting their relative as much as possible and were relieved to be able to fill in the perceived gaps in professional

support during the rehabilitation programme for example regarding emotional support (32), activities of daily living (33),(34) and functional support (35).

32) *I think if he had not had a sister who was Skyping him from [location] on almost a daily basis and chivvying him along, I think we wouldn't be where we are today. (RP4)*

33) *Had we not been around, I seriously don't know what he would have eaten. (RP3)*

34) *And partly to do with the activities of daily living the showering, the you know, self-preservation, doing your laundry, doing your shopping, the planning of all these activities. That's where I still took on the role of doing the planning with him about what he was going to prepare for meals. (RP4)*

35) *I mean I, I've, I help him with certain things that he can show me when I go and see him. He can show me what it is he doesn't understand and then we go through it together and I can sort of point him in the right direction. (RP1)*

Sub-theme 2.2: Communication

Many of the negative experiences RPs report centre around lack of communication from staff (36). For example, RP5 and RP6 report they received very little information about their son's prognosis, making it hard to plan for the future (37). Confusion, and lack of information, around discharge destination was also common (38). Once living in the community, RP 5 and RP6 report not receiving sufficient information from staff at their son's SLS and having to battle for information (39), (40). However, RPs generally report good understanding of how to access services and information (41) and appropriate provision of relevant contact details on discharge from the Transitional Unit (42).

36) *Communication is the big issue about all of the erm... any of the problems that have occurred I think. (RP4)*

37) *See we would like to know what the future holds for Simon. What his improvement will be, if any. I mean there's gotta be people about that have an idea. Cos we're getting rid of stuff and he might want it next week. You know what I mean?... we'd like to have an idea what's going to happen in the future, or if he's going to be virtually, with slight improvements, in the same state that he's in now. (RP5)*

38) *That was definitely a rushed job [moving to the SLS], because he was going to [alternative SLS] and then, "Oh we can't send him there". (RP5)*

39) *Well they only tell us if there's anything important. And sometimes not even then, the last time he had to go to hospital it wasn't until [unclear] I found out that he'd gone. RP6: Simon rang us. I'd rung Simon and there was no answer, to see if he was alright. And then he rang*

me back later to say he was in hospital. They hadn't...they said, made some excuse up here [SLS] didn't they? (RP5 and RP6)

40) All's we want is some... the information passing onto us, if and when necessary and er so as we can do with it as well. (RP5)

*41) Interviewer: And you're aware of how you can access services and information on-going?
RP1: Yeah, yes, yeah. It's all been really clear. (RP1)*

42) We had a plan, I think it was a written plan... [and a list] of phone numbers (RP4)

RP reports of consultation on decisions and options regarding care are highly variable. Some RPs report not being involved in planning (43), whereas others state that they were consulted (44). Satisfaction regarding consultation appears to depend on RP expectations (45). Lack of understanding by RPs of certain decisions and approaches can also lead to RP frustration. For example, understanding the role of the staff in the supported living unit and their power to enforce certain behaviours (46).

43) Interviewer: And was the transition from there [Transitional Unit] to here [community] supported? W: Well with [the AHP Consultant] sorted it all out, but we didn't have any say in it did we? (RP5)

44) Interviewer: And you were consulted about goals and discharge planning? RP1: Yes, yeah. (RP1)

45) But then again, I mean but then again, I mean we're 150 mile away you know we don't expect to be here every step. (RP5)

46) I can't see why they can't say, "Simon come on put them in a bag we'll take these downstairs and put them in the whatsit" [referring to removal of rubbish] (RP6)

RP's generally report being satisfied with the provision and delivery of information to their relative (47), (48).

47) You know I think everything was really explained to him (RP1)

48) Billy had his calendar and everyone was quite thorough in, you know, obviously his understanding, it was important to visualise, you know, the things, so it was very clear for all of us to see. Anyone who came to see him knew what was going on and when. (RP1)

One RP reported paucity of advice in relation to their relative as something that confounded their anxieties around his safety (49).

49) *I'm pleased in a way that he's got back on his bike. But we've had nobody saying, "You ought to let him have his bike", if you understand what I mean. (RP6)*

Theme 3: Perceptions of organisation and timing

Sub-theme 3.1: Discharge

Some RPs raised concerns about transfers between different units as their relative progressed through the programme. The identified issues included: uncertainty regarding timing (50); significant delays or rushed transfers (51); and a lack of clarity about which service their relative was being transferred to (52).

50) *The date was a bit of a moving feast, erm it got put back once or twice because the place here did not, [the Transitional Unit], did not open on that specified date, so we were, it's a bit like....the uncertainty of that is, can be slightly off putting. (RP4)*

51) *You know there was a bit of... a few delays with, you know, a few delays with getting the flat ready. There was a few delays from the hospital coming to here [the Transitional Unit] to get this place ready because it was brand new and I think there was a bit of delay. (RP1)*

52) *RP5: [moving to the Transitional Unit] was sort of a rushed thing wasn't it? To get to er [the Transitional Unit]. And the same when he come here [community], that was definitely a rushed job, because he was going to [SLS] and then, "Oh we can't send him there". (RP5)*

Once the location was settled, relatives generally found the organisation of the transfer smooth and efficient (53), (54). No issues were reported with waiting times for equipment or services.

53) *It was possibly as straightforward as it could be, within the bounds of the fact that erm [the AHP Consultant] was clearly juggling the actual opening of here [the Transitional Unit] so the transition to here was fairly OK, I think.... [the specialist nursing home] being in [location] to here, and being a non-NHS facility, was erm fairly straightforward from the professionals' point of view, I think the handover was quite good... so the discharge from [specialist nursing home] to here was fairly structured. (RP4)*

54) *But the organisation of it [the transfer to the Transitional Unit] was fine very, very good. (RP3)*

Sub-theme 3.2: Reliability of outpatient appointments

Concern over reliability and timing of outpatient appointments in the community was a common theme (55), (56).

55) *The OT who came to visit him from the community trust. I've observed a couple of her visits. They were not always on time. (RP4)*

56) *It was always really difficult to know when Billy had concerns or issues because of his communication.... skills. And erm, later on for example, when he eventually got housed in his own flat he was upset about some things and, you know, it was very difficult to understand whether it was him and his difficulty in accepting erm.... changes that people had to make to appointments or whether people weren't turning up for appointments. It was always really quite difficult to work out whether he was justified in his.... He insinuated to me ... appointments weren't always kept, but when I spoke to other people, it was that, you know, it was always explained to him. (RP1)*

Theme 4: Perceptions of Environment

Sub-theme 4.1: Location

A common theme is RPs discussion of the location, and relative convenience, of care settings, particularly the Transitional Unit. RPs value proximity and subsequent ease of visitation (57), (58). RPs also reflect on the advantage of their relative or friend being treated in their local community and, therefore, near their social network (59) (60).

57) *And easy for us to visit, easy for him to have day release every now and then at the weekend, it worked out very, very well. (RP3)*

58) *Allowing him to go, to take him, out for dinner around the corner to [unclear] all of that sort of stuff, all those things worked really well. And we kept saying to each other you know I wonder why we ever felt that this [specialist vocational placement] would be the place for him because it would have been so awkward, but we were thinking that when we were talking about it that this is the sort of thing for Nathan, it wouldn't have, this worked much better. (RP3)*

59) *RP2: It was no contest as far as Nathan was concerned.*

RP3: He wanted to be here.

RP2: He wanted to be as close to his flat and he has a lot of friends in this area as well so he didn't want to be shipped off down to [the specialist vocational placement]...

RP3: No he really didn't. (RP2 and RP3)

60) *His friends could come they took him out... [they] knew where he was it was easy. (RP2)*

Sub-theme 4.2 Atmosphere

The nature of the Transitional Units hospital-style environment is a recurring theme, leading one RP to describe the atmosphere as frightening (61), (62), (63). However, RPs generally perceived that their relative was happy at the Transitional Unit (64).

61) *It's also quite frightening. Quite a few of my son's friends used to have to really take a huge deep breath before they could come in the door. (RP4)*

62) *I mean, it is still very much a ward scenario. It is within a nursing home. (RP4)*

63) *RP5: I think it was a bit more, come and go as you please like this place is now like you know? Whereas [the Transitional Unit] it was sort of you've gotta ask permission to open the door. You've gotta have someone open the door for you to get out. RP6: It's more like an hospital really wasn't it, [the Transitional Unit]? (RP5 and RP6)*

64) *He was perfectly happy coming back here [The Transitional Unit] on a Monday morning and getting back to the routine. (RP3).*

Sub-theme 4.3: Facilities

Food provision (65), the kitchen (66) and laundry services (67) on the Transitional Unit attracted criticism.

65) *Big complaint about the food to be perfectly honest. (RP2)*

66) *Particularly for ADL, activities of daily living, the kitchen here [the Transitional Unit] was not particularly well equipped... it's a very communal kitchen there. Everybody from the staff who make themselves a coffee to you know people having their meals or, and then in that environment to try and get somebody who's had a head injury to create a meal, or do some cooking, is, I think, a little bit erm not that realistic. (RP4)*

67) *The other thing with here [the Transitional Unit] is [the laundry facilities], as it was at [the Level 1 unit], they sort of said, "Oh you know we've got a like a you know a washing facility so you don't have to cart all the...". You know..... there were obviously times.... I was carting it 50 miles on a train you know.... (RP4)*

Theme 5: Perceptions of transition

Generally, RPs perceived transitional process as successful (68) and appropriately gradual (69). However, one RP viewed the change from the Transitional Unit to the community to be too great (70) and suggested participants should be encouraged to be more self-reliant whilst on the Transitional Unit to prepare them for home. There is

evidence of good continuity between separate units in the pathway, which is valued, particularly in relation to neurology (71), (72).

- 68) *I just felt he was happier, he'd, you know. He was ready for here [the Transitional Unit] so this was a really good transitional place for him. You know, it was good. It was a good experience. (RP1)*
- 69) *Interviewer: And was the transition to home supported? RP2: Erm, yeah. RP3: Yes, they started it gradually, there was a... he could have one night at the weekend, then two nights and so on and then the whole weekend and it all went very well. (RP2 and RP3)*
- 70) *Here [the Transitional Unit], Richard could just walk down the corridor and one of the rehab assistants would put a lunch out for him or a dinner out. It was instantly available. Interviewer: So the jump to home felt a very large one from here? RP4: It was quite substantial. (RP4)*
- 71) *RP2: I remember saying to [Neurologist 1], "Is there a neurologist at the [the Transitional Unit]?" and he said, "yes" and I said, "OK who is it?" and he says, "It's a [neurologist 1]" (laughs). So I was really pleased to hear that. Interviewer: So you can be assured there was a seamless (laughs)] RP3: Continuity, absolutely. (RP2 and RP3)*
- 72) *One of the things I felt benefitted Richard was being able to follow up with [neurologist 1] I thought was very very helpful. Interviewer: That was a helpful thing? RP4: That was helpful (RP4)*

RP's perceptions of their relative or friend's readiness for change vary. Some reflect that their relative found adjustment anxiety provoking and stressful (73) due to difficulties coping with change (74). Whereas others perceived their relative to be ready to move forward (75), (76). Some RPs reported their relative/ friend struggled to adjust to independent living, in part, because of established reliance on staff at the Transitional Unit (77). Tension between eagerness to move through the process and anxiety about change is tangible for both RPs (78) and participants (79).

- 73) *He was quite anxious and I stayed with him for a one night I think and I then basically went home because you know you just literally have to make a break at some point. (RP4)*
- 74) *I knew it was quite a stressful time for Billy because... you know, it's like from each stage it takes a while for all the staff to get used to his ways and his personality and his particular frustrations and how he deals with things.... I was contacted quite frequently by the team there [SLS] because they didn't know how to deal with him and he was difficult at times. (RP1)*
- 75) *He was ready to come he'd, you know, there'd been a bit of a delay, but he was, he was, we were happy. He was really glad to move on to the next stage. (RP1)*
- 76) *RP2: But he's happy to have... He wants the place back to himself. RP3: Oh he does. He's ready. Yeah. RP2: He wants to be living his own life and he wants to be picking up the threads of it all. (RP2 and RP3)*

77) *But every time he had to have something printed off, and I physically couldn't print it off and bring it into him, he would come down here [the Transitional Unit] and I say, "I'm emailing you, can you print it off?" So I think he still felt that he could come in here without any reservations. Interviewer: So he'd visit the Transitional Unit for a long period after he went home for support? RP4: He visited for a while. (RP4)*

78) *The nurse manager for this particular unit, she was... she kept being extremely positive and I suppose we were still at the point of anxiety erm, questioning how well Richard would do. (RP4)*

79) *He was I think excited to be in a new environment but frightened. (RP4)*

Sub-theme 5.1: Independence

The importance of independence and promotion of independence was a strong theme (80), (81). Some RPs reported wanting staff to push their relatives harder to regain independence (82), (83). However, there is evidence of independence being encouraged on the Transitional Unit (84). And one RP reported valuing encouragement from staff to step back and give their relative space to develop more independence (85).

80) *And so he could see that he had managed a certain level of independence and... a life that was different to the one he had before but was still a fairly independent living (RP4)*

81) *There was a bit more of a level of privacy and independence here [the Transitional Unit] for him. So you know he had his own bathroom, which was really important. (RP1)*

82) *And they [the specialist nursing home] were prepared to take risks that perhaps here [the Transitional Unit] was not prepared to take, even though we were three months further along the line. (RP4)*

83) *Cos he used to [fend] for himself when he was, before he had his accident. He used to have to look after himself like but er, so, it's not being forced on him enough. (RP5)*

84) *RP3: He's still on medication er and he now collects all that himself from the chemist, which is just round the corner. Which was instituted when he was here.*

Interviewer: So that was set up by the [Transitional Unit]?

RP3: Yeah, yeah, so gets, does that himself now. (RP3)

85) *[OT] was saying... from the [Community Team] perspective, that it was probably time we backed off.... That was beneficial because I don't know on our own, whether we would have done that quite so early, and we really had to we've got a life by ourselves (laughs)... I think that was very helpful. (RP2)*

Some RPs reported feeling worried about their relative or friend living safely in the community, given their changed ability, personality and insight (86), (87). Similarly, RPs

had concerns over their relatives' ability to cope in the community due to issues such as personal hygiene (88), hoarding (89) and emotional control (90).

86) *But I mean Saturday he went out on his own, nobody. I don't know how (laughs) much he'd stop the traffic or what I don't know. RP6: It's a bit of a worry really.... RP5: Well I don't want him to be knocked off his bike again you see? That's the main thing. I mean... RP6: His safety really is the main thing, not him going out. (RP5 and RP6)*

87) *Well he's been out with us a few times when we went to [the pub] more or less across the main road. But he says, "Well I just come here and cross the road. I'm not using the crossings".... those sort of things that's what makes us uneasy about him going out in the traffic on his own. (RP5)*

88) *Well the next thing is his hygiene I've got to work on I think but he does go nasty if you mention it. Like today like I asked him something about his jumper... RP5: At times we was taking him out and he absolutely stunk, didn't he? RP6: Yeah it's embarrassing really to take him anywhere. (RP5 and RP6)*

89) *One time we went, I think it was about two month ago, he'd got about 20 of his meal boxes, you know the boxes they get with the meal in, empty. And milk bottles and everything else all stacked there. (RP6)*

90) *So I went off one day when I was clearly feeling Richard was being angry, upset, not able to cope. (RP4)*

Sub-theme 5.2: community integration

RPs generally perceive community integration (91) and involvement of their friend or relative in groups and social activities as valuable (92), (93). One RP, however, questions whether community integration is a realistic aim in a setting like the Transitional Unit (94).

91) *[At the specialist nursing home] I was able to take him into town and he was able to interact with... more of a community spirited town in [location]. I suppose here [the Transitional Unit] is just, you know, a high-density population and people are just doing their own thing. (RP4)*

92) *He does one day of wood work with them, which is on-going they don't appear to... nobody's pulled the plug on that one. He gets a lot of support from that [which has been] extremely valuable. (RP4)*

93) *The more he goes out the better cos I think his brain's gone stagnant since he was here [community] because he wouldn't associate with anybody and he's just kind of in his flat all the time apart from seeing the staff. (RP6)*

94) *And in a sense, erm.... trying to get people to intervene in the wider community, which was the alleged aim, or the alleged goal, erm. The outcome for that I think will never be achieved in a place like this. (RP4)*

One issue that emerges concerns the number of opportunities participants were given to go out into the community whilst on the Transitional Unit (95). Opportunities for social activities appear to become more prevalent once the participant is living back in the community (96).

95) He only went out when we went out. (RP5)

96) The group that come and take him out, that group were involved and he started getting involved in some social groups, the gym etc. (RP1)

RPs reflect on how their relative or friend's social integration and relationships have been affected by the ABI. Friends are reported to be a source of support to the person with ABI (97) but also to struggle to adjust to the participants' changed abilities (98).

97) Friends were still coming to him even when he was here [the Transitional Unit]. A few of his friends visited quite regularly so he felt supported. (RP4)

98) People have withdrawn, some of his friends have stepped back. Many of his friends have been amazing. While he was still here [the Transitional Unit] he was best man at a wedding, well he was a groomsman. He's been to [location], he's been to... on a few stag dos. So other people support him, they have not necessarily always had a really firm understanding, but he is still their mate. You know, he's got a big circle of friends, some of whom still are very supportive. So, you know, that's, they work they're young males you know young guys who are married now and I'm sure that will drift off because they will have families, wives, children. (RP4)

12.2. Summary

The themes presented above from Dennis (2017 Forthcoming) highlight the key issues that emerged from the RP interviews. In the next chapter, these themes will be considered, along with the points for discussion identified in the individual case studies, in the context of the whole case series.

13. Review of the case series results and analysis

The individual case studies presented in Chapters 6 to 10 provide examples of how the research intervention was adapted and individualised for each participant. The analysis and discussion in Chapter 11 explored whether the intervention was successfully implemented for each participant and whether the projected outcomes were achieved. The themes emerging from the relative participant interviews provide an additional valuable source of information about both the intervention and individual outcomes. In this chapter, all of the information presented so far will be reviewed against the original research hypotheses to draw out further important points in the evaluation of the research intervention. The discussion in this chapter will focus on the study participants; the next chapter (14) will place these findings in the context of the literature in this field.

13.1. Review of the outcomes against the research hypotheses

The following is a summary of the results tested against the research hypotheses set. The hypotheses set were supported by the theoretical framework that informed the design of the intervention. Reviewing the outcomes against these is useful therefore, to identify aspects of the intervention that were successful as well as areas for learning and improvement.

- Hypothesis 1: There will be significant change on all outcome measures across the whole intervention measured from the repeated baseline to the end of Intervention 2 (outcome points 2 to 4) indicating improved subjective report of community integration and improved function.

Hypothesis 1 was not supported by the study results as no single participant demonstrated significant change on all three measures through the whole intervention.

On the primary outcome measure (CIM), one participant (Simon) demonstrated significant positive change on the whole intervention (outcome points 2 to 4). In all

other cases, the changes on the primary outcome measure were not significant over this period. Louise demonstrated a trend of improving scores on the primary measure from outcome point 2 to 4, but this was not statistically significant. In the remaining three cases (Billy, Richard and Nathan) there was not a trend of improvement on this measure.

On the secondary measures, all five participants made statistically significant gains on the one measure (MPAI) across the whole intervention (outcome points 2 to 4). Only three out of five participants (Billy, Richard and Nathan) demonstrated significant change on the other (UKFIMFAM) over the same period. Of the remaining two participants, Louise again demonstrated a trend of improvement on this measure (UKFIMFAM) but this was not significant, Simon's scores improved overall but with a dip in score at the end of Intervention 1.

The key point to note from the review of hypothesis 1 is the lack of significant change over the course of the intervention on the primary outcome measure, which explores subjective reports of community integration, for all participants except for Simon. Participant specific reasons for this were explored in Chapter 11 but the general lack of change on this measure across the group needs to be further examined. One explanation for this could be that the intervention was not successful in increasing subjective feelings of integration in the participants. As noted in Chapter 11, the narrative captured in the videos of administration of the primary measure (CIM) gives some information to inform this and the participants also identified some sources of frustration throughout the intervention as noted in the case studies. There is scope to explore this feedback further to inform development of the study intervention and other similar services targeting community integration. However, given the points raised in Chapter 11 it is also important to consider whether the results are a true reflection of the participants feelings of integration and whether the measure was the correct one to use with this participant group. This is discussed further in section 13.2.3.

- Hypothesis 2: There will be no significant change on the primary or secondary outcome measures during the baseline period (outcome points 1 to 2)

This hypothesis was largely supported by the results as four of the five participants (Billy, Richard, Nathan and Simon) had stable baseline periods (outcome points 1 to 2) on all three measures (CIM, UKFIMFAM and MPAI). The remaining participant (Louise) had stable scores on the secondary measures during this baseline period, but demonstrated significant positive change on the primary measure (CIM). As discussed in section 11.12, there is evidence from the case study that level of anxiety may have contributed to this change on the primary measure for Louise.

It is reasonable therefore to state that the participants demonstrated a short stable period at the beginning of the intervention in terms of their level of function and that with one exception, they also had stable self-report of community integration during this period. This is important to the overall review of the intervention as a stable baseline period helps to isolate any effect of the intervention as part of an experimental approach to case study research.

- Hypothesis 3: There will be a pattern of greatest change on the secondary outcome measures during Intervention 1 (outcome points 2 to 3) when impairments and independence in function are being targeted.

This hypothesis is not supported as there was not a clear pattern on the secondary measures across all participants. The five participants all demonstrated different patterns of change and the individual reasons for this are discussed in Chapter 11.

The theoretical basis for this hypothesis was that as Intervention 1 was delivered in a structured inpatient environment, participant goals would be more likely to target ongoing improvement in function in personal and domestic tasks and that this would be reflected in the secondary outcome measures. Whereas in Intervention 2, goals were

more likely to target increased community access and integration that the secondary measures would be less sensitive to.

In practice, there are two potential reasons that this pattern was not demonstrated in the case studies. The first is that although all five participants had goals during Intervention 1 that targeted specific areas of impairment and/ or function, two participants (Billy and Louise) continued to have goals in these areas into Intervention 2 either due to their level of physical impairment or because of personal priorities in goal setting. This reduced the clear difference between the nature of the intervention at each stage. Even for the three remaining cases (Richard, Nathan and Simon) where the Intervention 2 goals were more community focussed, there continued to be elements of goals that related to impairment and/ or function. For example, accessing social activities in the community may also have an impact on verbal and non-verbal communication skills.

The second point is that the secondary measures (UKFIMFAM and MPAI) are both sensitive to a wider range of changes, including some elements of community integration. The first measure (UKFIMFAM) does largely reflect level of independence in personal and domestic tasks but the cognitive and extended activities of daily living items have a broader focus. The second measure (MPAI) has specific subscales for participation and adjustment, which reflect some elements of community integration such as family relationships, social contact and access to leisure activities.

Overall, the lack of the hypothesised pattern of gains suggests that whilst the focus of rehabilitation does shift between Intervention 1 and 2, the stages are less discrete and more continuous for some people. It also suggests that individual needs and priorities rightly influence the nature of goals at both stages. It will be important to consider the results relating to this hypothesis when considering where in-patient and community resources should be targeted and this will be discussed further in Chapter 14.

- Hypothesis 4: There will be a pattern of greatest change on the primary outcome measure during Intervention 2 (outcome points 3 to 4) when participants return home.

This hypothesis was not supported by the results of the cases studies. Two participants (Billy and Simon) demonstrated significant improvement on the primary measure (CIM) during Intervention 2 only (outcome points 3 to 4) but this was in the context of very low CIM scores at outcome point 3 for both participants. For the remaining participants (Richard, Nathan and Louise) there were not significant gains on this measure in either intervention stage.

This hypothesis is clearly linked to hypothesis 3 and has the same theoretical basis, that is that the primary measure should be most sensitive to the areas targeted in Intervention 2. However, it also links to the discussion in the individual cases and relating to Hypothesis 1, about the potential reasons that four out of five participants in this study did not demonstrate significant change on the primary measure. As noted, the more general issue relating to the use of this measure will be discussed in Chapter 14.

- Hypothesis 5: There will be no significant change on the outcome measures during the non-intervention period (outcome points 4 to 5).

This hypothesis was only partially supported by the results of this study. The non-intervention period was stable for two participants (Nathan and Billy) on both the primary and secondary outcome measures. In two cases (Simon and Louise) there were ongoing functional gains on the secondary measures during the non-intervention period, but no change on the primary measure. For one participant (Richard) there was a deterioration in performance on one of the secondary measures (MPAI) but not on the other secondary measure (UKFIMFAM) or the primary measure. One of the core aims of the service is to provide an intervention that will support stable community

access and integration via the set-up of a consistent care package and a regular routine. The basis of hypothesising a stable non-intervention period is that the intervention would be sustainable enough to prevent immediate deterioration. Improvements in the non-intervention period may still be partly attributable to the intervention if the support workers are continuing to use the strategies provided. An alternative explanation could be that participants start to feel more settled and attend more social activities when formal rehabilitation is finished. In Richard's case, the deterioration may be related to the withdrawal of his support worker at this point but it is also important to consider the risk of deterioration when formal rehabilitation finishes and to identify any learning for clinical services.

- Hypothesis 6: There will be a significant correlation between the scores on the two secondary outcome measures which both reflect ability in function.

This hypothesis was partially supported as there was a statistically significant correlation between the secondary outcome measures in three cases (Richard, Nathan and Louise). In the remaining two cases (Billy and Simon) there was not a statistically significant correlation but there was a similar trend in scores noted on the outcome graphs. As identified in section 5.9 and in the individual analyses in Chapter 11, non-significant correlations need to be interpreted cautiously due to the small sample of five outcome points.

It was important to have objective secondary measures in place as the primary measure (CIM) was subjective. The two secondary measures (UKFIMFAM and MPAI) used were chosen so that the items included would cover the breadth of the areas identified in individual goals. The basis for this hypothesis was therefore that the two objective measures would demonstrate a similar pattern of improvement if the intervention was successful in targeting the goal areas. Both goal setting and related outcome measures will be discussed further in Chapter 14.

- Hypothesis 7: There will be no significant correlation between the scores on the primary outcome measure (CIM) and the secondary measures (UKFIMFAM and MPAI) as the primary measure is a subjective scale and will not necessarily reflect independence in function.

This hypothesis was supported in all five case studies. The basis for this hypothesis, as stated, is that the subjective measure will not necessarily be sensitive to the same areas as the objective measures. Again, there will be a more detailed review of the effectiveness of the outcome measures used in evaluating the intervention in Chapter 14.

