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A QUALITITATIVE EXPLORATION OF THE EXPERIENCES OF THE HOSPITAL DISCHARGE PROCESS, VIA THE *TRANSFORMING CARE* AGENDA.

Section A: What is the experience of the hospital discharge process via *Transforming Care*, from the perspective of people in the system. A systematic review and thematic synthesis.

ACCURATE WORD COUNT: 8000 (173)

Section B: "*It's not easy work*". A grounded theory of community health and social care professionals' experiences of what contributes to a successful transition under *Transforming Care*.

ACCURATE WORD COUNT: 8000 (414)

For submission to the British Journal of Learning Disabilities

Overall word count: **16000 (+587)**

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

MAY 2023

SALOMONS INSTITUTE FOR APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgments

I would like to thank the participants who provided their time and experiences for this project. I was in admiration of your commitment to support people with learning disabilities and/or autism and the hard work you complete.

To my supervisors, Dr Annabel Head, Dr Simon Powell and Dr Helen Ellis-Caird, thank you for your guidance and support throughout the project. Your expertise and encouragement has been invaluable.

Finally, to my husband, family and friends. Thank you for being there and keeping me going, even when moments have felt tough. I could never have done this without you by my side.

Summary of the Major Research Project

Section A provides a systematic review of the available qualitative literature exploring the experiences of the discharge process from hospital to a community-based setting, via *Transforming Care*. Thirteen papers were synthesised using thematic analysis, which produced four over-arching themes: *Navigating within the system; Working within restrictions; Preparing to move; and Life after discharge.* Further research would benefit from gaining a deeper understanding of the experiences of a range of community health and social care professionals of working under *Transforming Care*, as this voice appears to be missing.

Section B presents a qualitative study exploring the processes community health and social care professionals go through when ensuring a successful discharge from hospital to a community-based setting, for individuals with learning disabilities and/or autism. Using a social-constructivist grounded theory approach, a 12-category model was produced which derived from four concepts: “Balancing the different levels of the system”, “Providing the ‘opportunity to thrive again’”, “Feeling stuck working within the system” and “It’s not easy work”. Findings indicate the importance of a joined-up approach, but also the emotional impact the job role can have. Clinical implications include protecting and promoting the wellbeing of community health and social care professionals and ensuring supervision is provided.

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Major Research Project: Section A

Word Count: 8000 (173)

Abstract

Background: *Transforming Care* was first introduced in 2012 to reduce the number of people with learning disabilities residing in hospital. Research has shown the process of supporting an individual to move out of hospital can be challenging and lengthy for all stakeholders involved.

Aim: The current review aimed to systematically review qualitative literature to explore the experiences of being part of the discharge process from hospital to a community-based setting, via *Transforming Care*.

Design: A systematic search was completed on five databases and relevant papers were used.

Findings: Thirteen papers met the inclusion criteria. The papers were synthesised using thematic analysis, which produced four over-arching themes: *Navigating within the system; Working within restrictions; Preparing to move; and Life after discharge.*

Clinical Implications: It was important for everyone involved in the discharge to communicate effectively to ensure the process was not delayed. It would be beneficial to have further training to understand the *Transforming Care* principles. Finally, providing further support in the hospital setting to explain the discharge process to the individual may help reduce anxiety levels.

Key words: *Transforming Care, learning disability, discharge.*

Introduction

Terminology

The British Psychological Society (BPS) defines the term ‘learning disability’ as “*significant impairment of intellectual functioning (usually taken as IQ < 70), significant impairment of adaptive/social functioning, and age of onset before adulthood*” (BPS, 2014). The terms ‘intellectual disability’ and ‘learning disability’ are used interchangeably, however ‘learning disability’ is the recognised terminology used within services in the United Kingdom (UK), with ‘intellectual disability’ increasingly being used in academic literature. However, individuals may prefer a different terminology, and this should be valued. As there is no clear guidance or consensus for terminology, ‘learning disability (LD)’ was the chosen term throughout this paper.

Transforming Care aims to support the lives of children, young people, and adults with LD and/or autism (NHS England, 2015). Across services that support individuals with LD, there is confusion around the inclusion of people without a LD but with autism (NHS England, 2019). Therefore, this review focused on only adults with LD who moved from hospital to a community-based setting. However, it may be possible to generalise the results to individuals with autism who have also moved out of hospital, via *Transforming Care*.

Historical Context

Institutionalisation

In the twentieth century, under the 1913 Mental Deficiency Act, people with LD were often isolated from the public and lived within large-scale institutions, that were described as unpleasant and restrictive (Walmsley, 2008). These institutions were overcrowded, and individuals had limited rights. As the number of institutions grew, due to economic difficulties, the financial resources provided were reduced and the individuals residing in these institutions did not receive the care they required (Bilir, 2018). Wolfensberger also spoke about the importance of “normalisation” and highlighted that individuals with LD should have received the same everyday life conditions as those in mainstream society (Wolfensberger, 1972). Due to unsuitable living standards, there was a push to close institutions and move towards people with LD receiving support whilst residing within the community, increasing social inclusion (Bouras & Ikkos, 2013; Chow & Priebe, 2013). It was also hoped that closing institutions would be more cost effective (Parker, 2014).