- Hypothesis 8: All end-of-intervention standardised (t-scores) for Goal Attainment Scaling will fall within the standard deviation range of 40-60 for both intervention stages, demonstrating overall goal achievement.

This hypothesis was supported in the five case studies. The Goal Attainment Scaling end-of-intervention t-scores were all in range between 44 and 50. This range is within the standard deviation range of normally distributed scores (around a mean of 50) and indicates overall goal attainment. As Goal Attainment Scaling was used in the current study to provide a validity indicator (that the changes made reflected the goal areas) it supports the argument that the intervention contributed to the improvements in function noted. Goals achieved and not achieved will be discussed later in this chapter to identify some of the issues raised by non-achievement of specific goals.

13.1.1. Summary of the hypotheses review

In summary, therefore not all the initial research hypotheses were supported. Probably the most significant point is that the primary outcome measure did not show significant change over the whole intervention for four out of five participants. However, the fact that the changes in the secondary measures were largely significant and the consistent

goal attainment provides some evidence to support the premise that the intervention targeted goal areas effectively. There is a need to look in more detail at the potential benefits of the different intervention stages for different needs which is explored later in this chapter and Chapter 14.

13.2. Case series themes for discussion

A number of factors emerge from the case series and the relative participant interviews that need to be further explored. Some of these relate to general issues that apply to the design and delivery of the intervention for all participants, others are specific to a single participant but are relevant to discuss because they have implications for how the service can improve.

These points for discussion fall into three broad areas:

- Factors relating to individual participant presentation or circumstances
- Factors relating to the planning or implementation of the intervention
- Factors relating to the measurement of outcomes

13.2.1. Factors relating to individual participant presentations or circumstances

For the participants in the current study, the intervention was individualised to match specific injuries, impairments and support needs. The intervention was shaped around participant centred goals using Goal Attainment Scaling as described in section 4.2.

There were some common challenges to setting goals relating to management of anxiety and impaired insight.

For Simon, Billy and Louise, high levels of anxiety had an impact on their ability to engage with the rehabilitation programme, set goals and anticipate the next step in rehabilitation or independence. For Simon, Nathan and Richard, impaired insight into their levels of disability had an impact on their ability to engage with goal setting. The multidisciplinary teams in the current study intervention followed an approach based on supporting participants to identify key goal areas and negotiating from this point to a

SMART (Specific, Measurable, Achievable, Realistic and Time limited) goal. For those participants who were highly anxious, this negotiation often involved presenting evidence from previous points in the pathway when the participant had made progress through following a structured programme, or offering reassurance about the amount of support that would be available to help achieve a goal. For those patients who lacked insight, this negotiation involved presenting feedback about communications or behaviours to support participants to understand current challenges they would have living in the community. The team also used the Goal Attainment Scaling structure of identifying anticipated outcome and better or worse than anticipated outcomes to help make the goal setting process less abstract. The consistent attainment of goals across the case series can be seen to support the argument that the goals were set to an appropriate level and that the interventions were successful in supporting this attainment. However, two important factors need to be considered before assuming this is the case. The first is whether the high goal attainment actually indicates that the goals were set too low and were too easily achievable. There is some evidence that goals were not set too low in this study; the end-of-intervention t-scores were all in the range equal to or just below the mean, if goal attainment was set too low, it would be reasonable to expect some of the end-of-intervention t-scores to be above the mean. In addition, there were a number of goals where the level of attainment was just below the goal level set, or the participant demonstrated the goal behaviour on one or more occasions but not consistently enough to achieve the goal level. These examples support the argument that goal setting was appropriately ambitious. The second important factor to consider before assuming that goals are set appropriately is whether there is a risk that negotiated goals with a lot of professional involvement may fail to reflect the participants own priorities. This will be discussed with reference to the consensus in the literature in Chapter 14. In the current study, all participants returned to their stated preferred living situation and expressed satisfaction with this outcome at the end of the non-intervention period, supporting the argument that the goals were set

in line with participant priorities. There is also senior clinical support for the multidisciplinary teams to help them to negotiate goals whilst still ensuring they respect the individual's values and beliefs. As summarised in section 3.1, materials to support consistent goal negotiation have also been developed as part of the induction and in-service training resources. It is important that this level of care within goal setting continues and the risk associated with negotiating goals is acknowledged.

The relative participant interviews did not generate much specific information about the goal setting process. There were brief mentions that relative participants were consulted during goal setting (sub-theme 2.4) and a concern was raised about whether community integration was a realistic goal for a Transitional Unit environment (sub-theme 5.2). There was no specific prompt about involvement with goal-setting on the interview schedule and, for future research; this would be a useful area to explore in more detail.

For all participants, planning of the intervention needed to be individualised to reflect what was known about their previous choices, values, beliefs or abilities. In the cases in the current study, this had an impact on assessments that the team made about capacity to make a decision, as well as how the intervention was delivered and what level of goal achievement was set. For Simon, the knowledge provided by his friends and sister about the things that had been important to him prior to his brain injury, informed the teams' decision to support him to move to his own property in London. If his cognitive presentation had been the same but his pre-morbid identity had been less strongly associated with living in London, then the team may have recommended a different plan. There were clear risks associated with Simon living on his own in a large urban environment and the decision could therefore be seen as unwise by some. This issue is captured in the key principles of the Mental Capacity Act (2005) which provides a clear framework for assessment of capacity and making decisions on behalf of someone who lacks capacity. The Act has a number of core principles, one of which is

that there should always be an assumption of capacity, until an assessment has been completed. Another is that people have the right to make an unwise decision, and even if they also have a cognitive impairment, they may still have capacity to make the unwise decision, or it may still be in line with previous beliefs. Principle 4 of the Act states:

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

(MCA, 2005, page 1)

The intervention teams in the current study used a process of risk assessment, combined with collaborative goal setting, to enable Simon to make decisions and to achieve the living situation of his choosing, whilst also mitigating risk to Simon or others. This method allowed the team to achieve a balance between respecting Simon's right to make what might be seen as an unwise decision with the need to protect him from harm. The team have developed resources to support staff when assessing capacity and risk. These include standard capacity and risk assessment proformas as well as an example script to support staff who need to assess capacity to make a specific decision during an activity or situation, for example if a patient expresses a wish to leave the unit and go to the pub in the evening when there are fewer senior staff available. The issue of application of Mental Capacity Act assessment and principles is discussed further in Chapter 14.

The same principle of applying the participants' values and beliefs to the planning of goals and intervention was also relevant for the other participants, although the level of risk was not always as significant. An example is Nathan's decision not to access formal vocational rehabilitation despite the team's recommendation that this route would be the most likely to lead to successful return to work. Again, this highlights the need to balance risk and personal choice. At the beginning of Intervention 2, when this

issue arose, it was the team's assessment that Nathan's community placement was reasonably stable. His independence in domestic and community tasks was increasing and he had regular contact with friends. He had also accepted the input from the brain injury support workers, despite having originally felt he did not need this service. The team therefore concluded that, although an unstructured return to work was unlikely to be successful, the risk to Nathan of his community placement deteriorating if the return to work failed was reasonably low.

The themes from the relative participant interviews provide feedback that, whilst the process of balancing risk and choice was carefully managed by the multidisciplinary team, relatives did not feel fully supported to understand this approach. Simon's parents make a number of points in their interview that indicate they did not always understand why one supported living scheme was chosen over another (sub theme 3.1) or why Simon was being supported to gradually increase his independence in the community despite the level of risk identified (sub theme 5.1). It will be important to incorporate this feedback into the recommendations from this study, for example by adding more frequent family meetings or provision of written information or feedback.

Another related point was the need to ensure that goals and interventions are culturally relevant to participants. This was relevant in Louise's case where she identified the need to re-connect with her religious community as a priority for discharge from hospital. Again, this had an impact on supported living scheme choice, carer choice and provision of training. By planning Louise's intervention within her very supportive community, carers and support workers demonstrated an understanding of her emotional and spiritual needs as well as her physical needs. This issue of ensuring goals and support packages were culturally or socially relevant to participants was important in all cases. None of the other participants in this study had strong religious beliefs but they all identified elements of their previous lifestyles that were important to them as a core part of their cultural or social context and these elements had to be

considered in the design of the interventions and support packages. For example, in Billy's case he had always spent time in Central London and it was a priority to him to be able to continue to access this area. Transport in London is not always wheelchair accessible and so this was challenging. Billy's support programme was planned with this constraint in mind, to ensure that he had brain injury support workers who were confident to support Billy to use public transport and negotiate Central London during busy times. In Simon's case, his friends identified that it had been important to him to be politically aware and active, prior to his injury, and the Intervention 1 team therefore supported him to re-join the electoral register and to vote. This was one of the activities that Simon appeared to find motivating during Intervention 1 and his engagement increased whilst it was being planned and carried out.

Relative participants referred to the importance of regaining independence in previously enjoyed activities or with previous social groups (sub- theme 5.2). A relative participant interview was not completed for Louise, so feedback was not gathered via this route which might have been helpful to understand how important this element was to Louise's rehabilitation.

The final participant-focussed element that will be discussed here is the impact that the acquired brain injury had on family relationships. In the cases of Richard, Nathan, Louise and Simon, the participants' parents all became very active in supporting their rehabilitation after the brain injury. The participants described different levels of contact and closeness to their parents prior to their injuries, but in all cases the contact between participants and their parents became much more frequent and parents started to provide practical support, such as washing clothes and supporting management of finances. During the administration of the primary outcome measure, participants made reference to this change of status with their parents, sometimes expressing gratitude for their parents' support and sometimes expressing frustration that they could not control when parents visited or how much influence they now had

on their plans. The multidisciplinary teams in both interventions, attempted to respect the boundaries that participants wanted to set, by encouraging family members to contact participants before visiting. The team involved parents in the goal setting and intervention planning if the participants gave consent, and offered both brain injury education and emotional support to participants' relatives. In the relative participant interviews, a number of points were raised relating to this area. Relatives expressed feelings of responsibility for supporting practical aspects of participants' rehabilitation, such as provision of food and managing laundry (sub theme 2.3) as well as finance and benefits (sub theme 1.5). Most relative participants felt supported by the multidisciplinary team in the interventions (theme 2), with Nathan's parents particularly acknowledging the benefit of support to think about starting to spend less time living with their son and allowing Nathan to live more independently (sub theme 5.1).

Taken together, these factors highlight the importance of being able to individualise the intervention. However, in order to support rehabilitation staff, standard training or assessment materials are also important. The points raised in this section will be revisited in Chapter 14 when considering some of the clinical implications of this study.

13.2.2. Factors relating to the planning or implementation of the intervention

A number of the themes emerging from both the case studies and the relative participant interviews have implications for the planning and implementation of the research intervention. These will be discussed in terms of areas where the intervention was successful or the relative participant feedback positive, followed by areas where the intervention was less successful or the relative participant feedback negative.

Overall, goal attainment was good for all participants, with 43 out of a total of 62 goals either achieved or exceeded. A further 16 goals were partially achieved, which are scored as being not achieved to maintain the standardisation of the scoring system, but often demonstrate considerable gains towards the goal in practice. As discussed, this level of achievement supports the assumption that goals set between participants and

the multidisciplinary team were broadly appropriate. It also provides some support to the argument that the intervention was appropriately targeted at these areas. Goals were set across a number of different topic areas. Goals relating to impairment level rehabilitation or improving function in activities of daily living were more likely to be set in Intervention 1 and were usually achieved. The interventions relating to these goals were usually directly delivered by members of the multidisciplinary team. This supports the importance of continuing to provide some impairment level rehabilitation at this stage of the pathway. Goals set for Intervention 2 were more likely to relate to living independently and accessing community leisure or social activities, again in most cases these were met. As per the discussion relating to hypothesis 3, the distinction between the types of goals set in each Intervention stage was more marked for some participants than others but there was a general shift away from impairment-based goals towards community access-based goals in Intervention 2. The consistent levels of goal achievement across the two stages with somewhat different focus in each, again provides support to the argument that the processes in place in both teams enables appropriate goal setting.

Goals at both intervention stages that specified handover and joint working with brain injury support workers were usually achieved and tended to target those activities that participants identified as priority such as accessing leisure activities or the community. In the cases of Billy, Richard, Nathan and Simon, the participants were supported in the community by specialist brain injury support workers who had already received general brain injury training and who received further training from the multidisciplinary teams in this study that was individually tailored to the participants. The support workers started to work with participants during Intervention 1 and continued into Intervention 2. This continuity of support workers between the interventions was designed to help support the transition. In Louise's case, she worked with the support workers in her supported living scheme, who were not brain injury trained but who

received a longer period of training and handover from the Intervention 1 team. She therefore did not have the same continuity of staff, but the longer period of graded discharge aimed to compensate for this.

Feedback from the relative participant interviews did not provide much detail about the support worker role. Again, this was not specifically prompted on the interview schedule and it would have been useful to explore this with relative participants in more detail. Richard's mother indicated how much she had valued the support worker role, but this was discussed in the context of the funding for the support worker being withdrawn. Relative participants did comment on a perceived lack of intensity of provision in Intervention 2 (sub theme 1.2) and this may be, in part, due to the indirect delivery of the intervention via the support workers. This was particularly apparent in Simon's case where most of Intervention 2 was delivered in this way, and Simon's parents commented a number of times during their interview on the lack of community intervention and communication from the team members. This indicates a need to explain the use of the support workers and the role of the multidisciplinary team in more detail and also a need to maintain more regular contact between the team and participant's relative, even if much of the intervention is delivered by the support workers. Models for delivering intervention via support workers will be discussed in Chapter 14.

Three positive themes to emerge from the RP interviews were the provision of emotional support (theme 2), support for transition (theme 5) and continuity of key staff members (sub theme 2.2 and theme 5). The theme about emotional and psychological support for relative participants has already been mentioned in section 13.2.1 in relation to individual participant needs. It is worth briefly mentioning here again to reinforce the need to maintain this element of support for relatives via education and emotional support as a core part of the interventions. The theme on transition indicated that relative participants valued the graded discharge element of the programme and

could see the benefit in grading the move from Intervention 1 to Intervention 2 in terms of reducing anxiety and reducing the sudden impact of change. Key to this is the fact that the two interventions are provided by the same service and therefore staff can co-ordinate a period of graded discharge and handover.

The relative participant interviews also supported the continuity of key members of senior staff through both intervention stages, examples given were Neurologist, Allied Health Professional Consultant and Neuropsychologist. The interventions were developed with this consistent senior team with the aim of providing continuity to patients and families and to support continuity of quality across the pathway in terms of goal setting and planning intervention. The data from the relative participant interviews suggests this was achieved in these case studies.

Considering the aspects of the intervention and relative participant feedback that were less positive, it is important to look at the goals that were not achieved to understand what might contribute to this non-achievement. In total, there were three goals not achieved or discontinued and the 16 goals partially achieved already referred to above. In most cases, for goals that were partially achieved, the level of actual attainment was slightly lower than the level set, examples of this are that Billy was able to mobilise with the quad stick but a shorter distance than set in the goal, or that Richard was able to use his memory strategies independently but did not achieve the 75% target set. This element of goal setting can be hard to get right all the time and there is a balance to be struck between setting goals that are both realistic and ambitious or motivating. Partial achievement could indicate the goal level was set too high, or it could indicate that the multidisciplinary team was not consistent in reinforcing a task or behaviour. As discussed, the level of goal achievement in this study appears to have been reasonably consistent but it would still be valuable for the team to review these partially achieved goals and incorporate this learning into ongoing training. There were nine goals that were either partially achieved or not achieved for different reasons and these need to

be understood to inform future service development. One of Billy's goals was only partially achieved because of waiting for a taxi card²⁶ this type of delay was very typical when the intervention was first introduced but the taxi card and other similar application processes were moved to earlier in the pathway and most such delays have been reduced. Such delays are unlikely to be completely eliminated, but this example shows the importance of having processes in place to minimise such delays. One of Louise's goals was only partially achieved due to the fracture that she sustained and the impact that this had on her physical ability and anxiety. This is clearly an unusual event and related to a number of factors, including Louise's complex medical history. However, risk of injury during rehabilitation as patients start to complete tasks independently is a broader issue and underlines the need for comprehensive risk assessment. Two of Louise's goals were not achieved, one because she chose to discontinue it which is always a possible outcome with participant focussed goals, the second she did not achieve (cooking in her kitchen) due largely to fatigue. Louise identified this goal and was motivated by it and so it was included for this reason but the non-achievement potentially indicates that the team did not negotiate appropriately with Louise based on her level of fatigue, or did not carry out sufficient assessment in the environment prior to goal setting. In total, five of Simon's goals (out of a total of 11) were partially achieved (4) or not achieved (1). This is likely to be due to his variable engagement in the structured rehabilitation programme, as discussed in section 11.5.3. Simon's presentation and engagement was particularly challenging for the team and it would be valuable to use this case for team reflection and training. It is also important to consider whether Simon's needs could have been better met by moving straight to the community with the right level of support instead of going through the transitional stage (Intervention 1).

²⁶ A taxi card allows the person to make supplemented taxi journeys. Eligibility is based on eligibility for another welfare benefit and therefore the application process can be slow as the first level of eligibility has to be confirmed before the application can be made

An area of concern that is not reflected in the goals is the deterioration in Richard's level of function and independence that coincided with his support worker being withdrawn. The impact was noted during the non-intervention period so it was after the goal period had finished, but it was illustrated by one of the end of non-intervention secondary outcome measures (MPAI). At this point, there was also a reported increase in the level of support that his mother had to provide and Richard reported a reduction in motivation to organise his routine. Richard's mother makes a number of statements about the withdrawal of this service that illustrate the level of concern that it caused both her and Richard (sub themes 1.2). As clarified in section 1.3, care services and support worker services are not part of the research intervention being examined in this study as they are not provided by the Intervention 1 and 2 teams, but by the Local Authority. However, they are linked because the long-term success of the study intervention is, in part, dependent on the provision of ongoing support from other services. As previously explained in section 3.2.3, the Intervention 1 team do not start to work with a brain injury support worker until ongoing funding for this service is confirmed by the Local Authority. However, this is always open to review throughout the rehabilitation pathway. Eligibility for services of this type is based on prioritising care for people who require physical help to live at home, while Richard's support needs were due to his cognitive and behavioural difficulties, and he was therefore not regarded as eligible by his Local Authority. The study period also coincided with a period when funding for Local Authority care in the UK was reduced. In Simon's case, the support worker was funded via NHS Continuing Healthcare which has different eligibility criteria. In Nathan's case, support for cognitive impairments was maintained, based on the risk assessments provided by the Intervention 1 and 2 teams. A risk assessment was also provided for Richard, but his risks were judged to be less severe. It is not possible to plan for this challenge in all cases as funding availability is subject to change in line with political and economic cycles, However, it is important that the multidisciplinary team are aware of the current availability of support and endeavour to

plan a sustainable package within these limitations. It is also important that there is sufficient flexibility to offer further rehabilitation support if required.

An area of negative comment from the relative participant interviews related to the intensity of community therapy and the reliability of community staff to attend appointments on time (sub theme 1.2 and 3.2). The community intervention (Intervention 2) is less intensive than the transitional stage (Intervention 1). This is partly due to the delivery of elements of this intervention via support workers as described, and partly because the intervention aims to establish sustainable long-term community supports to allow people to be discharged from the Intervention 2 service whilst maintaining independence. A lower number of goals were set during Intervention 2 (26) than Intervention 1 (32), reflecting this lower treatment intensity, but goal attainment was maintained as demonstrated by the consistent t-scores. The dissatisfaction expressed during the relative participant interview clearly requires consideration. This will be discussed further in Chapter 14 when considering how resources should be targeted and whether more resources should be targeted at intervention 2 or similar community interventions. Alternatively, the solution to this may be to review communication about the programme and how it is delivered rather than increasing the intensity of provision.

The final negative theme to emerge from the relative participant interviews, relates to concerns about the physical environment of the Transitional Unit (theme 4). As described in section 3.1 the Transitional Unit was initially set up as a pilot and it utilised a set of beds in a nursing home that was co-located with the Community Team base. The environment was therefore designed with nursing care in mind. It had private bedrooms and some ensuite bathrooms, but did not have a therapeutic kitchen or accessible shower. For the purposes of the pilot, a temporary wheelchair-accessible shower was fitted, a small accessible laundry was created and the kitchen was adapted to allow wheelchair access. Following the successful evaluation of the pilot, further

works have been carried out on the unit since the completion of the current study to bring the kitchen and bathrooms up to an appropriate standard to support active rehabilitation. This theme from the relative participant interviews does emphasise the importance of the correct environment to support goal attainment. For example, Richard's mother reflects on the need to practise domestic tasks prior to moving home and the environment needs to be suitable to facilitate this. It is therefore an important factor to consider in service planning.

In summary, therefore a number of key issues were identified through the case series that reflect both positive and negative aspects of the intervention and raise important points to be considered when planning future services.

13.2.3. Factors relating to the measurement of outcomes

The success of the interventions to target community integration was measured in this study using the primary outcome measure (CIM). The secondary measures (UKFIMFAM and MPAI) were used to provide comparative information about objective change and Goal Attainment Scaling was used as a validity measure to provide evidence that change had occurred in the areas targeted.

The analysis would suggest that the secondary measures were sensitive to change for this group of participants receiving this intervention. The use of Goal Attainment Scaling also provided useful information about where the intervention was targeted.

The point of concern is whether the primary measure was appropriate for either the intervention or the participant group. The measure is designed to be subjective to participants' own feelings and concepts of community integration. In the service evaluated in the current study, the Community Integration Measure has been used as one of a number of outcomes since the Transitional Unit (Intervention 1) was established. It demonstrated sensitivity to change over Intervention 1 on the pilot evaluation carried out prior to the start of this study (see section 3.1).

Three of the participants in this study presented with impaired insight and this raises a question about how or whether the measure can be adapted for this group. In the current study, the recommendations from Clay (2015) were used to structure the adaptations to the measure and ensure validity was not compromised. Adaptations were minimised to maintain the consistency of delivery for the purposes of the research. In usual clinical practice, the multidisciplinary team use the measure as an outcome but provide more informal support to patients to ensure they have understood the concepts and provide feedback to patients about their behaviour, communication and current abilities during the administration of the measure, to help them to structure their responses. This difference in approach between usual clinical practice and the research protocol may go some way to explaining why a significant change was noted on the evaluation of the Transitional Unit pilot outcomes but not for most participants in this study. The analysis was also performed differently in the pilot evaluation as the number of patients was high enough to compare total pre-and post-intervention scores across the whole groups rather than using the within participants analysis as per the current study. This group analysis may have hidden individuals who did not show positive change on the measure, if the majority of patients did, or could have been skewed by one or two patients making very large gains.

Finally, the participants in the current study had very complex needs and their presentations fluctuated. They also had a reasonably long period of rehabilitation in the study (between 10 and 15 months) and their presentations, in objective terms, improved over this time. It is likely therefore, that the participants' level of insight varied between outcome points and their subjective concept of community and other terms used in the measure changed over time. In two examples, Billy and Simon, the end of Intervention 1 score on the primary measure (CIM) potentially illustrates how sensitive the measure can be to short term anxiety or frustration with a situation. The timing of the end of Intervention 1 measures may also be significant. These were completed

during the graded discharge period which was appropriate timing for the objective (secondary) measures because the team were able to observe the participants in their home environment and assess current function. However, it may not have been an appropriate point for the primary (subjective) measure to be administered, as it was a time of transition and potential increased anxiety for clients. A more accurate picture of subjective reflection at the end of Intervention 1 may be gained if the measure was completed just before the graded discharge. A detailed analysis of the participants' narratives whilst completing the primary measure (CIM) may inform this discussion further, but was outside the scope of this study. With additional consent, the videos recordings of the administration of the primary measure could be analysed further to understand participants concepts of community integration and inform future service planning.

In terms of judging the overall value of the intervention, it is important to consider all the measures used (primary and secondary) as well as the goal attainment. It is also important to consider that, for all five participants, there was a question at the beginning of the intervention about whether they could safely return to live in the community. All five participants successfully returned to live in the community and at the end of the non-intervention period were continuing to manage with the level of support provided. In this way, all five participants can be viewed to have made clinically significant change over the course of the interventions, despite not making statistically significant change on the primary measure. This is discussed further in Chapter 14.

13.3. Summary

This chapter has framed the main points that arose from the case series whilst also considering the themes from the relative participant interviews. The next chapter will place the findings and learning from the current discussion in the context of the broader literature.

14. Discussion

This chapter examines the study findings in the context of the research questions and goes on to consider implications for clinical practice in acquired brain injury rehabilitation and service development. The limitations of the current study are presented in section 14.4 and final conclusions and recommendations in section 14.5.

14.1. Review of the research questions

The research questions in the current study were:

Primary research question:

For adults with severe acquired brain injury choosing to return to live in the community, is a multidisciplinary transitional and community rehabilitation programme successful in increasing community integration?

Secondary research questions:

- What is the relationship between outcomes based on level of impairment and outcomes based on level of community integration?
- What is the experience of close relatives of adults with severe acquired brain injury returning to live in the community?

The answer to the primary research question is not a simple one. Certainly the outcomes in the current study support the findings in the existing literature that transitional and community rehabilitation are effective in supporting improvements in function after acquired brain injury as evidenced by improvements on the secondary outcome measures (Cicerone et al., 2005; Geurtsen et al., 2010; Turner-Stokes et al., 2015). However, the lack of statistically significant change on the primary outcome measure makes it challenging to draw conclusions about improvements in community integration. The discussion in section 14.2 will examine the key findings from this study in the context of the literature, thereby providing a more narrative answer to the

research questions. This discussion will also incorporate the findings that relate to the secondary research questions.

14.2. Review of the study implications

The current study provides detailed qualitative information that captures a range of issues that can inform future service planning and development. To draw out the learning from this study, this discussion will first consider the research design and how the findings can be applied beyond the immediate clinical setting of this study. The discussion points that have arisen will then be considered in terms of the broader literature in the field, within the separate intervention stages of transitional and community rehabilitation and across the whole pathway.

14.2.1. Study design

The current study used a small sample and a case study design to evaluate a rehabilitation intervention. Service evaluations within the literature often use larger samples and tend toward experimental designs (Geurtsen et al., 2008; Geurtsen et al., 2012; Powell et al., 2002; Winkler et al., 2006). In the current study, evaluation of a larger cohort of participants through the study may have provided a more compelling argument for a causal link between the intervention and the outcomes. A larger sample would also have provided more quantitative data, enabling a cross-participant statistical analysis. However, increasing the sample size would have compromised the level of detail and the depth of the data collected for each participant. Case study research is supported in the literature and can be particularly relevant to help understand and evaluate a new service (Yin 2003). The key to whether case study research is helpful, lies primarily in the quality of the research design.

It is useful, therefore, to examine the current study in the context of published guidelines for producing good quality case studies. Both Yin (2014) and Baxter and Jack (2008) make the arguments that, to have an impact, case study research must be well matched to the research question, consider data from a number of sources and

follow a clear research protocol. The current study meets these criteria and also achieves a number of the criteria for an experimental case study design as described in the SCRIBE guidelines (Tate et al., 2016). In the current study, it was not possible to achieve randomisation of participants or blinding of assessors to the stage of intervention, but the design did incorporate a repeated baseline and period of non-intervention to help to isolate the effect of the intervention. A range of outcome measures including an indicator of clinical validity was used and all practicable attempts were made to minimise bias.

The current study was carried out when elements of the research intervention were still in the early stages of development. If this is considered in the context of the cycle of development illustrated in the Medical Research Council guidelines (2008) or Hart's model (Hart, 2009), then this study could be considered a pilot stage in the overall development and evaluation of the intervention. If considered in this way then the current study meets the criteria as an initial proof of concept and the case study design is well suited to this function.

For the basis of this discussion then, the assumption will be made that the study design was sufficiently robust and well match to the research aims. The findings can therefore potentially contribute to the broader evidence base despite the small sample.

14.2.2. Transitional and community rehabilitation

One of the strengths of the current study is the detailed description of the intervention and the theoretical model underpinning it. This very detailed description can be seen to complement the existing literature by providing qualitative information that can inform service delivery. There are established programmes that provide published detail about acquired brain injury interventions and the corresponding theoretical frameworks. Key examples are the transitional rehabilitation unit described by Jackson and colleagues (2014), the behavioural support programme described by Feeney and colleagues (2001), and the milieu based programme described by Cicerone (Cicerone et al.,

2008). These examples are all primarily cognitive and behavioural rehabilitation programmes. There are fewer examples of global interventions for people with physical and cognitive disability following acquired brain injury that are described in this detail with the corresponding theoretical framework. There are also very few examples of services that provide a co-ordinated two-part intervention incorporating transitional and community interventions. One example is the programme described by Tate and others (2004) as described in section 2.4. and 2.5, the authors describe a service model that incorporates both transitional and community rehabilitation and describe the interaction between the staff in different services. However, they do not provide a detailed description of the intervention or how it is individualised.

Taking the intervention stages individually, Intervention 1 in the current study can be viewed in the context of the evidence base for transitional rehabilitation programmes. A number of the themes generated by the relative participant interviews are relevant to consider in the context of the literature. Relative participants provided feedback that the nature of the programme and the continuity of staff across intervention stages helped to support the period of hospital to home transition. This element is consistent with other established services described in the literature that have either stepped transitional units and group homes arrangements (Jackson et al., 2014), or a linked transitional and Community Team (Tate et al., 2004). There is broad acknowledgement that the transition from hospital to home is often poorly planned and confusing (Piccenna et al., 2016; Turner et al., 2007; Turner et al., 2011). A study using patient feedback on the experience of transition, also provided support for the concepts of continuity of staff and co-ordination between stages to address this challenge with discharge planning (O'neil-Pirozzi et al., 2015). The detailed feedback from the relative participant interviews provided specific support for the continuity of key members of senior staff, the continuity of support workers involved in discharge planning and continuing into the community, and the practical support of a phased or graded

discharge to lessen the impact of a sudden move. Therefore, the examples of how this study intervention is designed to support transition in this way contributes to the discussion about what tools or service designs are needed to support successful transition.

There was a question raised in the relative participant interviews about whether transitional rehabilitation could be truly effective in an environment that still feels like a hospital, and in one case (Simon) the participant engaged more effectively in the community intervention than in the transitional intervention. To examine this stage in more detail it is useful to unpack the transitional intervention and compare elements to other service examples. Eligibility for Intervention 1 in the current study is based on an identified need for further in-patient rehabilitation to enable successful return to the community. This might include the need for more impairment-based therapy, the need to complete a community risk assessment or the need to transition to the level of support available in the community. These types of eligibility are reasonably consistent with other examples of transitional services (Jackson et al., 2014; Simpson et al., 2004). The set-up of the Transitional Unit, with a small number of beds based in a community location, is also consistent with elements of these other services. Reviewing the outcomes of the current study in the context of published service examples, there is a need to examine more carefully which patients most benefit from the transitional resource. The work described by Hopman and colleagues (2012) identifies that an increased level of healthcare resource is provided to patients in a transitional unit compared to a community intervention. This is certainly true of the two intervention stages in the current study, although it is important to consider total resource as other organisations and services provide more resource in the community (e.g. voluntary organisations and Local Authorities). It is therefore important to try to establish who will most benefit from this transitional rehabilitation and who might achieve the same or similar outcomes transferring directly to the community. The current study provides

data that can be used to help answer this question. The in-depth review of goal-based interventions and attainment along with the detailed feedback from participants' relatives provide useful information about what type of interventions are most effective and valued at this stage. The four participants (Billy, Richard, Nathan and Louise) whose secondary measures suggested they did benefit from the transitional intervention all required different supports, but a common theme was the need to structure the environment carefully to prepare the participants for the support available in the community and to establish a healthy routine. The focus of the routine was different in each case but the principle was the same: that the team all needed to provide consistent feedback and support, whether this was focussed on a personal care routine, management of medication, a routine of planned care visits or regular community access. The need for a skilled team to provide structure to allow a person with acquired brain injury to learn a routine and strategies is the basis for the theoretical framework described by Jackson and colleagues (Jackson et al., 2014). It would be possible to provide a very structured and consistent environment in the community if resources were redirected. However, if a person's need for structure is throughout 24 hours, relates to risk in the community or requires a number of staff members then it becomes increasingly challenging to provide this in the community. The findings from this study indicate that careful consideration should be given to whether the need for structure and risk assessment requires an in-patient environment or can be provided in the community.

In the current study, Intervention 2 is delivered in the community and an important component is that training and support is provided to brain injury support workers who, in turn, deliver much of the direct support to the participant. The current study provides detailed examples of how goals are translated to interventions, when in-direct provision via support workers might be appropriate and what type of training and support can be provided. Other interventions advocate the use of trained support workers to deliver

some of the intervention in a very practical or context-specific way (Feeney et al., 2001; Jackson et al., 2014). However, these studies do not provide detail about the how training and supervision should be delivered to support workers. The need to define what training carers or support workers require is identified in a study based on interviews with people with acquired brain injury and their paid carers (McCluskey, 2000). There are a large number of studies within the brain injury literature that address the training needs of family members caring for a relative (Fortune et al., 2016; Norup et al., 2015; Fisher et al., 2015; Tam et al., 2015). There are also examples of established programmes for paid carers that deliver effective training to provide specific support roles with adults with complex communication or cognitive impairments (Behn et al., 2012). The findings of the current study present an opportunity to use the detailed learning and examples in the case studies in the context of the established literature in this field, to formulate a support worker training approach that can be incorporated into a very individualised goal focused programme. In the cases in this study, the support worker training was largely individually designed to match the needs of participants. However, analysis of the areas where this approach was successful would identify themes that could inform a more standardised approach. Development of this support worker training approach could follow the same pattern as the development of the research intervention in the current study, based on frameworks of developing complex interventions (Medical Research Council, 2008; Hart, 2009). Themes based on successful elements of support worker delivery would essentially form the key components or active ingredients of the approach underpinned by a toolkit of training materials. A standardised approach of this type would support training of new staff and application of the programme across other clinical services.

In summary therefore, the current study provides detailed feedback in a number of areas that, taken with the existing evidence the field, can support ongoing service

refinement and improvement in both the transitional and community intervention stages of the rehabilitation pathway in severe acquired brain injury.

14.2.3. Community integration

The interventions in the current study specifically targeted increased community integration. It is relevant therefore to consider whether the findings contribute to the understanding of what defines community integration or what is effective in supporting or facilitating community integration.

The detailed exploration of the cases in the current study, supports the established theory that concepts of community integration in the acquired brain injury population are different to those in the general population (McColl et al., 1998; Minnes et al., 2003; Parvaneh & Cocks, 2012). The current study used the Community Integration Measure (McColl et al., 2001) as an outcome measure as it reflects this subjective view of community integration and was validated with people with acquired brain injury (Griffen et al., 2010). However, this presented a number of challenges in terms of how the measure should be used with a cohort of participants with complex communication and cognitive impairments. This identifies a need to balance the wish to collect subjective and representative views from participants whilst also ensuring there is some structure to support understanding of statements and concepts. The work described by Clay (2015) starts to explore this need and provides a set of themes to consider when using subjective outcome measures. However, the findings of this study indicate that even with a very structured method of administration, there is likely to be a significant discrepancy between subjective reports of integration and objective measures of activities that may indicate integration, especially in participants with impaired insight. One potential solution to this challenge is to use a range of outcome measures that reflect subjective and objective elements of community integration. The current study attempted to do this by including a secondary measure with a broad subscales (MPAI). This measure does aim to capture some elements of community integration within the

adjustment and participation sub scales. Items relating to family relationships, social contact, leisure activities and work activity should capture activity relevant to the components of community integration accepted in the literature (McColl et al., 1998; Parvaneh & Cocks, 2012). The comparison with goal attainment also helped to ensure that the participants own priorities were built into the programme. The use of goal attainment scaling can also be used as an indicator of clinically significant change where statistically significant change is not shown. In future research it may be valuable to use a second dedicated primary objective measure such as the Community Integration Questionnaire (CIQ) (Willer et al., 1993). It may also be useful to attempt to state what a clinically significant change would be on the measures as in the example from Powell and colleagues (Powell et al., 2002).

The findings of this study can be viewed in the context of established evidence about what works in rehabilitation targeting community integration. The service described in the current study aimed to incorporate evidenced elements of programmes in community integration into this intervention. Examples include the incorporation of carer and family training (Fortune et al., 2016; Fisher et al., 2015), use of mainstream services (Kolakowsky-Hayner et al., 2012; Gerber & Gargaro, 2015), provision of emotional supports (Sady et al. 2010; Kuipers et al. 2014) and use of culturally appropriate goals and activities (Doig et al. 2001; Sander et al., 2009). One of the aims of the current study was to see if this type of programme could benefit participants with severe acquired brain injury, as this group has been shown to have less good outcomes in relation to community integration (Reistetter & Abreu, 2005). The findings of the current study are interesting in this context because all participants improved on the objective (secondary) outcome measures and all achieved successful return to the community, however only one participant demonstrated improvement on the primary (subjective) outcome measure. The description of the cases, outcomes and participant narratives provides some indicators of what the barriers to integration were for this

client group. For example, review of Billy's case would suggest that one reason he does not report increased integration is because of the frustration that he feels with waiting for staff and relying on others to take him out. This information can help to guide clinicians and researchers about what changes can be made to interventions, care packages or accommodation to remove some of these barriers to enable people with higher levels of disability to live successfully in the community.

In the UK context, rehabilitation services such as the one in the current study, cannot always influence the provision of care or accommodation as these elements are funded, organised or provided by different services. At the time of writing, healthcare in England is going through a process of transformation under local Sustainability and Transformation Partnerships (previously Sustainability and Transformation Plans). These partnerships have been established to deliver locally formulated plans to meet the specific population need. Central to this transformation is the recognition that NHS, Local Authority, Public Health and Voluntary services need to work together to deliver co-ordinated care. A report by the Kings Fund (Ham et al., 2017) identifies the challenge of NHS services and Local Authority services working together as one of the biggest barriers to achieving the ambitions of the Sustainability and Transformation Partnerships. The report does identify examples of areas that have demonstrated collaboration between services from different sectors but it will be challenging to achieve these collaborations consistently across the country. The data from the current study provides further examples of the challenges of supporting people in the community if services are not co-ordinated or if the support in one area is withdrawn. In the current policy context described above, these findings provide useful examples to inform local collaboration between services.

In conclusion therefore, the current study, provides evidence to support the effectiveness of the intervention in successfully targeting components of community

integration. It also identifies areas for further work to support service improvement in this area.

14.2.4. Goal setting and individualised interventions

A number of the participant-specific issues discussed in Chapter 13 relate to the way the interventions were individualised to each participant and the factors that need to be considered

Setting of individual goals forms the core of the both interventions. This is how the standard intervention is defined for each participant and the goals shape the delivery of the intervention. In section 13.2.1, the team goal-setting process is described in terms of the negotiation between the participant, family and multidisciplinary team to agree goals that reflect personal priorities and are also SMART (Specific, Measurable, Achievable, Realistic and Time specified). There is support in the literature for using negotiating techniques as part of the goal setting process (Prescott et al., 2015; Turner-Stokes, 2009; Wade, 2009). The approach used by the multidisciplinary team in this study varied for different participants, depending on their ability to participate in this process. The aim was for the goals to be primarily participant-led with support from the team to define these. However, cases such as Simon's and Nathan's where some goals were expressed wholly or partially in the third person, reflect a greater level of professional input into setting the specific measurables in the goal. To guard against the risk of the process becoming too professionally led the team collected extensive background information from family and friends and formulated the measurables in the goals around the participants priorities. Senior clinical staff also supported the goal setting in these cases to ensure that the participants views remained at the centre of the goal, even if they were not able to engage in detailed setting of criteria for goal attainment. Playford and colleagues (2009) explored the concept of *levels of patient centeredness*, using a Delphi method to identify areas of professional consensus within goal setting. The authors identify key areas of patient-centred goal setting where there

is consensus such as the need to come to a shared understanding between the patient and professional, to reach agreement about the nature and priority of the problem and to understand the patient's context in terms of social, emotional and personal priorities. There was also consensus reported about the need for professional input to reach goals that can be expressed in a SMART manner. However, they acknowledge there is not always consensus about the extent to which this negotiation can or should be professionally led. In this context, the examples given in the current study of professionally negotiated goals in complex cases such as Simon and Nathan's, combined with the positive outcomes these participants achieved, can further inform this debate about goal setting.

A related issue is accurate assessment of capacity, and balancing responsibility to manage risk with responsibility to respect individual values and beliefs. The multidisciplinary teams in the current study use risk assessment, the recommendations of the team and Best Interest processes when indicated, to support assessment of capacity. There is recognition in the brain injury and learning disability literature of the need for more standardised resources for assessment of capacity to be developed (Reid-Proctor, Galin and Cummings, 2001; Beadle-Brown, 2015). The report by Beadle Brown (2015) emphasises that the aim of the Mental Capacity Act (2005) was to move from professionally-led, paternalistic decision-making to a supported and shared decision-making approach. The report refers to a 2014 House of Lords Select Committee Report (House of Lords Select Committee on the Mental Capacity Act 2005, 2014)²⁷ which concluded that application of the principles of the Act was not consistent in healthcare settings. These findings have been reinforced by more recent literature which has concluded that some healthcare staff find assessment of capacity a challenging task (Marshall & Sprung, 2016) and that NHS staff are keen to have

²⁷ The House of Lords is the second chamber of the UK parliament. House of Lords Select Committees are appointed to review and investigate public policy, proposed laws and government activity.

access to more standardised tools to support assessment (Jayes, Palmer and Endeby, 2016). The materials developed for the research intervention in the current study and the specific case examples can contribute to the development of frameworks and materials for assessment of capacity and supported decision making.

The final factor for discussion here is the issue highlighted in section 13.2.1 relating to family relationships and the impact that this has on the design and implementation of the interventions. The parents of four of the participants in the current study became very closely involved with supporting rehabilitation and longer-term care. The team attempted to work within the boundaries set by the participants and also provide emotional and education support to families. As with all other areas of the intervention, the team attempted to individualise this support to each participant and family. The participants reported differing levels of closeness to their parents pre-injury and set different parameters in terms of how much input and support they wanted. There is evidence that the quality of pre injury relationships combined with injury severity can impact on long term outcomes and family relationships after brain injury (Sady et al., 2010). The detailed descriptions of support provided in the current study give useful examples of how family members can be supported. The data in the relative participant interviews also give a perspective of what relatives valued from this support, to inform service planning.

14.2.5. Summary of study implications

The current study provides preliminary evidence to support the premise that the intervention is successful in supporting return to the community following acquired brain injury and effectively targets elements of community integration. Further evaluation, including use of a larger sample and exploration of different outcome measures, would be useful to make this evidence more compelling from a research perspective. The detailed nature of the service description, the exploration of the cases and the relative participant interviews, offer useful insights to complement the

evidence-base and support development of materials and frameworks for use in acquired brain injury rehabilitation.

14.3. Clinical implications

One of the core aims of the current study was to improve and develop the clinical service which has been described in this study. The intention was that this evaluation would enable the service to improve the quality and consistency of provision. The findings are therefore most easily applied to this individual service, where the information generated by the case studies and the relative participant interviews provides a rich level of detailed feedback to support ongoing development. However, there is also useful information generated for other similar services. The findings of this study highlight areas where intervention is successful or there is an opportunity for further research. This information is useful across a broad range of services and provides an argument for further development of services in the following areas:

- Support worker training: As referred to in section 14.2.2, there is an opportunity to use the learning from this evaluation to develop training materials used with brain injury support workers who deliver aspects of the intervention. The description of the interventions in this study, for examples the detailed strategies developed for the support workers to use with Simon, can inform development of more general resources in this area.
- Provision of a graded discharge period co-ordinated between the transitional and community elements of the programme: This was an area identified as positive by a number of relative participants and is not a common service model. There is an opportunity to define the graded discharge process so that it can be replicated. In particular, the information in the relative participant interviews highlights the aspects of this element that were valued by relatives and could be incorporated into other service models. For example, the

feedback from Nathan's parents about what elements of the programme helped them to gradually reduce their support.

- Management of assessment of capacity, risk and supported decision making: This is an area that the clinical service in the current study has focussed on to develop materials and tools to support members of the multidisciplinary team. The evidence from the case studies suggests this approach was successful in helping target intervention at the participants' priorities whilst minimising risk. The consensus in the literature is that this is an area where some healthcare staff would value more support and training. There is potential to use the learning and examples from the case studies in the current study to support this development of resource.
- Goal setting: As discussed in section 14.2.4, the examples of goal setting techniques in the current study can be developed to support goal negotiation in acquired brain injury rehabilitation services.

There is an opportunity in all of these areas to build on the intervention and increase the standardised materials and resources that can be used in the current service and in other acquired brain injury rehabilitation services.

The findings also identified areas that are working less well and should be reviewed. In some of these areas there was a disconnect between the multidisciplinary team and the participants relatives that could be addressed with appropriate communication and joint care planning. The relative participant interviews also gave a general impression of a rehabilitation pathway that is very long and confusing to navigate. This has implications for all clinical services in the acquired brain injury pathway to try to improve communication and co-ordination.

As described in section 1.2, neurorehabilitation services for people with acquired brain injury in London have developed over time and service provision remains variable, particularly in the community. Pickard and colleagues (2004) identify the need to map

rehabilitation services, establish what good practice looks like, and attempt to spread equity of access more evenly across geographical areas. The current study can support that discussion of 'what does good practice looks like' because the information provided is detailed and the relative participant interviews provide a useful perspective that is applicable to services beyond the one in this study. The case examples also help to inform which patients will most benefit from a dedicated transitional programme.

A final point to make about clinical applicability again relates to the current service context. As described in section 1.2, there is a shift towards people choosing to move home after acquired brain injury and this move is supported by current healthcare policy in the UK. The current study provides useful practical information about the challenges of returning to the community following acquired brain injury. There is an acknowledgement in the literature that placement of younger adults in nursing homes designed to care for older people is not clinically or socially appropriate and that services need to be able to support people to live in the community if they choose to (Winkler et al., 2011). The detailed information in these case studies, particularly the example of Simon who was supported to move to the community after a long period in nursing care, can contribute to service development in this area.

14.4. Limitations of the current study

The current study has a number of key limitations, most of which have already been mentioned but it is useful to summarise them here to place the conclusions in an appropriate context.

- The study uses in depth case studies to evaluate the research interventions. Case studies serve a useful purpose in increasing understanding of the nature and detail of an intervention, but they would not be deemed suitable for inclusion in most systematic reviews looking at effectiveness. In this way, they have less impact on the overall evidence base than larger experimental studies. The combination of the small sample and the inconsistent significance

demonstrated on the primary outcome measure means it is challenging to draw general conclusions regarding the effectiveness of the intervention from this study. The statistical analysis selected included a measurement of correlation which failed to show a statistically significant correlation in a number of cases, even though the outcome graphs did support similar patterns of change on the different measures. As identified in chapter 11, measuring correlation across only 5 points in time is likely to produce non-statistically significant results and this brings into question the validity or usefulness of analysing correlation in this way.

- This thesis used the Medical Research Council Guidelines on Evaluation of Complex Interventions (Medical Research Council 2008) to describe the process followed in developing and starting to evaluate the intervention. This structure was developed primarily for larger scale interventions and to an extent, the current study only serves as a pilot stage in the overall evaluation of the intervention using this model. It would therefore potentially have been valid to consider other models for evaluation from a quality improvement perspective that are designed to facilitate rapid improvement and evaluation within clinical services. A summary of commonly used models within the NHS is provided by Boaden and colleagues (Boaden et al., 2008). Relevant examples to this discussion would be the Plan, Act, Study, Do (PDSA) cycle or the Lean model of quality improvement. Both of these models use rapid improvement cycles to implement a change in practice and evaluate the impact in order to improve further. They are popular within active clinical services because each change to the service or intervention can be small and the evaluation therefore manageable alongside service delivery. Both models can be considered 'bottom up' models of improvement as they are informed by professional, patient and carer feedback. The Lean model has a particular focus on the underlying value principles of the service that would have been relevant in the current study to

maintain the primary focus on community integration. If repeating a similar study or progressing this work further, it would be appropriate therefore to consider a broader range of quality improvement methodologies to support the evaluation. This point is revisited in the recommendations given in section 14.5 below.

- The choice of outcome measures and the impact this had on the results of this study was discussed in section 13.2.3 but is relevant to reference again here. In future research it would be valuable to review use of the Community Integration Measure as the primary outcome. Whilst it was in use in the clinical service and there is precedent for use of this scale in previous work (Hopman et al, 2012), in most studies, a range of objective and subjective scales are used (Simpson et al., 2004, Dahlberg et al., 2007). Adding a broader range of outcomes, specifically targeting the measurable or objective elements of community integration, would therefore have been more consistent with other studies and provided an additional perspective on the outcomes.
- The interviews with relative participants provide a valuable additional feedback about the intervention. However as identified during case discussions in chapter 6 – 10 and again in section 13.2, the interview schedule was broad and did not prompt relative participants to reflect on all of the core elements of the interventions (e.g. goal setting and use of support workers). Interviews are used effectively to gather relative and carer feedback in other studies in this field (Kuipers et al., 2014, Kitter and Sharman, 2015). In the two examples given, the interviews schedules covered areas related to the research aims or questions. In the current study, the interview schedule and prompts related to the different stages of the rehabilitation pathway but the questions did not link directly to the research questions. There is also precedent in the literature for using published outcome scales and questionnaires to collect information from relatives and carers (Hopman et al, 2012, Fortune et al., 2016). In the current study, use of

interviews provided detailed feedback that helped inform evaluation. If repeated it would be useful to ensure the prompts in the interview schedule link explicitly to the research questions as well as to the core elements of the service, it would also be useful to consider whether additional published scales would add further value.

- A limiting factor in this study is the length of time post intervention that the participants were followed up. The inclusion of a non-intervention period aimed to explore whether gains were maintained after discharge from rehabilitation, but three months is not long enough to evaluate gains in the long term and it would be more robust to follow up again at six and twelve months or longer. In the same way, it would have been useful to provide a more detailed evaluation of the acute element of rehabilitation to provide a whole pathway overview and evaluation.
- The final point to note here is that this study was conducted in an active clinical service. The principal researcher provided clinical support to the treating team and had developed the transitional service. Neither the principal researcher or clinical teams were blind to the point of rehabilitation when completing outcomes measures. It is important to acknowledge that these factors could have led to an element of bias as the principal researcher and clinical team were invested in the service and the participants' care. All practical steps were taken to reduce such bias by removing the principal researcher from day to day delivery of rehabilitation, using senior team members to review goals and ensuring the manuals and decision trees were used during outcome measurement to increase objectivity. If this work is progressed in the future it would be more robust to use a researcher who was independent from the clinical team.

The limitations discussed here need to be considered when drawing conclusions from the findings in the current study. They should also inform the design of any future research that aims to build on the findings of this study.

14.5. Conclusions and recommendations:

The current study describes the development and initial evaluation of a community and transitional rehabilitation intervention in acquired brain injury. The study provides detailed information about how the research intervention was developed and applied in specific cases. The case descriptions, outcome data and relative participant interviews contribute to a rich source of data to support understanding and evaluation of the intervention.

In addition to the clinical implications identified in 14.2, this study will form the basis of ongoing work to define the theoretical framework for the intervention as advocated by Sloan and colleagues (2004), and to standardise the elements and quality of the intervention using the frameworks provided in the literature (Medical Research Council, 2008; Trudel et al., 2007; Hart, 2009).

Whilst the small sample size and inconsistent statistical significance on the primary measure are acknowledged as limitations, the case studies do demonstrate areas of clinically significant change and opportunities for learning. The case studies and interviews help to inform what the key benefits of a structured transitional programme are and which patients are likely to benefit most from a programme of this type. They also identify a number of key elements of the rehabilitation intervention that can be specified and replicated in other services such as goal setting protocols, support worker training and assessment of capacity and risk.

Ongoing consideration should be given to how NHS, Local Authority and voluntary sector services can be evaluated alongside the research intervention to gain an overall picture of the community services that a person receives. The cases in this study

emphasise how critical this is to successful outcomes and provide examples to support the development of services for people with complex needs that incorporate elements of health and social care support.

Current healthcare policy emphasises the need to ensure consistent access to services and close what is referred to as the 'care and quality gap' (NHS England, 2014, NHS England 2016). The current study embodies this principle as it was completed within a clinical service striving to improve the quality and consistency of the intervention. In the context of an increased demand for transitional and community services for people with acquired brain injury, this study provides detailed qualitative information that can support service design. It can be seen as a valuable first step in understanding, evaluating and ultimately improving the care that is provided to people with acquired brain injury.