Deinstitutionalisation

Towards the latter part of the twentieth century, the drive to close long-stay institutions resulted in the development of the *Better Services for the Mentally Handicapped* paper (Department of Health, 1971) which highlighted an increased focus on community care as opposed to institutionalised care (Kunitoh, 2013). This movement for more community-based support resulted in a process named deinstitutionalisation (Barron, Hassitotis & Paschos, 2011) and concentrated on developing smaller mental health centres that could be accessed within the community (Fakhoury & Priebe, 2007; Kunitoh, 2013). The focus of deinstitutionalisation was to avoid inappropriate admissions to hospital and introduce community care that was accessible for individuals with LD (Bachrach & Lamb, 1989). The rights for people with LD to exert choice over their living arrangements and to live independently, follows the principles highlighted by the United Nations Convention which referenced the Rights of Persons with Disabilities (United Nations, 2006). Since the twentieth century, in the UK, community living has been the focus of further policies such as *Valuing People* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009). As a result, the total number of individuals with LD residing in hospitals has reduced from 48,959 in 1976 (Department of Health and Social Security, 1980) to 2,045 in the most recent findings at the end of May 2023 (NHS England, 2023).

Community settings

The objective of community-based settings was to empower people with LD to have opportunities for ordinary living arrangements and to enhance quality of life by having choice over social activities and access to the community (Mansell & Beadle-Brown, 2010). Initially, the move to community-based settings consisted of large residential homes (Kushlick, 1976), which led to the development of group homes (Bredewold, Hermus & Trappenburg, 2020). Group homes typically consisted of three to ten individuals with LD, residing together with staff to support their high-level of needs (Bredewold et al., 2020; Mansell & Beadle-Brown, 2010). Group homes were at times clustered together, creating a small community of individuals with LD living on the same site (Bredewold et al., 2020). Following the development of community group homes, was the introduction of supported living. Supported living housing was designed to enable people with LD choice over their accommodation and who they lived with, whilst still receiving support from external staff members (Stevens, 2004).

Overall, research has demonstrated that community-based settings provided better results for individuals with LD and are superior compared to institutional settings (Mansell & Beadle-Brown, 2010; Kozma, Mansell & Beadle-Brown, 2009; Emerson & Hatton, 1994; Kim, Larson & Lakin, 2001). Overall, living in community-based settings has reduced ‘challenging behaviour’ (Kim et al., 2001), provided higher levels of client satisfaction, participation in community activities and more contact with family and friends (Young et al., 1998). These improvements have been linked with higher ratings of quality of life compared to institutionalised living (Kozma et al., 2009; Chowdhury & Benson, 2011).

Problems with deinstitutionalisation

Due to deinstitutionalisation many individuals with LD were moved out of long-stay hospitals without adequate planning and support, resulting in re-hospitalisation (Simpson & Price, 2010). Research carried out by Simpson and Price (2010) found that new community residential placements were being closed and individuals were moved before plans for long-term care were actioned. Also, staff providing support in the community placements, had limited training and were often low-skilled and low-paid (Littlewood, 2004). As a result of low wages and burnout, staff would frequently leave the role, creating an inconsistency in the support an individual with LD received and therefore heightened anxiety (Ryan et al., 2021). Also, Local Authorities sometimes withdrew funding and support once an individual had settled in their community placement, increasing the vulnerability and risk for the individuals (Mansell, 2006).

Also, community services were established to support people with LD whose needs were less complex. Therefore, local services were not equipped to support those with complex needs (Martin & Ashworth, 2010). This resulted in individuals with more complex needs either returning to hospital (Beadle-Brown et al., 2007) or moving to specialist placements out of area (Beadle-Brown et al., 2006). Allocating placements out of area created difficulties with communication between the locality funding the care, and the locality providing the care. As a result, the individual’s needs were often not fully understood (Mansell, 2006).

The deinstitutionalisation movement was also criticised due to the limited number of community-based services available, and this gap being filled with private hospitals, daycentres and nursing homes (Hudson & Cox, 1991). These private providers were found to purchase accommodation in quiet rural areas which were further away from individuals’ family and friends (Mansell, 2006), therefore removing people from their network and known community.

Although there was a push for individuals to obtain the care and support they needed in the community, as opposed to hospital settings, these difficulties highlighted the complexity of deinstitutionalisation and the importance of planning to prevent re-institutionalisation (Simpson & Price, 2010; Mansell, 2006).