In conclusion therefore, it is recommended that the findings of the current study can be taken forward in two ways. Firstly, a larger scale evaluation, potentially pairing this clinical service with another geographical area, would provide more substantial data about the effectiveness of the clinical intervention. The findings of this study and the detail included define the core elements or active ingredients of the intervention. Future work of this type would not need to focus on the same level of detail per participant but could explore outcomes with a larger sample. The key points made in section 14.4 should be considered in refining a methodology for future work, in particular, a range of outcome measures should be used to reflect all elements of the intervention and further steps should be taken to reduce the risk of bias.

The second recommendation is that the clinical service in this study and other similar services continue the quality improvement element of this study. Section 14.3 identified four key areas to focus this work, namely support worker training, graded discharge, assessment of capacity or risk and goal setting. Based on the findings from the detailed case studies presented here, rapid improvement cycles could be used to

evaluate and improve each of these elements so that more standard protocols can be developed in each area. This work would have an immediate impact on the clinical services involved, but would also help to inform development of future services.

15. References

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Appendix 1: Rehabilitation levels and categories

Figure 25: Level of specialist neurorehabilitation services (reproduced from Turner Stokes, 2015, page 5)

TERTIARY SPECIALISED REHABILITATION SERVICES- provided at regional / national level		
Level 1:	Specialised rehabilitation services Provided by specialised rehab teams led by consultants trained and accredited in the specialty of rehabilitation medicine (RM) (and/or neuropsychiatry):	
	Serving a regional or supra-regional population and taking patients with Category A needs – ie severe physical, cognitive communicative disabilities or challenging behaviours, with highly complex rehabilitation needs that are beyond the scope of their local specialist rehabilitation services, and have higher level facilities and skilled staff to support these. Collect and report full National Specialist Rehabilitation Dataset	Catchment: 1-3 million Predominantly highly complex caseload: At least 85% pts have Category A needs on admission At least 70% pts with RCS-E score ≥ 11 cross-sectionally
LOCAL REHABILITATION SERVICES - provided at district level		
Level 2:	Local (district) specialist rehabilitation services Provided by inter-disciplinary teams led/supported by a consultant in RM, and meeting the BSRM standards for specialist rehabilitation services	
Level 2a	Led by consultant in RM. Serving an extended local population in areas which have poor access to level 1 services. Take patients with a range of complexity, including Category B and some Category A with highly complex rehabilitation needs* Collect and report full National Specialist Rehabilitation Dataset	Catchment: 600K-1 million Mixed caseload 50-80% Category A needs on admission 50-70% RCS-E score ≥ 11 cross-sectionally
Level 2b	Led/supported by a consultant in RM. Serving a local population, predominantly patients with Category B needs. Collect and report at least the minimum national dataset	Catchment: 250-500K Less complex caseload eg 30-50 % Category A needs on admission 30-50% RCS-E score ≥ 11 cross-sectionally
Level 3:	Local non-specialist services. Includes generic rehabilitation for a wide range of conditions, provided in the context acute, intermediate care and community facilities, or other specialist services (eg stroke units)	
Level 3a	Other specialist services led or supported by consultants in specialties other than RM - eg services catering for patient in specific diagnostic groups (eg stroke) with Category C needs. Therapy / nursing teams have specialist expertise in the target condition	
Level 3b	Generic rehabilitation for a wide range of conditions, often led by non-medical staff, provided in the context acute, intermediate care and community facilities, for patients with Category D needs	

Figure 26: Patients categories for neurorehabilitation (reproduced from Turner Stokes 2015, page 7)

Patients with Category A rehabilitation needs

- Patient goals for rehabilitation may include:
 - Improved physical, cognitive, social and psychological function / independence in activities in and around the home;
 - Participation in societal roles (eg work / parenting / relationships);
 - Disability management eg to maintain existing function; manage unwanted behaviours / facilitate adjustment to change
 - Improved quality of life and living including symptom management, complex care planning, support for family and carers, including neuropalliative rehabilitation
- Patients have complex or profound disabilities e.g. severe physical, cognitive communicative disabilities or challenging behaviours.
- Patients have highly complex rehabilitation needs and require specialised facilities and a higher level of input from more skilled staff than provided in the local specialist rehabilitation unit. In particular rehabilitation will usually include one or more of the following:
 - intensive, co-ordinated interdisciplinary intervention from 4 or more therapy* disciplines, in addition to specialist rehabilitation medicine/nursing care in a rehabilitative environment
 - medium length to long term rehabilitation programme required to achieve rehabilitation goals – typically 2-4 months, but up 6 months or more, providing this can be justified by measurable outcomes
 - very high intensity staffing ratios e.g. 24 hour 1:1 nurse “specialling”, or individual patient therapy sessions involving 2-3 trained therapists at any one time
 - highest level facilities /equipment e.g. bespoke assistive technology / seating systems, orthotics, environmental control systems/computers or communication aids, ventilators.
 - complex vocational rehabilitation including inter-disciplinary assessment / multi-agency intervention to support return to work , vocational retraining, or withdrawal from work / financial planning as appropriate
- Patients may also require:
 - Highly specialist clinical input e.g. for tracheostomy weaning, cognitive and/or behavioural management, low awareness states, or dealing with families in extreme distress
 - ongoing investigation / treatment of complex / unstable medical problems in the context of an acute hospital setting
 - neuro-psychiatric care including: risk management, treatment under sections of the Mental Health Act,
 - support for medicolegal matters including mental capacity and consent issues
- Patients are treated in a specialised rehabilitation unit (i.e. a Level 1 unit).
- Patients may on occasion be treated in a Level 2 unit depending on the availability of expert staff and specialist facilities as well as appropriate staffing ratios.

Patients with Category B rehabilitation needs

- Patient goals for rehabilitation may be as for category A patients
- Patients have moderate to severe physical, cognitive and/or communicative disabilities which may include mild/moderate behavioural problems
- Patients require rehabilitation from expert staff in a dedicated rehabilitation unit with appropriate specialist facilities.
- In particular rehabilitation will usually include one or more of the following:
- Intensive co-ordinated interdisciplinary intervention from 2-4 therapy disciplines in addition to specialist rehabilitation medicine/nursing care in a rehabilitative environment
- medium length rehabilitation programme required to achieve rehabilitation goals – typically 1-3 months, but up to a maximum of 6 months, providing this can be justified by measurable outcomes
- special facilities/ equipment (e.g. specialist mobility/ training aids, orthotics, assistive technology) or interventions (e.g. spasticity management with botulinum toxin or intrathecal baclofen)
- interventions to support goals such as return to work, or resumption of other extended activities of daily living, eg home-making, managing personal finances etc
- Patients may also have medical problems requiring ongoing investigation/treatment Patients are treated in a local specialist rehabilitation unit (i.e. a Level 2 unit).

Patients with Category C rehabilitation needs

- Patient goals are typically focused in restoration of function / independence and co-ordinated discharge planning with a view to continuing rehabilitation in the community
- Patients require rehabilitation in the context of their specialist treatment as part of a specific diagnostic group (e.g. stroke)
- Patients may be medically unstable or require specialist medical investigation / procedures for the specific condition
- Patients usually require less intensive rehabilitation intervention from 1-3 therapy disciplines in relatively short rehabilitation programmes (i.e. up to 6 weeks)
- Patients are treated by a local specialist team (i.e. Level 3a service) which may be led by consultants in specialties other than Rehabilitative Medicine (e.g. neurology / stroke medicine) and staffed by therapy and nursing teams with specialist expertise in the target condition.

Patients with Category D rehabilitation needs

- Patient goals are typically focused in restoration of function / independence and co-ordinated discharge planning with a view to continuing rehabilitation in the community if necessary
- Patients have a wide range of conditions but are usually medically stable
- Patients require less intensive rehabilitation intervention from 1-3 therapy disciplines in relatively short rehabilitation programmes (i.e. 6-12 weeks)
- Patients receive an in-patient local non-specialist rehabilitation service (i.e. Level 3b) which is led by non-medical staff.

Appendix 2: Participant information sheets

Participant Information Sheet

Project Title: Evaluation of a multidisciplinary transitional and community rehabilitation intervention following severe acquired brain injury: A case series exploring community integration (Student Study)

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would include for you. This information sheet explains the study and a member of the research team will go through the information

Part 1: Information about the study:

1. What is the purpose of the study?

The purpose of the study is to evaluate the service provided by the [clinical service] We need to do this to make sure that the support we provide is helpful and to plan future services.

2. Why have I been invited?

You are being asked to take part in a study to evaluate the therapy service that you will receive at home or in the [Transitional Unit]. You have been asked to take part in the study because you are choosing to move home, or to a new home, after you leave hospital.

3. Do I have to take part?

No, it is up to you to decide whether to join the study. If you agree you will be asked to sign a consent form. You can withdraw from the study at any time and this won't affect the service you receive.

4. What will happen if I take part?

When you leave hospital, you will receive therapy assessment and support from [the clinical service], this will either be at the [Transitional Unit] and at home or just at home. [the clinical service] is a team of physiotherapists, occupational therapist, psychologists, speech and language therapists and rehabilitation assistants. You are likely to receive approximately 6 months of therapy input based on your rehabilitation goals. This will include a period of assessment and discussion between you and the team about what you want to achieve. You will then receive blocks of therapy focussed on your goals. You will see whichever members of the team you need to work on your goals. [the clinical service] will also be involved in providing the equipment that you need and training your carers so that they understand your needs.

You will receive the same service from [the clinical service] whether or not you join the study. If you join the study there will be two extra elements:

- You will need to complete some extra assessments; these will take approximately 1 hour and be repeated 5 times in total over the course of the study. Some of these sessions will be video recorded.
- One of your close relatives will be asked to complete an interview about their experiences of your move home and the input from [the clinical service].

5. What are the risks or disadvantages of taking part?

The risks of taking part in the study are very low as you will receive the same service from [the clinical service] that you would receive if you do not take part. There is a small risk that you will find the extra assessments tiring and if this is the case, we will split them into short sessions.

6. What are the benefits of taking part?

You will not receive extra therapy as part of the study because you will be receiving the same service as if you do not take part. If you take part in the study you will receive feedback from the additional assessments carried out which you may help you to understand your condition in more detail.

7. What happens if the research study stops?

If the study stops, you will continue to receive a service from [the clinical service]. You can choose to withdraw from the study at any point.

Part 2: Detailed information about how the research will be managed

1. What if new information becomes available during the study?

If new information about your condition becomes available during the study, we will decide if you should still be receiving the service from [the clinical service] or if you need a different service. If you need a different service then you can withdraw from the study at any time.

2. What happens if I decide to withdraw from the study?

You can withdraw from the study at any time. If you have already completed some of extra assessments, we will ask you if you consent to these assessments still being used in the study. If you do not consent then your assessments will not be used. All of the information collected about you will remain in your [the clinical service] notes which are confidential and stored in locked filing cabinets and a secure computer system.

3. What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the student investigator, Clare Thomas [telephone contact]. If you remain unhappy and wish to complain formally you can do this via the [research department in the sponsoring organisation].

4. Will my information be kept confidential during the study?

Yes. Your assessment results will be kept with your confidential patient notes, in locked cabinets and on a secure computer system. When you are no longer receiving therapy from [the clinical service] your notes will be archived by [the sponsoring organisation] in accordance with the data protection policy. The results from your assessments will be anonymised (all personal information removed) and transferred to a secure computer network at University College London (UCL) so that the data can be analysed. You will be asked to consent to your data being used in

presentations and written publications about the research. Your real name will not be used in these contexts.

In line with normal clinical practice and safeguarding guidance, information collected during the research will be shared if there is a risk of harm to either you or others.

We will inform your General Practitioner (GP) if you consent to take part in this study.

5. Who is organising the research?

The research is sponsored by University College London. It forms part of the Doctorate in Clinical Communication Science being completed by the Student Investigator (Clare Thomas). The time required to organise and complete the research is being provided by [the sponsoring organisation].

6. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed by the local Research Ethics Committee and also by [the sponsoring organisation] and UCL Research and Development Departments.

If you have any questions about the research you can contact: [Contact details removed]

Participant Information Sheet with Symbols to Support Understanding

Project Title: Evaluation of a multidisciplinary transitional and community rehabilitation intervention following severe acquired brain injury: A case series exploring community integration (Student Study)

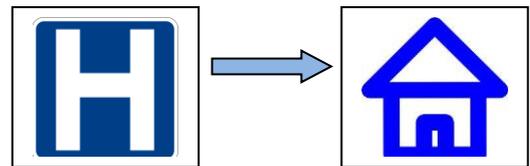
We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would include for you. This information sheet explains the study and a member of the research team will go through the information

This leaflet tells you about a research study that you are being asked to take part in. You will also be given the main information sheet (V2.0 12.05.14) which contains more detailed information but we will use the symbols on this sheet to help you understand the important points.

The study is evaluating the therapy available when you go home.

What will happen?

1. You will leave hospital and come home

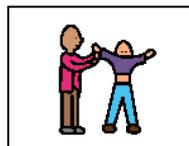


2. You will receive therapy from the [the clinical service]

3. [the clinical service] is a team that includes:



Physiotherapi



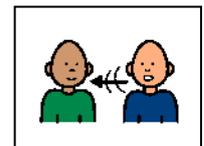
Occupational

Therapist



Speech and

Language Therapist



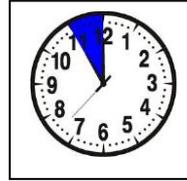
Psychologist

4. You will usually receive about 6 months of therapy.



5. If you take part in the study you will need to do 5 extra assessments which will take about 1 hour each

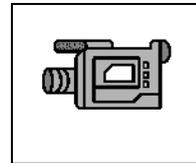
5 x 1 hour



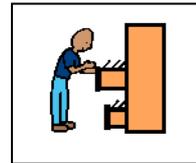
6. You can withdraw from the study at any point if you change your mind and this will not affect your right to continue to receive therapy



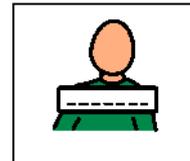
7. You will be video recorded during assessment sessions



8. Your notes, assessments and video will be locked in the [the clinical service offices. Information about you will be shared if there is a risk of harm to you or others.



9. Your data will be used in presentations and written publications about the research. Your real name will not be used in these contexts.



10. If you take part in the study, one of your relative will be asked to agree to be interviewed



If you have any questions about the research you can contact: [Contact Details Removed]

Information Sheet: For Participant's Relative

Project Title: Evaluation of a multidisciplinary transitional and community rehabilitation intervention following severe acquired brain injury: A case series exploring community integration (Student Study)

We have invited your relative to take part in a research study and we would like to tell you about it and invite you to also be involved. This information sheet tells you about the study and a member of the study team will go through this information with you and answer any questions

Part 1: Information about the study:

8. What is the purpose of the study?

The purpose of the study is to evaluate the service provided by the [the clinical service]. We need to do this to make sure that the support we provide is helpful and to plan future services.

9. Why have they been invited?

Your relative has been asked to take part in a study to evaluate the therapy service that they will receive at home or at the [the Transitional Unit]. They have been asked to take part in the study because they are choosing to move home, or to a new home, after they leave hospital. You have been given this information for two reasons, firstly so that you understand what is being asked of your relative, and secondly because we would also like you to take part in an interview as part of the study.

10. Do they have to take part?

No, it is up to them to decide whether to join the study. If they agree they will be asked to sign a consent form. They can withdraw from the study at any time and it won't affect the service they receive.

11. Do I have to take part?

No, even if your relative is taking part in the study, you can decide that you don't want to do the interview. If this happens we will still use your relative's assessment results in the study.

12. What will happen if they take part?

When your relative leaves hospital they will receive therapy assessment and support from [the clinical service], either at home or at the [the transitional service] and the home. [the clinical service] is a team of physiotherapists, occupational therapist, psychologists, speech and language therapists and rehabilitation assistants. Your relative is likely to receive approximately 6 months of therapy input based on their rehabilitation goals. This will include a period of assessment and discussion between you, your relative and the team about what they want to achieve. They will then receive blocks of therapy focussed on their goals. Your relative will see whichever members of the team they need to work on the goals. [the clinical service] will also be involved in providing the equipment needed and training your relative's carers so that they understand their needs.

Your relative will receive the same service from [the clinical service] whether or not they join the study. If they join the study there will be two extra elements:

- They will need to complete some extra assessments; these will take approximately 1 hour and be repeated 5 times in total over the course of the study.
- You will be asked to complete an interview about your experiences of your relative's move home and the input from [the clinical service].

13. What are the risks or disadvantages of taking part?

The risks of taking part in the study are very low as your relative will receive the same service from [the clinical service] that they would receive if they do not take part. There is a small risk that they will find the extra assessments tiring and if this is the case, we will split them into short sessions. The risks of you agreeing to the relative interview are also very low. There is a risk that you will find talking about your relative's experience distressing but we will provide support if this is the case.

14. What are the benefits of taking part?

Your relative will not receive extra therapy as part of the study because they will be receiving the same service as if they do not take part. If they take part in the study they will receive feedback from the additional assessments carried out which you may help you both to understand your condition in more detail. The information that you provide during the interview will help us to plan future services to meet the needs of families as well as patients.

15. What happens if the research study stops?

If the study stops, your relative will continue to receive a service from [the clinical service]. They can choose to withdraw from the study at any point and so can you.

Part 2: Detailed information about how the research will be managed

7. What if new information becomes available during the study?

If new information about your relative's condition becomes available during the study, we will decide if they should still be receiving the service from [the clinical service] or if they need a different service. If they need a different service then they can withdraw from the study at any time.

8. What happens if they or I decide to withdraw from the study?

You or your relative can withdraw from the study at any time. If they have already completed some of extra assessments, we will ask them if they consent to these assessments still being used in the study. If they do not consent then their assessments will not be used. All of the information collected about your relative, including your interview, will remain in their [the clinical service] notes which are confidential and stored in locked filing cabinets and a secure computer system.

9. What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the student investigator, Clare Thomas [telephone contact]. If you remain unhappy and wish to complain formally you can do this via the [research department in the sponsoring organisation].

10. Will my relative's information be kept confidential during the study?

Yes. Their assessment results will be kept with their confidential patient notes, in locked cabinets and on a secure computer system. When they are no longer receiving therapy from [the clinical service] their notes will be archived by [the sponsoring organisation] in accordance with the data protection policy. The results from their assessments will be anonymised (all personal information removed) and transferred to a secure computer network at University College London (UCL) so that the data can be analysed. The data from your interview will be transcribed and all personal information removed before it is transferred to UCL. You and your relative will be asked to consent to the data being used in presentations and written publications about the research. Your real name will not be used in these contexts.

In line with normal clinical practice and safeguarding guidance, information collected during the research will be shared if there is a risk of harm to you or your relative.

We will inform your relative's General Practitioner (GP) if they consent to take part in this study.

11. Who is organising the research?

The research is sponsored by University College London. It forms part of the Doctorate in Clinical Communication Science being completed by the Student Investigator (Clare Thomas). The time required to organise and complete the research is being provided by [the sponsoring organisation].

12. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed by the local Research Ethics Committee and also by [the sponsoring organisation] and UCL Research and Development Departments.

If you have any questions about the research you can contact: [contact details removed]

Appendix 3: Consent forms

Consent form: Participants

Project Title: Evaluation of a multidisciplinary transitional and community rehabilitation intervention following severe acquired brain injury: A case series exploring community integration (Student Study)

Please initial

all boxes

1. I confirm that I have read and understand the information sheet dated 12.05.2014 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from University College London, from regulatory authorities or from the [the sponsoring organisation], where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. I understand that information about me will be shared if there is a risk of harm to myself or others.
4. I understand that I will be video recorded during some assessments as part of the research so that another researcher can check my assessments.
5. I agree to my GP being informed of my participation in the study.
6. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

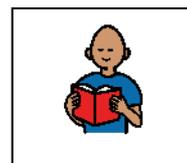
Consent form: Symbol Sheet

Project Title: Evaluation of a multidisciplinary transitional and community rehabilitation intervention following severe acquired brain injury: A case series exploring community integration

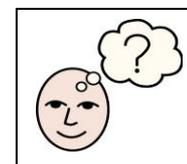
(Student Study)

Please initial all boxes

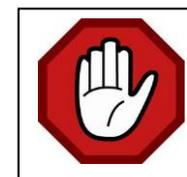
1. I have read and understood the information sheet



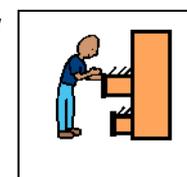
2. I have been given time to think about the information and ask questions



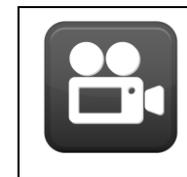
3. I understand that I can withdraw from the study if I want to stop.



4. I understand that people from UCL and [the sponsoring organisation] may need to look at my notes. I understand information will be shared if I am at risk of harm.



5. I understand that I will be videoed having some assessments



6. I agree to my GP being informed of my participation in the study.



7. I agree to take part in the study.

Name of Participant

Date

Signature

Name of Person

Date

Signature

taking consent.

Consent form: Participant's Relative

Project Title: Evaluation of a multidisciplinary transitional and community rehabilitation intervention following severe acquired brain injury: A case series exploring community integration (Student Study)

Please initial all
boxes

1. I confirm that I have read and understand the relative information sheet dated 12.05.2014 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my relative's medical care or legal rights being affected.

3. I understand that the transcript of my interview may be looked at by individuals from University College London, from regulatory authorities or from the [the sponsoring organisation], where it is relevant to this research. I give permission for these individuals to have access to my interview transcript. I understand that information about me will be shared if there is a risk of harm to myself or others.

4. I understand that my interview will be audio and video recorded to enable transcription and that direct quotes may be used in the report and any follow up publications.

5. I agree to my relative's GP being informed of my participation in the study.

6. I agree to take part in an interview as part of my relative's participation in the study.

Name of Participant	Date	Signature

Name of Person	Date	Signature

taking consent.

Appendix 4: Proforma for peer review of the community integration measure

Proforma for peer review of Community Integration Measure

Video reference:

Peer reviewer:

Please review the sample video and comment on the following questions. Please make reference to the summary of themes on adapting the Community Integration measure attached.

1. Did the assessor use materials or strategies appropriate to the participants cognitive and communication needs to support the participant to engage in the measure?
2. Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?
3. Do you have any other comments to make?

Signed: _____

Date: _____

Themes on adapting the Community Integration Measure

The following themes were taken into account when adapting the Community Integration Measure (CIM) for people with communication impairments in the current study, the themes are taken from the work described in section 4.2 by Clay (2015). The theme titles are taken directly from Clay (pages 19-45) with summaries and examples added by the researcher in the current study, with reference to Clay's focus group data.

1. Perspectives on how to make the CIM accessible for people with acquired communication disorders.

Clay does not provide a standardised proforma for adapting the measure because opinions within the focus groups differed. However, the themes provided can be used to guide researcher to consider different types of adaptations.

- **Facilitating comprehension of the measure and the need for comprehension Support**

The vocabulary, syntax and concepts within the CIM statements may be difficult to comprehend. Researcher should consider the following methods to facilitate comprehension.

- **Changing and rephrasing:** Statements could be rephrased if this can be done without losing the meaning of the statement. Care should be taken to not change the underlying concepts by using simplified concepts or statements.
- **Verbally clarifying concepts:** Concepts can be clarified at the start of the measure, for example, a background explanation could be given about the concept of community and what this refers to at the start of the measure. During individual items, clarification can be provided about concepts such as what is productive activity. However, the measure is designed to reflect the person's own concepts of community integration and therefore any clarification should not be leading.

- **Using non-verbal supports:** Non-verbal support can be used to assist comprehension including pictorial supports, large text or visual scales. Visual supports should be appropriate to the individual and not simplify or change the concepts.
- **Make more concrete and specific:** Concrete examples can be given to support understanding of the statements if this supports comprehension without simplifying the concepts.
- **Removing physical barriers and facilitating access:** Changes can be made to the measure to remove physical barriers to access, for example the font could be increased or the response options could be set out in a table or as a visual scale.
- **Enabling completion of the task:**
 - **Cognitive supports and prompts:** It may be appropriate to provide additional supports for people with cognitive impairments such as re-directing to the task or reducing distracting information. This support should enable general attention to the measure rather than giving direction about the concepts of how to respond.
 - **Explanation of the task and purpose:** It may be appropriate to provide an explanation about what information the measure is trying to gather at the beginning of administration, or to provide a recap if a person has completed the scale previously. This might include a practice statement if appropriate. However the researcher should be mindful of not adding to the complexity with a long explanation.
- **Emotional and social sensitivity:** Due to the personal nature of some of the concepts in the measure, it may be appropriate to build in some rapport building, if the researcher is not known to the person.

2. Considerations to take into account in making the CIM accessible:

The following themes emerged about what should be taken into account by the researcher when considering adaptations to the measure.

- **Ensuring the information gathered is meaningful and useful**
 - **Information is accurate and a true reflection:** Care should be taken to ensure that the response to each statement is an accurate reflection of the person's beliefs. This might involve checking back or clarifying answers.
 - **Sensitivity, responsiveness and the need for further information:** It may be valuable to record additional qualitative comments to understand why a person has made the rating they have.

- **Reducing error:** As above, recording qualitative information is a potential way to reduce error in the interpretation of the measure.
- **Potential pitfalls of making the CIM accessible**
 - **Losing key meanings:** There is a risk that key meanings will be lost by making adaptations to the statements or using physical supports (e.g. pictures). Researchers should be familiar with the communication needs of the person and make only the necessary adaptations to assist comprehension.
 - **Impacting on service user experience and responses:** strategies used to support comprehension may compromise the subjectivity of the measure if the researcher offers examples or explains concepts. As above, careful consideration should be given to where additional support is needed. If examples are offered to assist use of the scales, they should aim not to influence the person's own concepts or subjective feelings of integration.
 - **Impacting on the measure's properties:** There is a risk that the validity of the measure could be compromised by making adaptations and therefore care should be taken to only adapt the measure based on the person's communication needs and to minimise simplification or of wording or concepts.
- **Tailoring administration**
 - **Tailor to individual needs:** Administration of the measure should be by a skilled professional who is aware of the person's communication needs and able to make a judgement about adaptations.
 - **Tailor to the clinical context:** The researcher should consider the clinical context and adapt the measure appropriately to the purpose. More adaptation would be appropriate if the measure is used as a clinical goals setting support but if being used for research, the least possible adaptation should be used.
 - **Tailor to individual preference:** Adaptations to the measure should take into account the person's preferences. E.g. time and location of administration.

Appendix 5: Interview schedule

1. Can you describe your experience of the discharge planning process when your relative left hospital?

Potential prompts:

- Aware of timescales/ dates?
- Aware of services involved?
- Consulted about goals and discharge?
- Involved in discharge planning?

2. Can you describe your experience of the initial period when your relative was at the [the Transitional Unit]?

Potential prompts:

- Waiting times for services/ equipment?
- Support available?
- Challenges and positive experiences?
- Transition to home supported?

3. Can you describe your experience of the initial period when your relative was at home full time and working with the [the Community Team]?

Potential prompts:

- Equipment/ care in place/ successful
- Aware of where to seek support
- Handover/ transition period

4. Can you describe your experience now that your relative is home has been home for a longer period?

Potential prompts:

- Level of on-going support?
- On-going access to services/ information?
- Challenges and positive experiences?

5. What was your experience of the support provided by the [the clinical service] overall?
6. Do you have any feedback that you would like to add about your experience?

Appendix 6: Outcome measure data Billy

Name (pseudonym): Billy

Community Integration Measure:

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
I feel like part of this community, like I belong here	2	4	2	4	5
I know my way around this community	5	4	2	3	5
I know the rules in this community and I can fit in with them	5	2	2	5	5
I feel that I am accepted in this community	4	4	1	5	3
I can be independent in this community	5	5	1	5	3
I like where I am living now	4	2	1	3	5
There are people I feel close to in this community	3	5	4	1	4
I know a number of people in this community well enough to say hello and have them say hello back	4	5	1	3	4
There are things I can do in this community for fun in my spare time	3	5	1	1	3
I have something to do in this community during the main part of my day that is useful and productive	4	5	1	5	4
Total	39	41	16	35	41

Name (pseudonym): Billy

UKFIMFAM:

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Eating	5	5	6	6	6
Swallowing	6	7	7	6	6
Grooming	6	6	6	7	7
Bathing	6	6	7	7	7
Dressing Upper Body	5	5	5	7	7
Dressing Lower Body	3	2	6	6	6
Toileting	6	6	7	7	7
Bladder (assistance)	7	7	7	7	7
Bladder (frequency)	7	7	7	7	7
Bowel (assistance)	6	6	7	7	7
Bowel (frequency)	6	5	7	6	6
Bed, chair, wheelchair transfer	6	6	6	6	6
Toilet transfer	6	6	6	6	6
Tub, shower transfer	6	6	6	6	6
Car transfer	6	6	6	6	6
Locomotion (walking)	2	2	6	4	4
Locomotion (wheelchair)	6	5	5	6	6
Mode	c	c	c	c	c
Stairs	1	1	1	2	2
Community mobility	2	2	3	4	4
Mode	p	p	p	p	p
Comprehension	4	4	4	5	5
Expression	3	2	2	4	4
Reading	3	4	4	4	4
Writing	2	3	4	4	4
Speech Intelligibility	3	4	4	4	4
Social Interaction	4	5	5	5	5
Emotional status	3	3	3	4	5
Adjustment to limitations	4	3	5	5	5
Leisure activities	5	6	4	5	6
Problem solving	5	5	5	5	5
Memory	6	6	6	6	6
Orientation	6	5	6	6	6
Concentration	6	6	6	6	6
Safety awareness	5	5	5	6	6
Meal preparation	5	4	4	5	5
Laundry	5	3	4	5	5
Housework	2	3	3	5	5
Shopping	4	3	3	4	4
Financial Management	3	3	4	4	4
Work/ education	2	1	1	2	2
Total	163	159	173	189	191

Name (pseudonym): Billy

Mayo Portland Adaptability Index

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Mobility	4	4	3	3	3
Use of hands	4	4	4	3	3
Vision	0	0	0	0	0
Audition	0	0	0	0	0
Dizziness	0	0	0	0	0
Motor Speech	3	3	3	3	3
Verbal Communication	4	4	3	3	2
Non verbal communication	3	2	2	0	0
Attention/ concentration	1	0	0	1	1
Memory	1	1	1	0	1
Fund of Information	0	0	0	1	1
Novel problem solving	3	2	2	2	2
Visuospatial abilities	0	0	0	0	0
Anxiety	3	2	2	2	2
Depression	1	2	1	2	2
Irritability, anger, aggression	3	3	2	2	2
Pain and headache	3	3	2	1	1
Fatigue	3	2	2	2	2
Sensitivity to mild symptoms	3	2	2	1	2
Inappropriate social interaction	2	2	2	1	1
Impaired self-awareness	2	3	2	1	1
Family/ significant relationships	2	2	2	2	2
Initiation	1	0	0	0	0
Social contact with friends, work associates and others	3	3	3	2	2
Leisure and recreational activities	3	3	3	2	2
Self care	2	2	1	0	1
Residence	3	2	2	2	2
Transportation	3	4	4	2	2
Paid employment	n/a	n/a	n/a	n/a	n/a
Other employment	4	4	4	3	4
Managing money and finance	3	3	2	1	2
Ability subscale	20	18	16	16	16
Adjustment subscale	28	24	22	18	20
Participation subscale	19	19	17	11	13
Total (Raw)	60	58	49	41	44

Appendix 7: Outcome measure data Richard

Name (pseudonym): Richard

Community Integration Measure

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
I feel like part of this community, like I belong here	5	4	4	3	4
I know my way around this community	3	5	3	4	2
I know the rules in this community and I can fit in with them	5	5	4	5	5
I feel that I am accepted in this community	5	5	4	5	2
I can be independent in this community	5	2	5	5	5
I like where I am living now	3	4	5	5	5
There are people I feel close to in this community	5	3	4	4	3
I know a number of people in this community well enough to say hello and have them say hello back	4	5	4	1	4
There are things I can do in this community for fun in my spare time	5	5	5	5	5
I have something to do in this community during the main part of my day that is useful and productive	1	4	2	4	4
Total	41	42	40	41	39

Name (pseudonym): Richard

UKFIMFAM

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Eating	6	6	7	7	7
Swallowing	6	6	7	7	7
Grooming	6	6	7	7	7
Bathing	7	7	7	7	7
Dressing Upper Body	7	7	7	7	7
Dressing Lower Body	7	7	7	7	7
Toileting	7	7	7	7	7
Bladder (assistance)	7	7	7	7	7
Bladder (frequency)	7	7	7	7	7
Bowel (assistance)	7	7	7	7	7
Bowel (frequency)	7	7	7	7	7
Bed, chair, wheelchair transfer	7	7	7	7	7
Toilet transfer	7	7	7	7	7
Tub, shower transfer	7	7	7	7	7
Car transfer	7	7	7	7	7
Locomotion (walking)	7	7	7	7	7
Locomotion (wheelchair)	0	0	0	0	0
Mode	w	w	w	w	w
Stairs	7	7	7	7	7
Community mobility	5	4	7	7	7
Mode	p	p	p	p	p
Comprehension	6	6	6	6	6
Expression	6	6	6	6	6
Reading	6	6	6	6	6
Writing	6	6	6	6	6
Speech Intelligibility	5	5	5	5	5
Social Interaction	4	5	6	5	5
Emotional status	3	3	5	6	6
Adjustment to limitations	4	4	5	6	6
Leisure activities	5	5	6	6	6
Problem solving	5	5	6	5	5
Memory	3	3	5	5	5
Orientation	6	6	6	7	7
Concentration	4	6	6	6	6
Safety awareness	6	5	6	6	6
Meal preparation	6	5	6	7	7
Laundry	6	6	7	6	6
Housework	5	5	5	5	4
Shopping	4	4	6	7	7
Financial Management	3	2	3	5	5
Work/ education	1	1	1	4	3
Total	201	200	220	227	225

Name (pseudonym): Richard

Mayo Portland Adaptability Index

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Mobility	0	1	0	0	0
Use of hands	0	0	0	0	0
Vision	3	3	3	2	2
Audition	0	0	0	0	0
Dizziness	0	1	0	0	0
Motor Speech	2	3	2	2	2
Verbal Communication	1	1	1	1	1
Non verbal communication	3	2	2	2	2
Attention/ concentration	2	2	2	1	1
Memory	3	2	3	0	0
Fund of Information	2	1	2	1	1
Novel problem solving	1	2	1	2	2
Visuospatial abilities	3	2	2	0	0
Anxiety	2	2	2	1	1
Depression	2	1	1	0	0
Irritability, anger, aggression	2	2	2	1	1
Pain and headache	0	1	0	0	0
Fatigue	3	3	2	1	1
Sensitivity to mild symptoms	2	2	2	1	1
Inappropriate social interaction	2	2	2	2	2
Impaired self-awareness	3	3	2	2	2
Family/ significant relationships	4	4	4	3	3
Initiation	3	3	2	2	3
Social contact with friends, work associates and others	3	3	2	1	2
Leisure and recreational activities	2	3	2	2	3
Self care	0	1	0	0	0
Residence	3	3	2	1	2
Transportation	3	2	1	2	2
Paid employment					
Other employment	4	4	3	3	3
Managing money and finance	4	3	3	2	2
Ability subscale	19	19	17	11	10
Adjustment subscale	28	29	23	16	19
Participation subscale	19	20	14	12	16
Total (Raw)	58	59	48	34	37

Appendix 8: Outcome measure data Nathan

Name (pseudonym): Nathan

Community Integration Measure

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
I feel like part of this community, like I belong here	5	4	5	4	5
I know my way around this community	5	5	5	5	5
I know the rules in this community and I can fit in with them	5	5	5	5	4
I feel that I am accepted in this community	5	5	5	5	5
I can be independent in this community	5	5	5	5	5
I like where I am living now	5	4	5	5	5
There are people I feel close to in this community	5	5	5	5	5
I know a number of people in this community well enough to say hello and have them say hello back	5	5	5	5	5
There are things I can do in this community for fun in my spare time	5	5	5	5	5
I have something to do in this community during the main part of my day that is useful and productive	4	5	5	5	5
Total	49	48	50	49	49

Name (pseudonym): Nathan

UKFIMFAM

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Eating	6	6	7	7	7
Swallowing	6	6	7	7	7
Grooming	5	5	7	7	7
Bathing	4	5	7	7	7
Dressing Upper Body	5	5	7	7	7
Dressing Lower Body	5	5	7	7	7
Toileting	7	7	7	7	7
Bladder (assistance)	5	5	7	7	7
Bladder (frequency)	3	3	7	7	7
Bowel (assistance)	7	7	7	7	7
Bowel (frequency)	7	7	7	7	7
Bed, chair, wheelchair transfer	7	7	7	7	7
Toilet transfer	7	7	7	7	7
Tub, shower transfer	7	7	7	7	7
Car transfer	7	7	7	7	7
Locomotion (walking)	7	7	7	7	7
Locomotion (wheelchair)	0	0	0	0	0
Mode	w	w	w	w	w
Stairs	7	7	7	7	7
Community mobility	3	3	7	7	7
Mode	p	p	p	p	p
Comprehension	4	5	7	7	6
Expression	3	3	6	7	7
Reading	6	6	7	7	7
Writing	6	6	7	7	7
Speech Intelligibility	7	7	7	7	7
Social Interaction	3	5	7	7	7
Emotional status	6	5	7	7	6
Adjustment to limitations	3	2	5	6	5
Leisure activities	3	3	6	7	7
Problem solving	4	5	5	5	5
Memory	2	2	4	6	5
Orientation	4	5	7	7	7
Concentration	5	5	6	5	6
Safety awareness	4	2	6	6	6
Meal preparation	5	5	5	7	7
Laundry	2	2	5	7	7
Housework	2	1	6	7	7
Shopping	1	2	4	7	7
Financial Management	1	1	3	5	5
Work/ education	1	1	2	5	4
Total	165	167	224	241	237

Name (pseudonym): Nathan

Mayo Portland Adaptability Index

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Mobility	1	1	0	0	0
Use of hands	1	1	1	1	1
Vision	0	0	0	0	0
Audition	1	1	0	0	0
Dizziness	1	1	0	0	0
Motor Speech	0	0	0	0	0
Verbal Communication	2	2	2	1	1
Non verbal communication	2	2	0	1	1
Attention/ concentration	3	3	1	1	1
Memory	4	4	3	3	3
Fund of Information	3	3	1	1	1
Novel problem solving	4	4	3	2	2
Visuospatial abilities	3	2	2	2	2
Anxiety	1	1	0	0	0
Depression	2	1	0	0	0
Irritability, anger, aggression	2	1	0	0	0
Pain and headache	0	1	0	0	1
Fatigue	3	2	2	2	2
Sensitivity to mild symptoms	0	0	0	0	0
Inappropriate social interaction	0	0	0	0	0
Impaired self-awareness	4	4	3	3	3
Family/ significant relationships	4	4	3	3	3
Initiation	4	4	3	3	3
Social contact with friends, work associates and others	4	4	3	1	1
Leisure and recreational activities	4	4	3	1	1
Self care	3	4	1	0	0
Residence	4	4	3	2	1
Transportation	4	4	1	1	2
Paid employment	n/a	n/a	3	4	4
Other employment	4	4	n/a	n/a	n/a
Managing money and finance	4	4	3	2	2
Ability subscale	23	22	13	12	12
Adjustment subscale	28	26	17	13	14
Participation subscale	29	30	19	12	12
Total (Raw)	68	66	40	32	33

Appendix 9: Outcome measure data Louise

Name (pseudonym): Louise

Community Integration Measure

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
I feel like part of this community, like I belong here	2	4	4	5	5
I know my way around this community	2	4	2	4	4
I know the rules in this community and I can fit in with them	3	5	2	5	5
I feel that I am accepted in this community	4	5	1	3	5
I can be independent in this community	2	4	5	2	3
I like where I am living now	2	2	4	5	3
There are people I feel close to in this community	3	4	5	5	5
I know a number of people in this community well enough to say hello and have them say hello back	4	5	5	5	5
There are things I can do in this community for fun in my spare time	1	2	5	5	3
I have something to do in this community during the main part of my day that is useful and productive	2	2	4	5	4
Total	25	37	37	44	42

Name (pseudonym): Louise

UKFIMFAM

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Eating	5	5	5	7	7
Swallowing	4	4	6	7	7
Grooming	3	3	4	3	3
Bathing	2	2	3	2	2
Dressing Upper Body	2	2	2	2	2
Dressing Lower Body	2	2	1	2	2
Toileting	2	2	2	2	2
Bladder (assistance)	6	5	3	2	2
Bladder (frequency)	2	2	2	6	6
Bowel (assistance)	3	3	2	2	2
Bowel (frequency)	3	3	3	6	6
Bed, chair, wheelchair transfer	2	2	4	4	5
Toilet transfer	2	2	3	3	5
Tub, shower transfer	2	2	1	3	5
Car transfer	2	1	1	1	1
Locomotion (walking)	1	1	1	1	1
Locomotion (wheelchair)	2	1	2	2	3
Mode	c	c	c	c	c
Stairs	1	1	1	1	1
Community mobility	1	1	1	1	1
Mode	c	c	c	c	c
Comprehension	6	6	6	6	6
Expression	5	5	6	6	6
Reading	7	6	6	5	5
Writing	6	6	6	5	5
Speech Intelligibility	5	5	5	5	5
Social Interaction	5	6	6	6	6
Emotional status	3	3	1	6	6
Adjustment to limitations	3	3	5	7	6
Leisure activities	4	5	6	2	4
Problem solving	5	5	5	3	4
Memory	6	5	6	4	4
Orientation	7	7	7	7	7
Concentration	6	6	5	4	4
Safety awareness	3	3	4	6	6
Meal preparation	2	2	2	1	1
Laundry	1	1	1	1	1
Housework	1	1	1	1	1
Shopping	1	1	1	1	1
Financial Management	1	1	1	1	1
Work/ education	1	1	1	1	1
Total	115	113	121	122	130

Name (pseudonym): Louise

Mayo Portland Adaptability Index

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Mobility	4	4	4	4	4
Use of hands	4	4	4	4	4
Vision	2	2	3	0	0
Audition	0	0	0	0	0
Dizziness	1	2	2	1	1
Motor Speech	3	3	3	3	3
Verbal Communication	1	1	0	1	1
Non verbal communication	2	2	3	2	1
Attention/ concentration	2	2	2	2	2
Memory	1	2	0	2	2
Fund of Information	0	0	0	1	1
Novel problem solving	3	3	3	2	2
Visuospatial abilities	1	1	1	2	2
Anxiety	3	3	4	3	2
Depression	1	1	1	2	1
Irritability, anger, aggression	2	2	2	0	0
Pain and headache	3	3	2	2	0
Fatigue	3	3	2	3	1
Sensitivity to mild symptoms	3	3	2	3	3
Inappropriate social interaction	0	0	0	0	0
Impaired self-awareness	2	2	0	0	1
Family/ significant relationships	3	3	3	1	1
Initiation	2	2	2	2	2
Social contact with friends, work associates and others	4	4	1	2	1
Leisure and recreational activities	4	4	3	2	1
Self care	4	4	4	3	3
Residence	4	4	2	3	4
Transportation	4	4	3	4	4
Paid employment					
Other employment	4	4	4	3	3
Managing money and finance	4	4	3	4	4
Ability subscale	23	25	25	23	22
Adjustment subscale	29	29	21	17	13
Participation subscale	28	28	19	22	21
Total	70	72	59	56	56

Appendix 10: Outcome measure data Simon

Name (pseudonym): Simon Community Integration Measure

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
I feel like part of this community, like I belong here	4	2	1	4	3
I know my way around this community	5	2	1	3	4
I know the rules in this community and I can fit in with them	5	3	1	5	5
I feel that I am accepted in this community	3	4	1	5	4
I can be independent in this community	5	4	1	4	5
I like where I am living now	2	3	3	5	5
There are people I feel close to in this community	1	3	1	4	4
I know a number of people in this community well enough to say hello and have them say hello back	5	3	1	3	3
There are things I can do in this community for fun in my spare time	5	4	1	5	4
I have something to do in this community during the main part of my day that is useful and productive	2	4	1	5	4
Total	37	32	12	43	41

Name (pseudonym): Simon

UKFIMFAM

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Eating	7	7	7	7	7
Swallowing	7	7	7	7	7
Grooming	5	5	6	6	6
Bathing	5	5	1	6	6
Dressing Upper Body	7	7	7	6	6
Dressing Lower Body	7	7	7	6	6
Toileting	7	7	7	7	7
Bladder (assistance)	7	7	7	7	7
Bladder (frequency)	7	7	7	7	7
Bowel (assistance)	7	7	7	7	7
Bowel (frequency)	7	7	7	7	7
Bed, chair, wheelchair transfer	7	7	7	7	7
Toilet transfer	7	7	7	7	7
Tub, shower transfer	7	7	5	7	7
Car transfer	7	7	7	7	7
Locomotion (walking)	7	7	7	7	7
Locomotion (wheelchair)	0	0	0	0	0
Mode	w	w	w	w	w
Stairs	7	7	7	7	7
Community mobility	3	2	2	7	7
Mode	p	p	p	p	p
Comprehension	5	5	5	5	5
Expression	5	5	5	5	5
Reading	6	6	7	6	6
Writing	2	1	1	6	6
Speech Intelligibility	7	7	7	7	7
Social Interaction	2	3	2	4	5
Emotional status	3	3	1	4	5
Adjustment to limitations	1	1	2	4	4
Leisure activities	3	3	2	1	3
Problem solving	4	5	5	3	3
Memory	3	2	2	2	3
Orientation	4	4	3	5	5
Concentration	5	5	5	6	6
Safety awareness	5	5	5	4	4
Meal preparation	4	5	5	3	3
Laundry	2	2	1	3	4
Housework	2	2	1	3	4
Shopping	3	3	2	4	4
Financial Management	1	1	2	4	4
Work/ education	1	1	1	1	1
Total	172	172	162	188	195

Name (pseudonym): Simon

Mayo Portland Adaptability Index

Item	1. Baseline	2. Repeated Baseline	3. End of Intervention 1	4. End of Intervention 2	5. End of Non-Intervention
Mobility	1	0	0	0	0
Use of hands	0	0	0	0	0
Vision	0	0	0	0	0
Audition	0	0	0	0	0
Dizziness	1	0	0	0	0
Motor Speech	0	0	0	0	0
Verbal Communication	2	3	2	1	1
Non verbal communication	3	4	3	2	1
Attention/ concentration	2	2	2	2	1
Memory	4	4	4	3	3
Fund of Information	4	4	2	3	2
Novel problem solving	3	3	3	3	3
Visuospatial abilities	2	3	3	0	0
Anxiety	2	2	3	2	2
Depression	1	2	2	2	1
Irritability, anger, aggression	3	3	3	1	1
Pain and headache	0	0	0	2	1
Fatigue	2	2	2	2	2
Sensitivity to mild symptoms	2	0	1	1	1
Inappropriate social interaction	3	3	4	2	2
Impaired self-awareness	3	4	4	2	2
Family/ significant relationships	4	4	4	3	3
Initiation	3	3	2	3	2
Social contact with friends, work associates and others	3	2	2	2	3
Leisure and recreational activities	3	4	4	4	3
Self care	3	3	3	3	2
Residence	4	4	4	3	3
Transportation	4	4	4	3	3
Paid employment					
Other employment	4	4	4	4	4
Managing money and finance	4	3	3	2	2
Ability subscale	20	20	17	13	10
Adjustment subscale	29	29	31	25	23
Participation subscale	26	25	24	21	19
Total	66	65	64	50	44

Appendix 11: Peer review forms

Proforma for peer review of Community Integration Measure

Video reference: Billy Video 1

Peer reviewer: [Name removed]

Please review the sample video and comment on the following questions. Please make reference to the summary of themes on adapting the Community Integration measure attached.

1. Did the researcher use materials or strategies appropriate to the participants cognitive and communication needs, to support the participant to engage in the measure?
Yes. Billy was provided with an explanation of the measure at the start. Non-verbal supports (written version of the measure and visual rating scale) were used to enable Billy to express his opinion on each statement. An explanation was provided on how to use the visual rating scale. The researcher used gestures to emphasise key words. Billy was redirected to the response options of the measure when he provided a non-specific verbal 'no' response. His response was clarified using the written response options when required.
2. Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?
No. The statements within the measure were not changed so test validity should be unchanged. The one incident of clarification to check response only required repetition, not rephrasing or simplification. Use of written rating scale enabled Billy to complete the questionnaire and gain his opinion.
3. Do you have any other comments to make?
Billy attended appropriately to survey and scale. His responses were made without hesitation and supported by his facial expression and intonation. The strategies employed to enable Billy to access the measure were clearly tailored to him.

Proforma for peer review of Community Integration Measure

Video reference: Richard Video 2

Peer reviewer: [Name removed]

Please review the sample video and comment on the following questions.
Please make reference to the summary of themes on adapting the Community Integration measure attached.

1. Did the researcher use materials or strategies appropriate to the participants cognitive and communication needs, to support the participant to engage in the measure?
No clear adaptation evident. An explanation of measure and scale was provided at the start and the concept of 'community' was clarified as per protocol.
2. Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?
No: Richard wanted to rate some statements 'in between' scale points and did so for one statement. It is not known to the peer reviewer if this permissible by the measure's authors.
3. Do you have any other comments to make?
Richard actively engaged with the measure and made many additional comments to supplement and justify his responses. Richard made concrete interpretation of the concept of 'rules' (re related this to criminal convictions). In a clinical situation it may have been beneficial to clarify this concept and check his response.

Proforma for peer review of Community Integration Measure

Video reference: Nathan Video 3

Peer reviewer: [Name removed]

Please review the sample video and comment on the following questions. Please make reference to the summary of themes on adapting the Community Integration measure attached.

1. Did the researcher use materials or strategies appropriate to the participants cognitive and communication needs, to support the participant to engage in the measure?
Yes. The researcher provided an explanation of measure and scale at the start and clarified the concept of 'community'. The rate at each statement were presented were clearly adapted to the Nathan's processing speed.
2. Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?
No, the statements and mode of delivery did not require adaptation.
3. Do you have any other comments to make?
Nathan often elaborated on the statement of the measure or justified his choices with personally salient statements. The information gained from the measure appeared to be an accurate reflection of Nathan's beliefs.

Proforma for peer review of Community Integration Measure

Video reference: Louise Video 4

Peer reviewer: [Name removed]

Please review the sample video and comment on the following questions. Please make reference to the summary of themes on adapting the Community Integration measure attached.

1. Did the researcher use materials or strategies appropriate to the participants cognitive and communication needs, to support the participant to engage in the measure?
Yes. An explanation of measure and scale was provided at the start and the concept of 'community' was clarified. The rate of presentation appeared appropriate to the processing/response speed of Louise. Comprehension of the task was checked and confirmed. Non-verbal supports were provided (visual rating scale). An example was used to practice use of the scale. Louise used the rating scale to provide her response to each statement. Louise was redirected to the scale when needed. The researcher checked and confirmed each response against the scale used in the measure.
2. Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?
No. The statements did not require adaptation and responses on the visual rating scale were converted into the scale employed by the measure. This process was checked and confirmed with Louise every time to ensure that the response to each statement was accurate reflection of her belief's
3. Do you have any other comments to make?
Louise was actively participating in completion of the measure, making additional qualitative comments to justify or amend her responses.

Proforma for peer review of Community Integration Measure

Video reference: Simon Video 5

Peer reviewer: [Name removed]

Please review the sample video and comment on the following questions. Please make reference to the summary of themes on adapting the Community Integration measure attached.

1. Did the researcher use materials or strategies appropriate to the participants cognitive and communication needs, to support the participant to engage in the measure?
Yes. An explanation of measure and scale was provided at the start. Simon made qualitative comments that indicated his comprehension. A written version of the scale was provided to aid Simon's memory. This was a clear adaptation to Simon's needs as he made comments relating to his memory impairment. Simon made many appropriate additional qualitative comments to question the statements and qualify his responses/potential responses. The researcher provided cognitive supports to acknowledge his comments and redirect him to completing the measure, this included repetition, explanation of how task needs to be completed (i.e. without influence), clarification of concepts (e.g. 'people in the community' includes carers) and making the statement more concrete (e.g. how would you rate that other the past few weeks).
2. Did the use of these materials or strategies impact on the validity of the assessment in the opinion of the peer reviewer?
No. Statements and mode of delivery did not require adaptation.
3. Do you have any other comments to make?
Simon actively participated in completing the measure, making additional qualitative comments to qualify his responses. He made some interesting insights into the challenges of the current wording of the statements and scale e.g. 'sometimes agree feels much lower down than always agree'.

Appendix 12: Interview transcripts

Interview 1: Transcript

I = Interviewer

RP = Relative Participant

A pseudonym is used for the participant referred to in this interview. All other names of people and services have been removed, text in brackets [] provides the description of the service or role referred to.

I: Thank you so much for coming.

RP: It's alright

I: So this is a semi-structured interview, to find out your experiences. So first of all, can you describe your experience of the discharge planning process when Billy left hospital?

RP: I, I.... When he left hospital at [Level 1 Unit] or when he left this unit (Transitional Unit)?

I: [Level 1 Unit]

RP: Erm.... Well.... it was quite well done. I mean this was brand new, I believe. He was one of the first intake of patients to come here. And erm he was ready to come he'd, you know, there'd been a bit of a delay, but he was, he was, we were happy. He was really glad to move on to the next stage.

I: And were you aware of timings and dates?

RP: Yeah, yeah, yeah. Billy had his calendar and everyone was quite thorough in, you know, obviously his understanding, it was important to visualise, you know, the things, so it was very clear for all of us to see. Anyone who came to see him knew what was going on and when.

I: And you were consulted about goals and discharge planning?

RP: Yes, yeah.

I: Can you describe your experience of the initial period when he was here the [Transitional Unit]

RP: Well I think it was, erm, there was a bit more of a level of privacy and independence here for him. So you know he had his own bathroom, which was really important. And erm he, I just felt he was happier, he'd, you know. He was ready for here so this was a really good transitional place for him. You know, it was good. It was a good experience.

I: And how about waiting times for other services or equipment?

RP: Like? I don't know if there was any... there obviously wasn't an experience?

RP: It wasn't anything that I experienced.

I: No.

RP: No, I don't think so no.

I: So there were positive experiences. Were there any challenges you found over that initial period?

RP: Erm, sometimes. It was always really difficult to know when Billy had concerns or issues because of his communication.... skills. And erm, later on for example, when he eventually got housed in his own flat he was upset about some things and, you know, it was very difficult to understand whether it was him and his difficulty in accepting erm.... changes that people had to make to appointments or whether people weren't turning up for appointments. It was always really quite difficult to work out whether he was justified in his.... You know he used to get quite frustrated with some issues, you know some of his erm... physio for example. He insinuated to me that they weren't... appointments weren't always kept, *but* when I spoke to other people, it was that, you know, it was always explained to him and things like that. We got through it, you know, we got through it. But not here. I mean here, when he was here things were fine yeah.

I: And the transition from here to his new accommodation was supported?

RP: Yeah, yeah, it was good yeah. I think he was given loads of support you know by his.... I can't remember the erm, some of the people's names. There was a young man, I can't remember the name of him. You know I think everything was really explained to him and er, I personally, you know obviously I can't speak for Billy, but personally I think it erm was handled well that.

I: That's great. Can you describe your experience of the Initial period when Billy was home full time and working with the [Community Team]?

RP: My experience or his experience?

I: Your experience.

RP: Well it, I knew it was quite a stressful time for Billy because... you know, it's like from each stage it takes a while for all the staff to get used to his ways and his personality and his particular frustrations and how he deals with things. And I knew the transitional period going there was going to be quite difficult for him because he was so determined to be independent that he, if people did things incorrectly, I knew he was quite aggressive and quite, so it was quite a stressful period at first for him and I was contacted quite frequently by the team there because they didn't know how to deal with him and he was difficult at times. But erm it got better, you know, the more they got to know him and understand what he did like and what he didn't like and how much care he actually needed and how much he valued his privacy, it all settled down quite quickly. I think it was just a natural...you know every time we moved to, you know, this step and then the next step, his final move, it was difficult because he got very settled and then had to adjust, you know, accordingly.

I: And things like the equipment and care that was all in place was it?

RP: Er, Yeah, yeah, the flat was good. We er, he, you know, needed very little equipment really. He had his wheelchair, his stick. But.... no, it was fine. He had his care workers, [Unclear], the group that come and take him out, that group were involved and he started getting involved in some social groups, the gym etc., so I think he's been extremely lucky. I mean the area generally seems to have this particular erm area of care for stroke and brain injuries really well covered. I thought. I thought he was lucky. Yeah.

RP: Can you describe your experience *now* that Billy's been home for a longer period of time?

I: Erm yeah I'm satisfied. I mean... I'm satisfied that he's in the right place. Erm the care's there if he needs it, although he doesn't have much, erm you know he washes himself, he does his own clothes. He does, he relies on very little care from the actual staff, but they are there if needed. He needs to be in a situation like that. Erm I... yeah, he's in a great flat. Erm, we've furnished it for him, he seems happy. Yeah, I think it's great, for him.

I: And you're aware of how you can access services and information on-going?

RP: Yeah, yes, yeah. It's all been really clear. I mean I, I've, I help him with certain things that he can show me when I go and see him. He can show me what it is he doesn't understand and then we go through it together and I can sort of point him in the right direction. And he's got a good relationship with the erm, with [SLS staff manager] there who is in charge and he, she sort of is very patient with him so he seems happy, yeah.

I: Ah, That's great. And what was your experience of the support provided by [The Transitional and Community Service] overall? So that includes both his time on the [Transitional Unit] and when you first went home and had community support?

RP: How does that differ from...

I: Just, just overall what was your experience of both aspects, both the [Intervention stages] and...

RP: All bases seemed to be covered. He, he erm.... you know there was a bit of... a few delays with, you know, a few delays with getting the flat ready. There was a few delays from the hospital coming to here to get this place ready because it was brand new and I think there was a bit of delay, but apart from that it was, it was all smooth and successful as far as I'm concerned.

I: Yeah. And do you have any feedback you'd like to add about your experience?

RP: Erm... not really. I mean, the thing is for each patient it's going to be different and I think he was, you know he was... care, the care was.... seemed to be thorough and all aspects of his problems were being considered. I think erm, I really personally wouldn't have had any complaints [laughs].

I: That's great. Well that's the end of that.

RP: I wasn't sort of just... I mean, you know, I'm not just paying lip service. It was just genuinely it seemed to work you now, he went through the process and at the end of it he was looked after, given the services he needed, and housed. I mean, brilliant, yeah, back into the community so, good.

I: Which is what he wanted.

RP: Which is what he really wanted yeah.

I: That's fantastic.

Interview 2: Transcript

I = Interviewer

F = Father of Participant/ Nathan

M = Mother of Participant/ Nathan

A pseudonym is used for the participant referred to in this interview. All other names of people and services have been removed, text in brackets [] provides the description of the service or role referred to.

I: Well thank you very much for coming. So as I explained, this is a semi-structured interview to get your views.

F: Right

I: And so we've got both of Nathan's parent here. So the first question is, can you describe your experience of the discharge planning process when your relative left hospital, so that's for him to, erm, come here to the [Transitional Unit].

F: From [The Level 1 Unit]?

I: Yes

F: Right. So it's got nothing to do with the [Acute] discharge to [The Level 1 Unit]?

I: Talk about that if that's [inaudible]

F: Well no that, that was... well he's discharged, I actually don't have the exact dates.

I: That doesn't matter. Just your experience of how.... were you aware of time scales and dates and services that were...

F: yes...they were clear. The one thing we were, at the time, and given the condition that Nathan was in when he left [Level 1 Unit] which was vastly improved on what er he was when he entered [Level 1 Unit], erm we were hoping, and he was assessed by the doctor who runs a place in [County name], I can't remember the name...

M: [Specialist Vocational Placement]

F: [Specialist Vocational Placement]

F: And it sounded to us like this [Specialist Vocational Placement] sounds ideal for Nathan and we were thinking, you know cos he was, he was... he had still lots of issues but erm we thought [Specialist Vocational Placement] sounded wonderful and the doctor who assessed him ran [Specialist Vocational Placement], he happened to be in [The Level 1 Unit], I forget his name, but he said, "oh you seem ideal for this" so we thought well that's it, so when then the discussions started, and all of a sudden we noticed that the discussion was not concerning [Specialist Vocational Placement], in [The Level 1 Unit], it was talking about this place, [The Transitional Unit], and we thought, well gosh that doesn't maybe sound like anything like what [Specialist Vocational Placement] was going to offer and er [Specialist Vocational Placement] would frankly from a family point of view have been quite awkward for us because we live in [County name] but and then but we came to look, at look at [Transitional Unit] at the time and there was no, in fact that's probably the time we met [AHP Consultant], way back in that period, and she was saying they thought, and [Neurologist 1] from [Level 1 Unit] and [Neurologist 2] from [Level 1 Unit] were saying, "we think this is fine and its very close to where he lives", you know its like half a mile to his house from here and when we came and saw the arrangement and met the people we thought, you know well maybe it would be fine and it was explained quite clearly to us.

I: So you were involved in that process?

F: Yes we were.

M: It was no contest as far as Nathan was concerned

F: He wanted to be here

M: He wanted to be as close to his flat and he has a lot of friends in this area as well so he didn't want to be shipped off down to [County name]...

F: No he really didn't.

M: ... But At the time we wondered whether that would have been a better move for him. But I think the [Specialist Vocational Placement] thing was really a get back to work program.

F: Yeah

M: ... and as it turns out he was a long way from that so...

F: Yeah. But and the results here were we were very, very happy with this, it's great. And easy for us to visit, easy for him to have day release every now and then at the weekend, it worked out very, very well. But the organisation of it was fine very, very good.

I: And can you describe your experience of the initial period when Nathan was at, on the [Transitional Unit]?

M: Erm

F: You mean how it operated?

I: Erm, so when he was actually here, so the support that was available here, any challenges or positive experiences you had about him being here?

F: Well personally, I mean, we were very happy.

M: Yeah I think the whole program went very well.

F: We liked the people, and they were always available when we have a question and erm...

M: It was a very nice team.

F: Very nice team.

M: Big complaint about the food to be perfectly honest.

F: [Laughs]

M: Had we not been around, I seriously don't have what he would have eaten erm because we were either bringing in meals from Marks and Spencer or once a week he would have Dominos pizza that sort of thing.

F: But it was easy to do.

M: Yeah so but that was...

I: You were supporting that autonomy?

M: Yeah

M: But yeah apart from that...the team were really..... great

F: No the team were great, really great.

I: And was the transition to home supported?

M: Erm, yeah

F: Yes, they started it gradually, there was a... he could have one night at the weekend, then two nights and so on and then the whole weekend and it all went very well and he was perfectly happy coming back here on a Monday morning and getting back to the routine and er, mind you as I say we were here every day and his brothers too. And then allowing him to go to take him out for dinner around the corner to [unclear] all of that sort of stuff, all those things worked really well. And we kept saying to each other you know I wonder why we ever felt that this [Specialist Vocational Placement] would be the place for him because it would have been so awkward, but we were thinking that when we were talking about it that this is the sort of thing for Nathan, it wouldn't have, this worked much better.

I: And one of the big things was that it was local?

F: Yes local and we were very happy...

M: His friends could come they took him out.

F: Yes friends came and would sit and chat with him too and knew where he was it was easy to...

I: And were there any challenges with respect to waiting times for equipment or services that he needed whilst he was here?

M: No, no

F: No, not that I can think of

I: So onto the next thing, can you describe your experience of the initial period when your relative was at home full time and working with the [Community Team]?

F: That's where I thought this doctor [unclear] was... I forgot the acronym. That's where some of the mail is still going, so OK.

I: And we'll work that one out, we'll solve that problem. So if you could describe the experience of the initial period when he went home and he started working with the community rehab team.

M: It was very good. [OT] he really liked. He's a very personable guy. He's in the fashion business and he is, he's gay, he's a really good talker, he can be very cutting and very funny, and all the girls who, the [Brain Injury Charity] girls and [OT] from the [unclear] got on really, really well with him, you know they end up hugging and kissing and [laughs]...

F: So that transition was very good

M: Yeah it was

I: And so things like the equipment and care that he needed went in quickly?

F: Well, he didn't need much. They examined, they looked at that from [Level 1 Unit] and erm...

M: He's very mobile. I mean there's nothing, you know what I mean...

F: He didn't really need anything. There was one, a bath mat, I think, an inch-in-bath mat for when he was showering, they suggested that and that [unclear] fairly quickly. He's been physically, in quite, in very good condition for quite a long time.

I: And in this initial period he knew, and you knew, where to seek support if required?

F: Mmmm

I: So the handover and transition?

F: Yeah

I: Can you describe your experience now that your relative is home for a longer period? He's been back at home...

F: Experience in relation to?

I: Just how he's finding things. The support that you've been getting. The on-going support, access to services?

F: Yeah he's erm. Well he now. He's still on medication er and he now collects all that himself from the chemist, which is just round the corner. Which was instituted when he was here.

I: So that was set up by the [Transitional Unit]?

F: Yeah, yeah, so gets, does that himself now. And as I say even to the point that we're now, cos he still has meetings with, at the [Specialist Hospital], which is where they changed the shunt, which turned out he'd had a shunt probably for almost a year which we, was not working, wasn't doing it's job, and they changed it, replaced the shunt that wasn't working and he still sees them. In fact he's got an appointment with them next week. But we've asked him to go on his own to that. It'll be the very first time he's going to appointment like that on his own and we've asked him now that we think that's the sort of stuff he should be doing because [OT] was saying, she had said to us a few months back that it was, from the [Community Team] perspective, that it was probably time we backed off.

I: So they have you that support to know when to support him and when not to support him? So they gave you that education?

F: Exactly. Exactly yes. And so yeah and that was beneficial because I don't know on our own, whether we would have done that quite so early, and we really had to we've got a life by ourselves [laughs] with the property that we need to be looking after and stuff like, but erm yeah... I think that was very helpful.

I: So that was a positive experience?

F: Positive [inaudible]

I: Have there been any challenges? Before this interview you talked about difficulties with the GP getting information.

F: Yes and that was er something we've noticed very recently because we, [unclear] told the desk at [Level 1 Unit] on a number of occasions that the letters seemed to be going to people we had never come across and wondered who they were. And they were in error so and, mind you at the very beginning, Nathan had a GP that he'd never seen and he'd never changed GP when he came to move erm to live in a different part of London so that was an issue and we didn't realise what an issue that was until they told us that that GP was respon... was getting still information, and had nothing to do with anything. So we then registered him with another GP in [Local area] which is what came up on the list at the [Acute Hospital] they said, "Well he looks physically closer" but until he, when he moved to [Transitional Unit], we suddenly realised that there was a...

M: Well they have, they used a lot in practice...

F: Yeah, and that was... Yeah so the doctor that was seeing him said, "Well he's never been to [GP surgery] either so why don't we change it?" and they very kindly did that for us.

I: So they supported you for that?

F: Absolutely.

M: Yeah

F: Cos that would have been a bit of a nuisance for everyone. But the organisation of within the NHS, how the letters go to er address... I don't for example how on earth they got the name of the doctor who performed that operation on him, but there he is now. He only got that one that I noticed.

I: So the information went to people that shouldn't have had access to it?

F: Right, right. Unless this [GP] actually is in er, [The Community Team] then I don't know what he's doing on there either, but it does say [Address]. But we would like it obviously to go... and I will send it to [GP] in the [unclear] practice.

I: OK, So what was your experience of the support provided by the [Transitional and Community Team] overall, so both the community bit, with the OT you talked about, and the [Transitional Unit], so when he was here?

M: Erm, yeah good.

F: Good. I think. I can't...

M: I mean we only saw [Community OT] a couple of times.

F: Yeah. She came to Nathan's flat [unclear]. Probably [OT] was the only one who we had any interface with and er....

M: We didn't have any.... Did you call her at any point?

F: Yes, yes and she called me. I was very happy with it. And erm, but it was [OT] who first was talking about, I think it's time we had a meeting with [OT] and somebody else, I think the [Brain Injury Charity] people, together. And [unclear] we had that meeting I think at [Brain Injury Charity] and er....

M: Hmm. That was in August time.

F: Yeah and there was... [OT] was saying, "I think it's time that you two sort of step backwards". [Unclear] good news er [unclear] still we'll come up, you know, on a monthly or a bimonth...

M: Oh I'll be up 2 or 3 weeks

F: Every 2 or 3 weeks. Just to...

M: For a while.

F: Yeah for a while, but er yeah and backing off.

M: But he's happy to have... He wants the place back to himself.

F: Oh he does. He's ready. Yeah.

M: He wants to be living his own life and he wants to be picking up the threads of it all. Erm, I mean he's coping. He's not a cook but he won't starve, you know so there's nothing's changed there because that's exactly the way he was before the accident happened.

F: Yeah

M: Erm and he does eat out quite a bit with friends and [unclear]

F: It's exactly...I should mention too that it was [The Transitional Unit] support via [Neurologist] that got the shunt thing er revisited er because that would not have happened. We were er... The fact that this [inaudible] the right hand, he's got two plates erm [? with a] cranioplasty that was done, one is offset because the brain was swollen and er the shunt erm ... it was really the [Transitional team] who contacted [Neurologist] saying they really, the parents and the family really think there's something wrong there and [Neurologist] got him into the [Specialist Hospital], which...

I: So the advantage of having a neurologist...

F and M together: Absolutely

F: Well that was essential. I remember asking [Neurologist] when he said, er he said, "No, no we think [The Transitional Unit] is a good thing" and we would still have [Specialist Vocational Placement] in our head and this neurologist came up and chatted and said, "oh Nathan's just the sort of candidate we work with", and I remember saying to [Neurologist], "Is there a neurologist at [The Transitional Unit]?" and he said, "yes" and I said, "OK who is it?" and he says, "It's a [Same Neurologist]" [laughs]. So I was really pleased to hear that.

I: So you can assured there was a seamless [laughs]

F: Continuity, absolutely.

I: You mentioned work a few times but I've noticed it hasn't come up in the interview. Has there been support for Nathan in resuming work or having discussions around work.

F: From?

I: Have [Transitional team or Community Team] supported him with that?

F: Well we did inform them that his former job he was a [job role] in a company called [Name of company]. And they were very supportive and allowed him to go and spend a few hours one day a week with them and we thought that's terrific cos it's just, you know, keeping his toe in the water. Nathan still to this days says, because now that that's stopped, because he realised that he really wasn't contributing, he didn't have a role and there was a [job role] who'd been appointed, anyway, because it's now almost two years since the accident, and they couldn't hang around, they had to march on with someone else and it's someone who Nathan knows and doesn't ...

M: It's a bone of contention

F: doesn't particularly have any respect for and so he felt it was awkward, [unclear] so he finally said to the boss of the place, who's a very good friend of his, that he would, er, pack in. But he started saying to others, that we'd hear him talking to some friends and saying, "Yes, but I've given in my notice" that he was working. There was no pennant it was a just sort of a sitting for two or three hours in the place and answering questions if somebody said, "what do you think of this [work related question]" and stuff like that [unclear] he'd give an opinion. That part, that shows you know to me that there are still issues with Nathan. I mean he's absolutely...He presents so well we would...anybody that didn't know him would have difficulty thinking he's, he's got a brain injury and er...but we notice it things like that I can still see that there is...

I: Erm and just last of all, do you have feedback that you would like to have about your experience?

M: Well I wish we had never had it in the first place [laughs]. But other than that I, we really have been very, very happy and overwhelmed by the amount of encouragement and support that we've received throughout the whole journey.

F: Yeah, yeah.

M: We really couldn't fault it to be perfectly honest. I mean there've been hiccups, obviously we didn't want him to have a second shunt and things like that but then you know... but, but erm, as far as the rehab and being here, we've been very, very happy with the way he's been treated, with such encouragement and respect and yeah. So we're very, very grateful to the NHS, I can't tell you how grateful, yeah.

F: Yeah

I: Thank you very much

F: Not at all

I: And thanks for coming today.

Interview 3: Transcript

I = interviewer

M = mother of Richard

A pseudonym is used for the participant referred to in this interview. All other names of people and services have been removed, text in brackets [] provides the description of the service or role referred to.

I: Thank you [Name] for coming today. So as I've explained were going to do an interview that's going to be semi-structured. So I've just got 5 questions I'm going to go through about your experience. The first one is, can you describe your experience of the discharge planning process when Richard left hospital?

M: The discharge process was initiated at an appointment that erm was held here and I wasn't present...

I: Actually... the discharge planning to be able to come here, when he actually left hospital

M: Oh to come here. I thought you meant leaving here... To come here, erm it was... at [Level 1 Unit] it was that Richard was then going to go as an interim to [Specialist Nursing Home]. And when he was at [Specialist Nursing Home] which he was at for approximately three months, so the discharge from [Specialist Nursing Home] to here was fairly structured, the speech and language therapist and, one on occasion [Transitional Unit Manager] also, the lead person from here and [AHP Consultant] I think was mainly in the background. [AHP Consultant] made one visit to [Specialist Nursing Home]. So I knew what to erm anticipate. The date was a bit of a moving feast, erm it got put back once or twice because the place here did not, [Transitional Unit], did not open on that specified date, so we were, it's a bit like... the uncertainty of that is, can be slightly off putting erm and then the process of moving, physically moving here was that erm... [Sister] and myself, [Sister] drove my car and brought the majority of Richard's possessions, which by that time was fairly substantial, and a taxi took Richard and myself here.

The process to get here was er basically organised for us with the exception of us bringing the majority of his possessions. Did I think it was straightforward? It was possibly as straightforward as it could be, within the bounds of the fact that erm [AHP Consultant] was clearly juggling the actual opening of here. So when Richard came, he was one of two people in the first for instance that were actual operations for approximately a week, so everybody was a little bit like bushy eyed and bushy tailed so the transition to here was fairly OK, I think.

[Specialist Nursing Home] being in [County] to here, and being a non-NHS facility, was erm fairly straightforward from the professionals point of view, I think the handover was quite good but I, you know I had a lot of respect for [Specialist Nursing Home]. I think they did a significantly better job at rehabbing than [Level 1 Unit] did. In the main, I mean there were parts of [Level 1 Unit] that you know, which was the early place, erm where I mean Richard went from the [Acute Hospital] to [Level 1 Unit] and he was in [Level 1 Unit] and that, we waited for a long time for that transition. At the [Acute Hospital] he, you know, he was on the waiting list for, well, probably about 3 and a half months, from the Christmas right round to the end... beginning of April time and that was much more complicated because every erm possible erm reason, you know, no reason, you know, "It's just not happening to day... it could be next week".

I: So this was the move when he was ready for rehab first onto the [Level 1 Unit]?

M: yes

I: That was a really extended period of time you had to wait?

M: That was a very extended... It was probably 3 and a half months and in that period Richard did make quite reasonable progress but he actually was ready for rehab much earlier in that 3 months and it was complicated because erm I mean you know at the time going to the [Acute

Hospital] was relatively more straightforward for me in terms of transportation erm. The transportation erm was easier than going to [Level 1 Unit] itself because from [County] was an extra [? couple of] journey or so. So there are a lot... I'm not... I wasn't totally familiar with parts of London so it made it more tenuous and more sort of anxiety provoking.

I: Thank you. Can you describe your experience of the initial period when your relative was at [The Transitional Unit]? the so when he came here to [The Transitional Unit]?

M: The staffing erm the key worker was easily identified but was not always available. The nurse in charge was, erm the name escapes me actually, er I should get the lady's name, I'm sure she's still here, anyhow. In the main the nursing staff were really really friendly. We had had unfortunately had a previous experience with [staff name] which had been not very good at [Level 1 Unit]. Richard was quite anxious about actually the occupational therapy intervention. Erm the speech and language component of his daily living was erm you know intermittent and the two identified areas we were very concerned, well three identified areas at the very outset we were very [? adamant]

I mean [sister] came to the initial day that he was transferred here and then there was a meeting held more or less on that same day, but I had gone home again erm and she was fighting on all fronts actually at that point so... The result of it was there was lots of communication between [sister] and myself and Richard, so we were Skyping, so in effect erm I was trying to identify if problems were existing but the three areas we were looking and asking about, in the main, were his sleeping which was atrocious, his interrupted sleep and grinding his teeth and lots of other things so and his sleep deprivation from erm you know very interrupted sleep. Interrupted also because of this irritable bladder and his need for psychology for his outbursts and distress. I mean he was adjusting and it was, it's still probably even an on-going process now, er I think he's very well adjusted now but erm it was difficult to identify how the more str... alleged more structured approach here.... was, and the comparison in a way was very much with [Specialist Nursing Home] and [Specialist Nursing Home] was an area where there were similarly erm a small number of people erm... The managers were very accessible they were more accessible than they are here. So in that respect it was a friendly place, very friendly and, you know, at the time I thought the... all the professions that worked there were excellent. I mean in a private institution you probably don't expect that but things happened more or less when they said, and they were prepared to take risks that perhaps here was not prepared to take, even though we were three months further along the line.

I: So that was a challenge for you?

M: That was a bit you know erm... The NHS, you know having worked in it, I mean I've got the t-shirt so I would defend it to the hilt, however, that doesn't make me blind to the failings that it has. And some of the communication, or some of the interactions appeared to be more erm... Whether it's that people in the private sector are, you know, there's no logical reason why they would be better communicators but in that for instance, the majority of people were perhaps better communicators. Which was sort of like, I wouldn't say that my hackles were up but my antennas were waiting for any interventions or any interactions that weren't positive and, of course, there are always some, you know erm.

I: So one of the challenges was around initial communication?

M: Yes definitely. Communication is the big issue about all of the erm... any of the problems that have occurred I think. I mean Richard himself is, you know, has a, or had, and he had several outbursts here you know that were not, that were managed. In essence, I think he had very few outbursts, that I observed, when he was at [Level 1 Unit]. Well that's not true, at [Level 1 Unit] when he was in the initial phase he quite a lot of outbursts. Erm the next bit along was the [Specialist Nursing Home] bit. He had very few there. But then I was able to take him into town and he was able to interact with much more, sort of, a calm... not calm necessarily, but more of a community spirited town in [Town name]. Erm and I suppose here is just you know a high density population and people are just doing their own thing, there's lots of them.

There were several staff here, you know, and it was often er some of the assistants who were really good, really really supportive. You know that's a skill isn't it? that's a skill and that's a personal erm, that's a biochemistry type of a thing isn't it, it's almost intuitive some of them are just you know... There was a couple of professionals who I think probably they have their professional boundaries and often that doesn't allow them to be particularly empathetic. I've got a friend who's a nurse who's written for the Nursing Standard and one of the big, one of the massive articles that she's written is literally about the empathy or compassion that nurses have, and it applies to all other health professionals.

I: Yeah. And so at times you didn't feel there was that empathy?

M: It's variable.

I: Yeah it was variable

M: Highly variable. Very often it was totally fine. You know I remember I had to go to [location] on a couple of occasions, erm and I was just told, "Well we won't, you know... a taxi or something will be arranged" or whatever. Well I went I can't just get him across London, you know, I can't get him to be at an appointment at [location] by I don't know, one o'clock or something and they said, "Well it's like, that's part of his rehab". And I said, "well, is a staff member going to take him?" "No, no". Well I said, "I plan to go because, you know, I need to know what his, what the medical expectation is" and, "No, it's fine, you get on with it". And I was like "OK", "deal with it".

I: So you didn't feel supported in him attending other medical appointments out of, away from the [Transitional Unit]?

M: That was the one that actually stood out

I: Yeah, that was an example of the experience?

M: That was the one that stood out.

I: Yeah and how was the transition to home supported?

M: Erm, [Name] the OT came and visited once, erm the occupational therapist who then subsequently left erm who was in the acute section, I think she was a [name], erm it's almost like I've discarded their names because I know they've disappeared. Erm I think Richard himself and I made one or two calls to here. We had a plan, I think it was a written plan...

I: Oh sorry...

M: of phone numbers and so the actual discharge planning went on, erm so that we were provided with a sheet of numbers in case we needed.... I mean obviously I knew the number for here already but...

I: So this was when he was at home you had numbers you could call if there were any difficulties.

M: More or less. Basically you know the support that he had was from a [Brain Injury Charity] worker called [Name]. [Brain Injury Support Worker] was excellent. The fact that he was young and male and had huge insight. He didn't have the medical training but he was very well versed in head injuries.

I: And I might ask you more about him. So from the [Transitional Unit], the actual transition home they gave you the list of numbers and they did the visit?

M: Yes, essentially

I: Can you describe your experience of the initial period when your relative was at home full time and when you worked with the community rehab team [team name] who then supported....so after here you then went home and that's when you had the [Brain Injury Charity] support worker that was very good.

M: Yes the [Brain Injury Charity] support worker worked er I think it was 2 hours 3 times a week Monday, Wednesday, Friday and helped Richard set up erm his you know... relooked at his goals because he was aware of the goals from being involved in the discharge planning. Richard then, very definitely, sort of did a ... he was quite anxious and I stayed with him for a one night I think and I then basically went home because you know you just literally have to make a break at some point. He was I think excited to be in a new environment but frightened and the lady who was here or is here still, the nurse manager for this particular unit, she was... she kept being extremely positive and I suppose we were still at the point of anxiety erm, questioning how well Richard would do because here is not home, [The Transitional Unit] is definitely not a home environment. Erm if this was a flat that then had motion erm sensors or video intervention but actually, OK once you come through the front door we leave you alone, you know overnight, you know you've got to go out and do your shopping. We're just you know basically a call away. I think that would prove to be sort of slightly more of a structured way of doing it. Because here Richard could just walk down the corridor and one of the rehab assistants would put a lunch out for him or a dinner out. It was instantly available.

I: So the jump to home felt a very large one form here?

M: It was quite substantial. And partly to do with the activities of daily living the showering, the you know, self-preservation, doing your laundry, doing your shopping, the planning of all these activities. That's where I still took on the role of doing the planning with him about what he was going to prepare for meals. And he really had limited erm, he had done some cooking here. He'd invited his friends in and they'd be cooking lamb, slow cooked roast lamb for his mates for about three or four weeks you know on a Wednesday night on a consistent basis before he left. So friends were still coming to him even when he was here. A few of his friends visited quite regularly so he felt supported. He was a bit like a puppy off its lead, you know, he was like wanting to do lots of things without much structure. The OT who came to visit him, was this [name] I believe...

I: So this is when he was home?

M: Yes, when he was home [inaudible], from the community trust. I've observed a couple of her visits. They were very... they were not always on time. You know, I mean to Richard it was completely irrelevant, but you know they were set up as appointments. And I think, in a community, having done it myself, you can't always be exactly where you're supposed to be, on time. So he was completely unaware of that. What was complex was he didn't really get the fact that if he didn't have regular meals, or he didn't do things regularly, he couldn't just expect that at 8 or 9 o'clock at night to be thinking, "Oh I'll pop down to the kitchen to see if there's a spare dinner" and so it was.... curious to watch him because he didn't have erm he didn't have.... possibly stress from it, when he then started coming to see the physio, he saw [name] the physio a few times, for structured exercise, he didn't really... He needed the familiarity of it, he didn't need the actual physio per se. Erm speech and language I think was a little bit... appeared to be more haphazard. It wasn't very structured, it wasn't, "you will get 6 sessions and they will be weekly, 2 weekly" or whatever. And Richard himself is somebody who is disorganised now he has not.... Erm, if it's something he wants, he's very structured about it. If it's you know, checking his phone, which he does 100 times a day to check his emails, or check his bank balance or check something else. So some routines are now very ingrained. I think that's happened as much from me being assertive with him as well as his sister basically er encouraging him actively because I think if he had not had a sister who was Skyping him from [location] on almost a daily basis and chivvying him along, I think we wouldn't be where we are today. Erm, Psychology, basically didn't... there was no further psychology, which I think....

I: When he was at home?

M: When he was at home. I think [AHP Consultant] did speak to erm the psychologist who here on the ward and because Richard then started to be concerned about whether he would go back to some of his less lovely habits which were that he might go back to drinking or gambling or other additive behaviours and he himself was.... He didn't initially say it, he didn't initially come out with that as being... but there was, you know, an underlying sort of anxiety and tension and because he'd had... his amnesia was protracted at the beginning, post traumatic amnesia was probably nearly three and a half to four months, erm it was that he had to have a dialogue between his sister, myself the psychologist, so we tried to support him to actually understand what happened when he had his accident...

I: And that was while he was on the [Transitional Unit]?

M: That was on the [Transitional Unit].... And I think he kept going over that. He kept trying to you know re-establish it into his brain. It's very difficult to always get erm the... because some of it would appear that he's more disinhibited than he was. In the main he's not. It's not.... He, I think what he's found is that... His main supports are myself and his sister. His father has, you know, got his own medical problems and lives a long way away and you know, he's not that actually involved, he rings or Skypes, but he's very controlling about when people can approach him. So I think Richard had er, his toenail, other treatments you know that were going, so we were coming back to this environment, not specifically to this ward. But every time he had to have something printed off, and I physically couldn't print it off and bring it into him, he would come down here and I say, "I'm emailing you, can you print it off?" So I think he still felt that he couldn't come in here without any reservations.

I: So he'd visit [Transitional Unit] for a long period after he went home for support?

M: He visited for a while. There was another lady that was a patient here, who was much older than him, probably [describes other patient]. I could probably identify her to you but it's probably not appropriate to do that now. And then when he felt that her discharge was imminent or was coming, he was very concerned and agitated by seeing how that person was discharged. He then deliberately... would go and visit this.... that person would er phone him and sort of say, you know like more or less plead "can you come and visit me cos I don't get any visitors". And so he could see that he had managed a certain level of independence and... a life that was different to the one he had before but was still a fairly independent living, and they discharged this other individual home, so you know there's always complexities isn't there? There's no erm easy way is there? And you know, he's had a life-changing event.

I: Yeah. So the handover transition period, you said [Transitional Unit] provided you with contact details or Richard, your son, with contact details, both of you were aware of where to seek support if necessary?

M: It was limited. I mean [Local Authority] are, for want of a better word, as useful as a chocolate teapot.

I: So you found those, that support was not there for you?

M: It was completely.... Clearly they were paying for [The support workers]. The social worker made, and has made a contact around Christmas time recently, and I have since contacted them again.

I: And so that's over a year after the initial discharge from the [The Transitional Unit]?

M: Yeah. They are literally not available. And I'm not even attempting to really be the you know the mother from hell with them because actually that disables Richard even more and doesn't make me feel great when I have to make a fuss, make that sort of er aggressive approach. Because on one occasion Richard's key worker from [Brain Injury Charity] was clearly saying, "I am going to finish on Friday, that is it, I will not be here any more, and like you've you know got to make representations". So I made an attempt... and then there was a community, there was a notice on [address] or whatever the road's called where the bus goes, with a big sign saying community centre with an arrow pointing down the road. So I went off one day when I was

clearly feeling Richard was being angry, upset, not able to cope and so I went round to this unit to find that it previously had had a str... elderly care unit in it, but currently that elderly care people, support from [Local Authority] had been moved out like two years previously, so they'd still not taken the sign down. And it was currently used by a learning difficulty... [Local Authority] support. And the other thing was that there was supposed to be the [Service name] floating support worker, because he then moved to an area and they said, "we don't cover than area" and so they then indicated that they would contact another organisation called [Service name] I think it is. I'll have to double-check that for you.

I: So just to clarify, so initially when he went home he had the [Brain Injury] support worker for the hours you said and that was very helpful, but that stopped suddenly and then you didn't get support after that?

M: That's correct

I: And they recommended that you access [Organisation name], support but that didn't cover his area, and then he never got support after that?

M: Well, the {Support organisation} was actually arranged even when he was here. The two people that I had made contact with was [Support Organisation]. And [AHP Consultant] initially had said well [Support Organisation] is basically for people with learning disabilities and it's more or less like a housing trust. Well actually as I explained to her, it is literally near [Location] station, you know 500 yards from the front door here, and actually it's not. It's to do with.... it has quite a lot of facilities and they work from [Address] hub which is on [Address] and they do worker education programs, they do design fabric, art type work. Richard does wood work with them. And he does one day of wood work with them, which is on-going they don't appear to... er nobody's pulled the plug on that one. He gets a lot of support from that, that's one whole day from like 10 o'clock to about 3 o'clock and...

I: So that's been valuable for him having that day of wood work?

M: Extremely valuable yes. He...When he was here, er he'd gone to because [Name] the OT had provided him with a list of, you know, "These are the areas you're thinking about" and one of them was at [Address] there's a woodwork course. Richard had paid 100 pounds to do that, and basically he just about chopped his thumb off with an axe and nobody at that point... and [OT] had spoken to the people at [Organisation name] and they thought they would be able to just cope with him. I think probably it had not been risk analysed very well. Certainly [OT] had not been to see.... He'd spoken to them erm... but I think there's a big difference between language communicated when somebody wants to actively encourage you to join them and what you actually see when you go and visit and take a, sort of, more structured look at it. So I thought that was a bit of a... I gave it the benefit of the doubt and Richard went for the month and then continued to go for a few weeks after that. They are prepared to take him back but he's not really gone back because were using, they were going around [Organisation name] where the cemetery is and collecting green wood and trying to utilise it... they made things like... carved a few spoons and they were teaching him but they obviously didn't realise his vision.... You know, the fact that he was supporting himself and he did a fairly substantial chunk, you know, right into his knuckle which he then had to take himself to [Accident and Emergency Department] you know er and basically we went back there regularly to get this thumb dressed.

Arranging to be registered to change to a different GP was something we do together. There are a few other things. He went to [Community Organisation]. He found a few more situations where art was a possibility.

I: So just going back... Registering with a GP was something that wasn't done when he was here he had to do it when he left?

M: He was registered at a practice just around the corner here.

I: So then you supported him to do that when he left?

M: Yes found them you know, he navigated himself there he, you know

I: That was quite straightforward?

M: Yes they did an interview with him and that was uncomplicated.

I: Can you describe your experience now that your son has been home now for a longer period of time? You might have talked about some of those things.

M: His speech and communication in the main is reasonable. I think he..... you know, I have to allow him some privacy. He's not a child. Although I am officially his legal representative, although I don't have a power of attorney, but I do have from the Department of Works and Pensions, you know, benefits they have made me his appointee. Now that was one thing that was really really irritating when he was in [The Transitional Unit] and it was extremely irritating for the simple reason that his key worker, who was the Speech and Language person, a lady, erm [name], who basically said.... Because he kept saying, "I want to know what my benefits are. I want to do my benefits, I want to... ". Now I'd explained to [name], as I had at the team meetings, look from the word go when it was immediately almost after he had his injury, I had contact with DwP and because I'd had experience of doing it for my previous work, I then said, "This is how it is, I'm his appointee". Now, he's getting this level of benefit, this is, it says, erm, you know, PIB and ESA employment support allowance. He will be paid the employment support allowance but he won't get the PIP, he won't get it because he's in an institution" You can't have it both ways, the government's not going to pay for you to be in the institution and the PIP. So fine, they then contacted me when I was on holiday I'd gone to [holiday destination], which I do for a month or so at a time.

And it was almost as if Richard had said, "well if you don't help me do it". That's my only impression is that he must have made it difficult, or they thought that it was straightforward and he should have access to all that information. He had a file in his room with the benefits he was entitled to. They weren't being paid. A, I had explained it initially and B the information was available in his folders in a bookcase in his room. He didn't always remember where it was but [SLT Name] should have known that, and as a consequence of that, it took quite a lot of re-jigging with the Department of Works and Pensions, because they were a little bit.... after a little while, fortunately I struck a really really helpful person who I can now email and as a consequence, because there were weeks and weeks when over weekends I took Richard out. Over the Christmas period I had Richard at home with me for a protracted period. Even when he was at Homerton we took him out for weekends. All of those periods, allegedly, we're entitled to make a claim, even though I'd spoken to the social worker at [The Level 1 Unit] and I thought [SLT name] perhaps didn't know what she triggered when she triggered that because it created quite a lot erm questioning. Richard himself became more and more frustrated because he kept thinking that he was getting all of these benefits. In fact he wasn't getting paid for them, there was no money being distributed to him because he was in an institution. Now, if health professionals don't understand that, and then they potentially make a bad call then the client doesn't, you know, client, patient whatever. When it's my son and I'm thinking, hold on a minute, when I was working if I had made that mistake my boss would have actually rollicked me.... I would have been given, you know, a serious dressing down. And what I'm very carefully trying to sort of say look, maybe you didn't understand, maybe this wasn't something you did with any intention, but the effect is a lot of stress. It's a lot of stress to me because Richard questions it and when he questions it, he then gets himself in a state and then his sister and I spend time explaining to him, well, "bit unfortunate but this is how it is" so....

I: So that was about lack of understanding of the benefit process by the team that was here?

M: Absolutely.

I: And so he's home, so the on-going level of support that he has now? How are you finding that?

M: I think I provide it. I think that's it. His dad is not... Last year, Christmas 12 months ago he went to [Location]. That was a big big step. That was a massive erm... Basically for six weeks Richard was off British soil and he... the DwP were totally upfront and they were quite prepared to say, "as long as he's not out of the country for more than 42 days, then that's fine". And so we [? were] indicating that he was going to be with two people, his sister and brother in law and another couple who are friends of theirs, one, the male, the man friend's brother got killed in a motorbike accident at approximately the same time as Richard was injured. His partner, his girlfriend, or she's now his wife, erm had worked for the DwP and they were very aware, and were emotionally very supportive A to my daughter, because my daughter had volunteered and she is now a counsellor with the equivalent [Brain Injury Charity] organisation in [Location]. [Sister] was still working full time doing this counselling business. Richard had to survive and manage himself in a city that he couldn't remember that he'd been to as a child with me several times, so he very rapidly got a sort of, slightly, a bit of a cold sharp shower, you know, albeit that he was so excited to be going to stay with his sister. And because, you know, but you know, the support was on-going because he, Richard does make lots of Whatsapps, erm phone calls and whatever so I am literally....

I: So the on-going support was from you...

M: and his sister.

I: always from you and often that's electronically, because there's only you and your daughter's out of the country to support him.

M: She's still whatsapping... She isn't now she's had the baby it's a bit more complicated. People have withdrawn, some of his friends have stepped back. Many of his friends have been amazing. While he was still here he was best man at a wedding, well he was a groomsman. He's been to France, he's been to... on a few stag dos. So other people support him, they have not necessarily always had a really firm understanding, but he is still their mate. You know, he's got a big circle of friends, some of whom still are very supportive. So, you know, that's, they work they're young males you know young guys who are married now and I'm sure that will drift off because they will have families, wives, children. The support from other directions, erm, [Community Support Organisation], [Friend] there, is and erm [Community Support Manager] who was the manager up until Christmas, there's another manager now. He was like their star pupil. He was doing more things than they anticipated most of their workers did. I think he's, I think the speech and language was involved from the [Community Team] part. Whether there was conflict, or whether the delivery of the service with a rehab assistant, who I believe was a young male, was unsatisfactory.... We repeat to Richard he has to practice. I think in many respects, it's partly about expectation. It's partly about what level of recovery ultimately you know, what is the level you are ultimately going to reach. Now, [Sister] because of her research background, and one of her friends, [Name of friend], is a geology friend who works at the [Academic Institution]. It seems that she had a head injury, a very minor head injury relativity, a concussive head injury, and the hugely impacted of that on her professional and private life was really significant. Now Richard's injury was massive and one of the things that you know at the time stood out like, I don't know, almost like a flashing beacon was the specialist nurse at the [Specialist Acute Hospital], took us all aside one day, took Richard's father and myself aside and just kept repeating, "He's had a massive head injury, a very severe head injury". Well, I think the last thing you need... I mean I understood the words. I understood the fact that it perhaps needed to be repeated. I had spent six weeks in [Location of accident] with Richard, from the point, a week after his injury 'till the time I physically, basically escorted him back, air ambulance. And a lot of the time I did that unsupported, in the sense of erm, professionals because in [Location] it's like, erm with the exception of the consultant actually. The consultant who did the surgery was amazing. When the, erm when all of that period was over, the combination of having to process it intellectually and to try and understand it and to actually know what the feelings felt like erm it was quite significant and I think, certainly, at [Specialist Nursing Home] the psychologist was, I think, sort of slightly observational of Richard, very observational I think but slightly of myself. The other, when he came here, the psychologist here was also spending time with me as well as Richard. I think that was helpful, I think that was quite helpful. Some of it is that...

I: So it was useful to have support for the relatives while he was on the [Transitional Unit]?

M: I think the psychologist, actually, was probably you know on par almost with the sister who was in charge here. Because we had very uncomplicated erm discussions and you know, about everything from everyday you know trivia to whatever. What I think what was more curious was the professional boundaries and remoteness that people, some of the professional staff here had. And I'm not saying the nursing staff were particularly different. In the main, I think they were more human for a want of a better.... I can't describe it any other way, I think they were more intuitive about their emotional involvement. To the extent that you know a couple of, one or two weekends we had barbeques out in the back garden. They were you know er...

I: They supported you quite spontaneously?

M: They were much more uncomplicated. You know I spent a lot of time with the other patients. I mean many of them had no other relatives who came to visit I was a bit like the person who popped up all the time, on a very consistent basis. And some of the time, some of the time that was very supportive you know, not the least of which was around meal times. Richard would always feel obliged to want to sort of share his meal with me. And so it was complicated because if I would go out to bring in something, and a few of the staff members here were sort of like [whisper] [? I'll get you a dinner] and I'd feel slightly awkward because I think it's... I mean with the greatest respect, I had lost quite a bit of weight. I also wasn't hungry ever. I think other people, I mean particularly right at the very beginning, at the [Specialist Acute Hospital], the psychologist that was there absolutely was... er it's really difficult to know whether they don't have the skill, or whether they really believe that you are so vulnerable, and feeling and knowing that in a sense you are trying to maintain your integrity, your persona and carry on to be this person who's going to support.... was a.... I mean it's a it's a complicated process. I think I had a bit of a psychological understanding of it from having had patients myself who'd had head injuries and we knew another close friend who'd had a severe head injury, ten years before so it wasn't like it was something we hadn't experienced. What was particularly distressing was this person telling me, in particular, and telling me in front of my partner, that if I didn't do, if I didn't take more of a backseat and didn't ultimately give myself some time then I was going to have ulcers, I was going to have a breakdown, I was going to have all sorts of personal trauma.

I: And so that was before you came to the [Level 1 Unit] that was early on?

M: Yeah that was early on. And this nurse telling me.... this specialist nurse... I mean it was ironic, the specialist nurse who, you know, one assumes has got all the right attributes and is a good erm... and the other person was the psychologist. And it was like, everybody had... all the team within that organisation had a lot of respect for those two individuals, "Oh let's get them involved... let's get them involved". And as soon as they became involved they were almost confrontational. That was *really* difficult and it was more difficult because Richard's father and I had separated a quite a few years before, a couple of years before, and the answer really was, when he saw this specialist, the erm the specialist nurse being really difficult, he told.... He had gone to this lady and said basically she.... he needed *her*.... he was being very manipulative, he went to her and sort of said, "I need you to basically tell her", meaning me, to take a [clears throat]... and clear off". There were lots of guilt feelings from his dad being projected towards this lady, and then she was then coming back with... and really black and whi... absolute... sort of concrete... "This is how it is. This is how it is!" and you're thinking, well that's how you see it. It perhaps isn't exactly how I see it, or this other person... you know, there are the different interpretations that's....

I: I'm just going to move onto the next question. So what was your experience of the support provided by the [The Transitional and Community Teams] overall. That includes [The Transitional Unit] and the community. Again you've probably talked about...

M: Yeah I think the.. the inpatient [Transitional Unit] was better. I think the community component of it is definitely needing reviewing. It was fairly thin, very thin on the ground. It didn't feel.... Now if the interpretation is, "Well Richard's the client, Richard's the patient. It's up to his to start organising himself". Knowing that his head injury was a, you know his erm....

[phone call interruption]

M: He's very, I think Richard.... That was the one issue, is that when he was here, when erm when Richard became assertive and aggressive and was losing say it with [OT] or, erm you know because I think he did a few throwing the door into the door frame a few times. Erm, if there was ever any erm, come back. Because I think you know that sort of makes people a bit nervous, makes staff a bit nervous. And the reality is, is that [OT] became mister cool, you know he tried to demonstrate, "OK fine I'm just walking out of the room". That's one way of dealing with it and when I took Richard on a route march around the block or you know diffusing his aggression or whatever or.... his lack of ability to control his emotions. The interventions here clearly can, because you're physically on the spot, I think are more identifiable. When it was the community I think it was much thinner on the ground. The assumption.... and we were led to believe that he'd get on-going psychology. That didn't happen. That did not happen at all. Erm, it came sort of [AHP Consultant] tried her best to sort of run it back past the psychologist who was part time here, er and you never know whether somebody's left or gone away or you know found another job whatever. The speech and language didn't.... and that's clearly why [SLT name] is trying to resurrect it, or erm deal with it. The reality is [Participant's sister] took the bull by the horns and started emailing the College of whatever, she tried speaking.... talking to private practitioners in speech and language. And her attitude was well, "just as I have to buy my healthcare in [location] or [location], you know maybe we've just got to, you know, bite the bullet and invest, you know, in Richard because this is his future"...

I: Because you felt he wasn't getting the required speech therapy?

M: He wasn't... he wasn't managing it, the way he was.... the intervention was seriously not being particularly... er. There was no struc..., there didn't appear to be a structure. But because I was actually.... all I was doing was hearing Richard's version of it. And he was not, he did not appear to think... he did not value it, and not only was he not valuing it, I don't think he was possibly conforming to it. So I can't say it was bad, it just didn't appear to happen very frequently and the delivery with a rehab assistant, could be... erm fabulous. I've worked with a rehab assistant who was amazing, who did lots of speech and language who had fabulous results. So I know it's possible. I don't think it worked in this for instance, and I don't think it worked because it was delivered by somebody who perhaps didn't have that rapport and skill and the communication ability you know? It is personality driven isn't it?

I: Yeah.

M: It is very personality driven. And since then we've done a bit more investigation. I don't know the erm three possible speech and language interventions. I personally feel that it was a little bit unwise of [Participant's sister] doing it but trying to step on her toes and reign her in. One of the things I felt benefitted Richard was being able to follow up with [Neurologist], I thought was very very helpful.

I: That was a helpful thing?

M: That was helpful, but actually I had to more or less, not demand it, but make it obvious at the point of discharge, or you know when coming up to discharge that that actually that was an appropriate follow up. [Neurologist] was a bit surprised I think but he is a very thoughtful man I think and he realised that actually even if it didn't create a erm a major... But I think he's quite intuitive and he's also skilful and [AHP Consultant] was very good. I mean [AHP Consultant] I think gave us a lot of support and she was in theory able to be accessed by email which erm you know, people can deal with in their own time can't they? They can deal with it like...

I: So that was a helpful thing to be able to contact her by email to coordinate things?

M: Yes I think [AHP Consultant] and [Transitional Unit Manger] is, have both been, really erm very professional you know? And very human, but also good communicators, and they have very different styles. I, you know, what can you say? I suppose only time and experience teaches the other things, if you have the ability to learn. Because many therapists who have

spent many years doing the job still haven't got the, they don't have the erm the best abilities. It is, erm you either do have it, or you develop it, and that takes time effort, training, education...

I: To get the right communication?

M: Yes

I: Just the last question, as you have a time constraint, do you have any feedback you'd like to add about your experience? You've probably said...

M: When I was being upset, when I was in the establishment, I think there were certain people who could deal with that easily. The two experiences with the specialist nurse and the physiologist at the [Specialist Acute Hospital], and bearing in mind that is quite early on in the process, they made a substantial impression both of which.... The... this is a learning scenario isn't it? The things that you regain when you're... when you've any head injury, particularly a massive head injury, the negative things that happen are the things that stick. The things that stick, because they're negative, can reverberate, they come back and they recycle and so that leaves an indelible impression. What would I say about how you could change the service to improve that? In the main, the staffing here, erm particularly in the office, always appeared to be accessible, I would say. You know, I think you have to, as a relative, respect their privacy because they obviously have paperwork and other things they have to do as part of their role. Particularly for ADL, activities of daily living, the kitchen here was not particularly well equipped, or like an OT kitchen in other situations. I think, more so than the physio, because you can use a plinth and a mat and you can use high-low beds and, you know, standing frames or whatever else here, and you've got a few of those, but for activities of daily living, in a kitchen, erm it's a very communal kitchen there. Everybody from the staff who make themselves a coffee to you know people having their meals or, and then in that environment to try and get somebody who's had a head injury to create a meal, or do some cooking, is, I think, a little bit erm not that realistic. The other thing with here is, as it was at Homerton Hospital, they sort of said, "Oh you know we've got a like a you know a washing facility so you don't have to cart all the...". You know.... there were obviously times when Richard had uriferous clothing, whatever and I was carting it 50 miles on a train you know....

I: So this is the laundry facilities at the [unclear]?

M: The laundry facilities are another thing. And in a sense, erm.... trying to get people to intervene in the wider community, which was the alleged aim, or the alleged goal, erm. The outcome for that I think will never be achieved in a place like this. I think it's difficult cos... having worked in the community myself I've met people in every place from the local swimming pool to erm involving the local person who's er function it is to facilitate disability erm.... access and support, on-going support, exercise particularly. Now speech and language is a bit different, you know, it basically means you've got to have a team or a therapist like the Community Team here. If that doesn't work for you, and you go back to your GP, who's your... your... gatekeeper once you've been discharged from here. If I felt that I hadn't had [AHP Consultant] to go back to. Because [AHP Consultant] was much more fundamentally important. So, it's a bit like if there's a judge and jury you know if you're assessing your service or looking for how to make improvements, I think there are quite a few ways. I mean, it is still very much a ward scenario. It is within a nursing home. You know, you're in London you know, parking or getting people to come and visit. It's also quite frightening. I wasn't frightened by it because I've been in many hospitals and nursing homes in my working life. Quite a few of my son's friends used to have to really take a huge deep breath before they could come in the door and... particularly when at the [Specialist Acute Hospital] it was that a couple of them passed out, physically ended up on the deck. You know, some of that's seeing Richard in that very, very vulnerable, frail position. In a scenario like here, erm you can't make rooms pe.... up to a point Richard made that room personal to himself, he had blue tack everywhere and pictures and whatever. I think... I don't know that you could utilise volunteers a bit more, see if that would be a possibility? And, that is perhaps a big possible area, particularly for speech and language because the communication erm programs or whatever that seem to work at.... erm what's that.... the organisation.... it's the one that [name] something [name] erm particularly that.... as a... because that's part of a university, erm some of their skills that allegedly are going to be

part of a program. They're all still saying, "Oh were planning it, we're trying to organise it, were trying to take people from"... but it's almost said as if it's an up and running thing but it's not an up and running thing. They're waiting till they get 10 people and then they'll...

I: So these are the speech and language therapy groups that are running that your son hasn't been able to access yet?

M: Yes external. I don't think he will be able to because they're physically not running, they are physically not running. So that's an area I would... I mean.... the staff here did a erm.... they used to have everybody who was on the ward would come to a speech and language sort of sharing communication process. And it was often about, well you know, what could be made better here. And I think Richard always had a whole.... You know.... his thought processes were still active and they weren't always logical, but they were still you know firing and trying to....

I: So he had lots of ideas for the commination groups?

M: Yes, I think that's an area that....

I: could be....

M: Yeah, obviously the kitchen is the other area because that ultimately.... I mean, fine you can go to Sainsbury's and Waitrose and buy something off the shelf but not everybody has the financial capacity or the inclination to do it, but they have to survive and if you're not going to get help in an active way from social services, you know, that's what.... more or less, what having social services.... what does, you know, like... The only communication I ever had was, "Well does he need meals on wheels?" and I went, "I think that would not do". There's clearly something you've not understood, because you know, if you're thinking he would accept that, it's not happening. He's more able than that. Erm but you now the cooking....

I: But he still has on-going support needs.

M: Absolutely yeah, yeah.

I: thank you very much [name] for coming today and I'll let you get back to Richard.

Interview 4: Transcript

I = Interviewer

F = Father of Simon

M = Mother of Simon

A pseudonym is used for the participant referred to in this interview. All other names of people and services have been removed, text in brackets [] provides the description of the service or role referred to.

I: Hello [Father's name] and [Mother's name] thank you for coming. So as I explained this is a semi-structured interview for the research that [Researcher] explained. So I've got five questions that I'm going to ask and it's for you... for your experience of what has happened over the last few years. So the first question is, can you describe your experience of the discharge planning process...

F: of the what?

I: Sorry, of the discharge planning process when your relative left hospital? And I know that you've had lots of different hospitals, so if we say it's when he left [Specialist Nursing Home] to get to the [Transitional Unit].

F: That was alright but er from the.....

M: Hospital

I: Ok talk about that from the [Acute Hospital]

M: From the [Acute Hospital] to [Specialist Behavioural Level 1 Unit] wasn't very good was it? Cos we was trying to find somewhere decent for him to go and we wasn't happy with erm Catford was it?

I: Yeah, yeah. And that was because there was a delay for him going from the [Acute Hospital] to [Specialist Behavioural Level 1 Unit], there was a massive waiting list so he had to go somewhere else didn't he?

M: Yeah for his safety really because he tried to get out of the hospital, or he had got out once.

F: He went to [Specialist Nursing Home] first didn't he?

I: Yes, yeah

F: That was... Cos we didn't want him to go to [Placement name] cos it was...

M: Not safe really in some respects.

I: Yes, yeah

F: And then from [Specialist Nursing Home] to er [name]....

M: He went to [Specialist Behavioural Level 1 Unit] after [Specialist Nursing Home] first

F: Yeah but that was a matter of course cos he was knocking the place about, he was knocking the doors down at [Specialist Nursing Home].

I: The first time.

F: The first time yeah. He was only there for three weeks I think, something like that. And then he was transferred to [Specialist Behavioural Level 1 Unit] which.... it seemed a very detached sort of hospital, not really.... Didn't really want people there, other than the patients, whatever they call them. And... there wasn't very much cooperation there. The basic thing was at that time Simon was very conscious about his things and he carried everything that he'd got about with him and that was the time when he was into all these insects and [unclear] and fighting the Germans and all that you know? And, he kept saying that this coloured chap next door was going into his... his flat. And I said, "Well can't you put a lock on the door and give Simon the key?" "Oh yeah we'll arrange that, well get a lock we'll get a this that and t'other" and [unclear] I kept asking. "We can't get a lock cos if we get a lock we've gotta get 37 keys for all the staff". I thought what a load of poppycock. I said why couldn't you have like you have a fire alarm with a little box with a window on, everybody's got access to it and they just help him to get his key out. Because he was very conscious of that and I mean [unclear] laptops and all sorts in it.

I: And when he left [Specialist Behavioural Level 1 Unit] do you.... were you supported erm did you know what his goals were and what the plans for when he was moving to the next step, to [Specialist Nursing Home]?

F: Well there might have been goals, this that and t'other but when he got [Specialist Nursing Home], after a few weeks I think they threw the [? Book] in the air and said well it's a waste of time. Because he used to have a program, and then.... at [Specialist Behavioural Level 1 Unit] he had a program and he'd come and say, "Well I've got a meeting today with such and such" and er but when he went to [Specialist Nursing Home], the program... half the time they never give him one, so then they didn't know what was what. And I thought it was important because the people, they could help him while seeing him when he had [unclear].

I: And when he was moving to the next step, to the [Transitional Unit], were you informed about that step and about dates and time scales?

F: That was sort of a rushed thing wasn't it? To get to er [name of co-located service] what is it? [name of co-located service]?

I: [Transitional Unit]

M: He always tells me off because I call it er [name of co-located service]...

F: So that was a bit of a rushed job. And the same when he come here, that was definitely a rushed job, because he was going to [SLS] and then, "Oh we can't send him there".

M: Who was that we had?

F: [Social Worker]

M: I didn't like him whatsoever.

F: social worker....

M: I didn't find him any help whatsoever.

I: That was the social worker that was supporting his discharge....

F: I don't think he was supporting Simon, I think he was supporting him self because he was a [? wiz kid]

M: As soon as there was that trouble that was supposed to have happened at erm [Transitional Unit], erm he rang us or emailed you the next day and said he couldn't go there and he kind of disappeared.

F: Off the system.

M: He kind of washed his hands off Simon as far as we could see.

F: He transferred to another part of the....

M: And then we had [AHP Consultant] like. Erm I was never keen on him. He couldn't even come on time for the appointment, for a meeting and yet Simon's friend had come from the same place and she was there well in time. I wasn't keen on him.

F: I think he was just all about himself. Well, to put in comparison, he couldn't hold a candle to [name] [unclear]. Do you know [name]?

M: [name]

F: [name]

M: [name] or something was his name.

F: And that was the previous social worker?

M: He was really [unclear] to us

F: That was the... at the [Acute Hospital] yeah. He was far more supportive, but this [social worker], he got something in his mind and if you gotta go that way and er...

I: And were you involved in the discharge planning?

M: Not for this place too much was we?

F: It was.... It's not [SLS]. And er... so we looked around where car parking space was, cos I was driving at the time. And this that and t'other and contacted 'em. I think it was a bit more, come and go as you please like this place is now like you know? Whereas [Transitional Unit] it was sort of you've gotta ask permission to open the door. You've gotta have someone open the door for you to get out.

M: It's more like an hospital really wasn't it, [Transitional Unit]?

I: And that was where he had some rehabilitation. So if I go onto the next one. What as your experience of the initial period when your relative was at the [Transitional Unit], so [Transitional Unit]? So when he first.... your experience of the initial period he was there.

F: Well when he was there they looked after his clothes. Everything was hung up weren't it?

M: Yeah and his bed was changed regular and things like that.

F: And er other than that we can't say cos he only went out when we went out. Mind we been down practically every week then.

M: Yeah we was going twice sometimes a week then.

I: That's a lot

F: So we can't really say anything about that only he had this confrontation with this coloured bloke and that was it.

I: So were there any challenges or positive experiences when he was there on the... at [Transitional Unit]?

M: No. As far as we know just that one. Just at a lunchtime and no one saw it so we was told.

F: He had his meals served there, whereas I mean even here I mean....

M: Meals are not great for him really, he has these ready meals here...

F: But then they all [unclear]

M: But he's happy enough he see[Transitional Unit] happy enough here don't he?

I: When he was in the [Transitional Unit], was there lots of support available? Was there... all the equipment that he needed and...

M: No. There was nothing at [Transitional Unit] was there? [Transitional Unit] are you talking about?

I: Mmm at [Transitional Unit] yeah.

M: No he didn't have....

F: [name] is it? Arranged for him to get housing benefit which he hadn't needed at [Specialist Nursing Home] or anywhere or [Transitional Unit] and er.... but that [social worker], I mean he never applied for benefits or anything. You know the DWP and the EWP or whatever they are.

I: So that was a challenge initially on the [Transitional Unit], the delay supporting Simon to get benefits?

M: Yeah. Well he's only had them like since he's been here, which is nearly four years afterwards, so...

I: And was the transition from there to here supported?

M: Well with [AHP Consultant], [AHP Consultant] sorted it all out, but we didn't have any say in it did we?

F: As I say, most of the stuff has been up to yourself and [AHP Consultant], that's sorted things out. But that's vanished, we've got nobody, this [Psychologist] we never hear hide nor hair from him. Whereas from [AHP Consultant], I mean every two or three weeks we'd hear from her how things was going this that and t'other, but we don't hear nothing now.

I: And is that useful? To have that....

F: Well it is because.... Its my fault really because when I'm talking to [SLS Manager] I can't hear half of what he's saying so we just.... unless I pick up on certain words you know? It's in one ear and out the other so you can't really get to know. And it's the same with [Supported Living staff member]. But [Supported Living staff member] now, I don't know if you know [Supported Living staff member] do you? She... she's... as far as I'm concerned speaks lot better, but it's only my concern because of my hearing like. So...

M: They all seem very good here.

I: So this moves onto the next question really. Can you describe your experience of the initial period when Simon came home full time? So we're classifying [SLS] as his home, so when he came back here and was supported by the [Community Team], so the community rehabilitation team, so the therapists that supported him when he first came back.

F: Here?

I: Yeah

M: No to [Transitional Unit].

I: No to here, to here. How was the first bit when he came here?

F: Well it was only erm....

M: He did have somebody come didn't he?

F: No but [AHP Consultant], there was only [AHP Consultant].

M: No he did have another person come but he wasn't very... getting on very... She said she was making no headway with him [unclear]

F: Oh that was from [Brain Injury Charity].

M:..... for a coffee or something... somebody.

F: That was from [Brain Injury Charity]. First of all we had a young lady but she left and he got on well with her. She left to go to further studies or something like you know. She was Scandinavian in think.

I: These were additional carers that....

F: From [Brain Injury Charity]

I: From [Brain Injury Charity] that used to come in and they still do but they spend time with Simon and....

M: He did have a psychologist I think but she couldn't.... she give it up I think because she was getting nowhere with him. I think somewhere along the line there was a psychologist when he first moved.

F: Well this was the same as [Specialist Nursing Home] actually she was getting a psychologist or whatever and er they would go out for a coffee and he was fine with that. And then when he came here I say that part was taken up more of less by [Brain Injury Charity]. Which, this [Social Worker], or whatever his name was, says, "We'll support him with a personal attendant"; whatever it is, full time sort of thing. And then we didn't know it would be somebody from [Brain Injury Charity], which are volunteers. That didn't make no difference, the first one he had, I can't remember her name, but she was good but the second one was terrified of him, she wouldn't even go upstairs to his room.

M: So she shouldn't have been sent really for her own [? being] comfortable.

F: So I don't know who it is now. Who it is know, I don't know. Cos they said they was going to train somebody up, because the last one, [name] I think her name was, she was too young to have been put into that situation like. And er very, very quiet.

M: I mean he's a big chap and she's only little and well..... [Supported Living staff member] is... [Supported Living staff member] gets on quite well with him and [Supported Living staff member] is it? The new girl, she gets on fine with him.

I: So these are all some of the team at [SLS]...?

M: Yeah, he gets on OK with... He see[Transitional Unit] to get on better with women though somehow, I don't know why but...

I: And so when he first came here were you aware of how to seek support if you needed support?

F: How?

I: How to seek support if you needed to know anything or find anything out?

F: Well the only person we...

M: [AHP Consultant] we used to ask, or...

M: We used to contact [AHP Consultant] like you know? And we used to contact you from time to time, but er as I say, since [AHP Consultant] there's been nobody other than [Supported Living Manager]] and I half the time I can't tell what he's saying, it's not his fault its mine. You know so, and then [Supported Living staff member] was the other one and he, if she talked any lower...

M: Cos they talk quiet you see? And he shouts [laughs]

F: So other than that I mean....

I: And was there a transition period so when he first came here, did any of the team from the [Transitional Unit] support him to visit here to see if he liked it or anything like that?

M: [AHP Consultant] [unclear]

F: I think when he was in [Transitional Unit]

M: She said here

F: [Social Worker] or whatever his name was brought him here to have a look and he seemed quite happy with the flat, cos we hadn't seen it, so I mean but then again I mean we're 150 mile away you know we don't expect to be here every step but er so he was already in this flat when we visited him wasn't he?

M: Mmmm

I: OK so the next one is, can you describe your experience now that your relative, so Simon, has been back here for a longer period of time. So how are things now, what's your experience been of him being here? So being back home or having found a home?

F: Well he seems to be the last....

M: Three, four weeks.

F: Month, 6 weeks or something like that, he's improved socially.

M: He seems much pleasanter than the conversation previous used to be, "What you asking me that for?" "What do you want to know?" If you asked him something or where have you been? "Why are you asking me that?" but now, there's a conversation. The last few weeks whether his luck changed I don't know.

F: See. I said to him when he asked for his other bike, the one that he's got now. I says well I can't see them letting you go out on it Simon, which I couldn't. I don't know what control they'd have to stop him I don't know. But er he says, "Pa that'll be you, don't want me to let me go out on it." That don't mean I don't know. The last time anybody went out with him was [friend] you know [friend]?

I: Mmmm

M: and another [friend] wasn't it?

F: And another person right?

M: And they said he wasn't safe.

F: He was at [Transitional Unit] and they took him to the er maintenance thing on a Saturday or a Sunday for the [location] cycling place. And they said you've gotta have somebody in front and you've gotta have somebody behind, you know, because you're not capable. But I mean Saturday he went out on his own, nobody. I don't know how [laughs] much he'd stop the traffic or what I don't know.

M: It's a bit of a worry really.

I: Mmmmm

F: I said how does he get down to [location]? He says well I did a circular route down [unclear] Road. Now, how did he know the [unclear] Road? Without a map unless he's got some other way. I've got him some maps anyway but...

I: So that's a type of challenge, you not knowing what he's doing when he's here?

F: Well I don't want him to be knocked off his bike again you see? That's the main thing. I mean...

M: His safety really is the main thing, not him going out. The more he goes out the better cos I think his brain's gone stagnant since he was here because he wouldn't associate with anybody and he's just kind of in his flat all the time apart from seeing the staff. And then sometimes he wouldn't let the staff in. It's only been in the last few weeks that he's let them come in and clean his flat more.

I: So that was one of the things initially? He wouldn't let people come in to help him?

M: No...

F: Up until the in the last few weeks to be fair, for twelve months he wouldn't let them in.

M: I mean his flat was in a bit of a state really wasn't it? At times. I mean we have complained to the staff about it but it wasn't really their fault if they can't get in and they can't force him. Well the next thing is his hygiene I've got to work on I think but he does go nasty if you mention it. Like today like I asked him something about his jumper...

F: At times we was taking him out and he absolutely stunk, didn't he?

M: Yeah it's embarrassing really to take him anywhere.

F: We took him just before Christmas, we didn't realise until then how bad it was, to get a pair of trainers for his Christmas present. He took his shoes off at the JD Sports and the chap who was serving him went off and never come back because of the smell of his feet weren't it?

M: Mmmm

I: And do you know who to talk to about those issues?

F: No

M: No I only talk to the staff here.

I: So you speak to the team here?

M: Yeah but of course they can't make him have a shower and he's got loads of shower stuff, obviously it's built up because I kept bringing and he's not used it. See and his clothes I think he tends to wear the same clothes all the time. And he don't know he's got other clothes. They're put away. Like [sister] bought him new clothes when she came three weeks ago, but he's not had them on. They're probably still at the bottom of his wardrobe.

I: So he wears the same clothes?

M: I think he tends to yeah.

F: See I think in a way the system is wrong up to a point because they say downstairs, "We can't make him do anything at all. If he doesn't want to do it, that's it". But I think that's wrong because people might be hurting themselves somehow. You know, I mean skin diseases and god knows what through not washing and things like that, so somebody ought to have something somewhere to be able to say, "You've gotta do it", and not physically force them, but I mean there's other ways of forcing them to do things isn't there?

M: There's a probably a way of talking them round because there was one nurse in [Acute hospital]. I mean, is that the right name for the hospital?

I: Yeah that's fine. So right at the beginning.

M: Well. The one nurse she was really good she got a way of getting his clothes off and getting him to change himself. And when we used to visit and stop at [Acute Hospital] she used to have them in a bag behind the desk waiting for me to take and I used to wash them at [Acute Hospital] so I could leave all clean clothes for him. And she'd got a way with him somehow of talking to him and persuading him to change. So perhaps just it's the way you [? are].

I: And that's been a real challenge here?

M: Mmmmm

F: It's... it's the same with [Supported Living staff member], [Supported Living staff member] can get him to do things that the others can't you know but er but er it's only up to a point you know and then Simon.... I mean she can't make him do and get a bath and things like that.

I: And do you, apart from the cycling, the new thing that's happened, do you feel he's safe and supported here, with the support?

F: Well he's been out with us a few times when we [? went] to [pub] more or less across the main road. But he says, "Well I just come here and cross the road. I'm not using the crossings". And he says, "Come on we'll go". I says, "No I can't compete with the traffic. I can't break into a run if the traffic's coming". So we go up to the crossings. It not far it's only a hundred yards.

M: But he thinks he can cross on red, not on when the green....

F: He doesn't now. Not now he doesn't.

M: Don't he?

F: He must have been under a wrong impression at that one time. But er, sort of things that's what makes us uneasy about him going out in the traffic on his own but I mean that might be a good thing sometimes, like when you're learning to drive, when the pressure's on and you've passed your test you're [? quieter] and then you've learned to drive. But I've never learned to drive round here [laughs].

I: And he's got on-going access to other services or information?

F: Well they only tell us if there's anything important. And sometimes not even then, the last time he had to go to hospital it wasn't until [unclear] I found out that he'd gone.

M: Simon rang us. I'd rung Simon and there was no answer, to see if he was alright. And then he rang me back later to say he was in hospital. They hadn't...they said, made some excuse up here didn't they?

I: So they support him to go to hospital....

F: Oh yeah they take him

I... but you're not informed?

M: yeah

F: They take him and bring him back like he has done today and things like that. but er even... he's had his [unclear] today so hopefully they gonna pick him up tomorrow for his bank to pay 'em which [? he] did the last time. You know which er... they didn't know how to pay him. I says, "Well get Simon to go up to the bank and get his money out so as he can see where the money's going". I says, "If he doesn't we'll pay it anyway".

M: See they need cleaning stuff but he won't pay for that out of his money.

F: He's got no toilet paper again. Sometimes he goes weeks without toilet paper.

M: He says he don't need it. So what I do when I visit him, I go down to Iceland on my way as you come in and get a big pack.

I: And leave it here?

M: Yeah. But sometimes he goes mad. He hasn't like the last couple of times but sometimes he goes mad, says he don't need it.

I: Yeah

F: And he'll go and it's... the one time we went, I think it was about two month ago, he'd got about 20 of his meal boxes, you know the boxes they get with the meal in, empty. And milk bottles and everything else all stacked there. Stacked neat and everything.

M: He puts them all back in the sleeve.

I: So he stores all the rubbish?

F: But er... Yeah but I can't see why they can't say, "Simon come on [unclear] a bag we'll take these down stairs and put em in the whatsit"

F: Cos he... He's got it into his brain everybody's [unclear]. You know, I mean we took him to the shop the other day, he says, "I ain't carrying that stuff you can carry that".

M: He did, milk and toilet roles, "It's too heavy I ait carrying that". Really nice.

F: So it's, that's just... not being educated enough. Cos he used to [fend] for hi[Transitional Unit]elf when he was, before he had his accident. He used to have to look after hi[Transitional Unit]elf like but er, so, it's not being forced on him enough. So, I don't know. I mean they say you can't restrain him, this that and t'other but we visited him in [Acute Hospital in overseas location of accident], which is supposed to be all the same. You know and the same....

M: He was tied.

F: He was tied, his hand and his feet like. His hands was strapped to the bed. Give him a bit of movement like. And his ankles was the same. You've never seen such a mess in your life as that flippin' hospital.

I: And this was because he has his accident in [location]?

M: Yes

F: He was in a wet nappy. All hypodermic needles under his bed. You know I mean he couldn't get out and use them but I mean the point is it's there and... the cleanliness was absolutely vile. You used [unclear] some steps to like [? a conference] suite you know in between the wards and everything else. And this one day we went and there was poo all over the floor, all the way to the toilets and people had been walking in and out and going into the wards and everything else and nobody had thought to clean it up, which you'd think that would be a major thing...

I: So that was right at the beginning when you had [unclear]?

F: Yeah, oh yeah that's nowt to do with this place.

I: The next question is, what was your experience of the support provided by the [Transitional Unit], so [Transitional Unit], and all the community therapists and that included the support from [AHP Consultant]. What's been your experience of this?

F: Well the support from [AHP Consultant] has been fine.

M: Same with yourself.

F: But it was only periodical if you understand what I mean. Every two or three weeks or something like that which.... I'm not saying anything against [AHP Consultant] it's just that that's how it was. I mean she's perhaps got other jobs to do or things like that, I don't know.

M: Well they haven't only got us have they?

F: Ey?

M: I say they haven't only got us to see to.

F: I know. All's we want is some... the information passing onto us, if and when necessary and er so as we can do with it as well. Sometimes [laughs] it's ironical like, last week, the beginning of last week, he phoned he says, "[Friend] and [Friend] are coming, they're buying a van and they're coming up on Thursday to fetch my bike." Right? She [referring to his wife/ [Mother]] gotta go to an appointment on the Thursday morning, at the hospital, and then she got an appointment for the doctors in the afternoon. It couldn't have been a worse situation you know cos I mean....

M: I said Simon you can't come today, Thursday, I says it's not a very good day. "Oh you're just making excuses", he says. But we fitted round it.

F: We managed in the end.

M: I changed my appointment at the doctors when I got back, cos I got a text message off Mary to say they'd be there at three o'clock, mid afternoon. So it turned out they come twenty past six at night. So it all worked out. So he bought... I tell you he bought his other bike down so he's got two bikes now. I was dreading him going in the garage in case he wanted to bring more stuff here [Sylvester House], because then his flat would have been just.... I just cleared it and made him move his boxes. He had boxes here from when he moved in, and he's been in 18 months.

F: See we would like to know what the future holds for Simon. What his improvement will be, if any. I mean there's gotta be people about that have an idea. Cos we're getting rid of stuff and he might want it next week. You know what I mean?

M: He's still got a unit being paid for, 46 pound a month.

F: That's another thing. This [name], social worker, says, "You've got two store boxes for Simon with his stuff in from this place." I said yeah. "Well we think he'd be better off if it was stored down here". So I had a look. I mean it was costing 80 odd pound a month, it was going to cost 80 odd pound a week down here for the same sort of facility. And it would've been a waste of time, wouldn't it?

M: Yeah

F: Because we couldn't have got rid of stuff. Eventually we got rid of the one and had the stuff in our garage at home, which I dwindled down and got rid of stuff as we think he won't need [laughs]. This is what I'm saying we don't know what he wants in the future. I mean if, with him riding his bicycle, bearing in mind the people took him up to get his bicycle from Maternity Worldwide, that's the charity he used to ride for, whether they've got something in their mind about the future, which then he'll need all of his camping equipment and everything else.

M: Well that's gone.

F: Some of it has but not all of it but a lot of it, so, I say we'd like to have an idea what's going to happen in the future, or if he's going to be virtually, with slight improvements, in the same state that he's in now.

I: So one of your experiences, the support it's been difficult to know.... you haven't had that support as to know how your son's going to be in the future for you to plan?

F: I mean we... this is completely alien to us you know anything that happens to the mind. I know I've got no mind at all but still [laughs]. There was one of his friends, she emailed me once, I mean they ain't in touch now sort of thing, but she was... did a lot of work for the [Cycling group] and she said, "well we've just had one of our chaps that's had a brain injury. Four and a half years and now he's got a job" and everything else. So, we don't know. We don't know how bad he was. We don't really know how bad Simon is, you know? We know he's has a terrific knock of the head and it's damaged some of his components but whether they can be sort of stimulated back in some way, not completely I know but I mean.... Cos most times we see him he'll come up with something and we'll think, well where's he got that from? Out of the past somewhere you know what I mean? And er if you were to talk to him about it he wouldn't know. I mean Net, when I had my operation, I had an operation in November, and she [Mother] came down on her own [to London to see Simon].

M: I did

F: And er I phoned them up and they happened to be in [Pub] and Simon.... Simon says.... he was talking about [unclear] and he says, "Anyway my mother's coming down tomorrow" and she says, [? no I'm visiting!] So he can't put two and two together if you understand what I mean?

I: And then do you have any other... So just to finish off do you have any feedback that you'd like to add about your experience?

F: No, other than what we've been saying you know? I mean we know [? nobody's] perfect no matter what it is. I'm pleased in a way that he's got back on his bike. But we've had nobody saying, "You ought to let him have his bike", if you understand what I mean? Cos his other bike he had in his flat on his trainer and it never moved did it.

M: No

F: So, he did use it when he was at er [Specialist Nursing Home] for a while, but then he got off cycling. Sometimes, if you ask Simon a question that he doesn't really like he'll get very nasty.

I: Thank you very much

M: You're welcome