Winterbourne view and introduction of *Transforming Care*

In May 2011, BBC Panorama uncovered criminal abuse at the private hospital Winterbourne Hospital, which cared for people with LD (BBC, 2011). Serious case reviews highlighted several inappropriate physical interventions, such as restraint; evidence for poor quality healthcare; and management failures (Department of Health, 2012). The exposure of this mistreatment triggered a large-scale review of care across England which included 150 LD services. The findings concluded that individuals in hospital for assessment and treatment were remaining there for longer periods of time than necessary. Also, there were high levels of restraints being used, poor quality of care and a lack of meaningful activities for the individuals (Department of Health, 2012). The exposure of maltreatment at Winterbourne Hospital, combined with the large-scale review, resulted in a report being written by the NHS Commissioning Board, Local Government Authority and Adult Social Care introducing the *Transforming Care* agenda (Department of Health, 2012).

The aim of the report was to reduce the number of people with LD residing in hospital or long-stay institutions. *Transforming Care* was developed as a national programme with "£25 million capital fund for housing and technology to support people with LD to live as independently as possible" (Local Government Association, 2021) and receive person-centred care in the community (Department of Health, 2015).

In 2015, NHS England identified six “fast-track” geographical areas to expedite development of plans for service transformation and supported this transition with £10 million funding to help speed up implementation of the national *Building the Right Support* policy (NHS England, 2015). This policy provided guidance on how to reduce the number of individuals with LD in an inpatient setting and develop alternative community provisions. In all other geographical areas, this funding was not provided and the commissioning services for people with LD was split between NHS England, local authorities, and CCGs (Care Commissioning Group), therefore making it challenging to move funding for inpatient services to community-based services (NHS England, 2015).

Rationale and aims

Data at the end of May 2023 showed 2045 individuals were residing in hospital (NHS Digital, 2023), suggesting the Long-Term Plan was still not effective in implementing *Transforming Care*. Therefore, this review was needed to help understand the difficulties with implementing *Transforming Care,* to prevent individuals with LD residing in hospital unnecessarily. Also, to ensure successful transitions back to the community to avoid placement breakdowns and the ‘revolving door’ phenomenon (Royal College of Nursing, 2016).

There are many perspectives on why the *Transforming Care* project has not achieved its aims, one being that insufficient extra resources were allocated to the project (NHS England, 2015). From the perspective of several organisational and systems models, it can be argued that the various levels making up the *Transforming Care* project were not connected. For example, the theory of change (Drucker, 1954; 2012) emphasises the need for organisations to identify high and low order goals to meet the outcome. McKinsey’s 7-S (Peters & Waterman, 1984) model highlights how organisational change occurs when there is the balance of seven principles: structure, strategy, system, shared values, skill, style and staff.

The NHS at a macro level (Curry & Ham, 2010) has demonstrated difficulties with communication and agreement between providers and commissioners to institute change in relation to *Transforming Care*. This has contributed to the increased difficulties of facilitating *Transforming Care* and the large number of individuals continuing to reside in hospital. The King's Fund (2018) suggested the need for organisational change in order to respond to the increased pressures in the HaSC system and that this should be initiated by service users and frontline staff. Systems theory highlights the importance of acknowledging the different systems and contexts within an individual's life, whilst holding in mind the interactions between different levels of the system (Von Bertalanffy, 1973).

For *Transforming Care* to be successful there needs to be alignment between everyone (e.g. clinicians, commissioners, family and the individual) at the service level. Dobbs et al. (2012) has applied the ecological systems theory (Bronfenbrenner, 1989; Bronfenbrenner & Evans, 2000) to healthcare settings and highlighted the complex interactions that occur between different levels of the system and the need for compatibility amongst the different levels for processes to proceed smoothly. Taylor (2021) has also highlighted the need for meaningful consultation with clinicians who provide the direct care, to understand what is possible, as opposed to relying on NHS Commissioners to make these decisions (NHS England, 2015). Individuals with LD often have a large network, consisting of professionals and/or family members, who are responsible for making decisions about their quality of life. It is important that the system works together to ensure a discharge process progresses and happens smoothly.

Therefore, this review aimed to understand the difficulties with implementing *Transforming Care* by exploring the experiences of discharges from hospitals (i.e. forensic hospitals, institutions and secure hospitals) to community-based settings (i.e. supported living, residential settings and family homes), from the perspectives of people involved (i.e. health professionals, family members, the individual with LD and community support workers).

Previous reviews by Head (2017) and Taylor (2019) have focused exclusively on the experiences of transitions for people with LD and ‘complex’ needs, prior to the *Transforming Care* initiative and involved transitions between various settings. In contrast, this review expands the focus to include the experiences of the whole network involved in supporting an individual to move from hospital. Furthermore, since the introduction of *Transforming Care* and policies such as *Building the Right Support*, the economic, social and policy contexts have changed within England (NHS England, 2015). Therefore, this review focuses solely on transitions from hospitals to community-based settings, post 2012. Also, only research conducted in England was chosen, due to *Transforming Care* being commissioned by NHS England and Local Authority commissioners (NHS England, 2015).

Methodology

Review structure

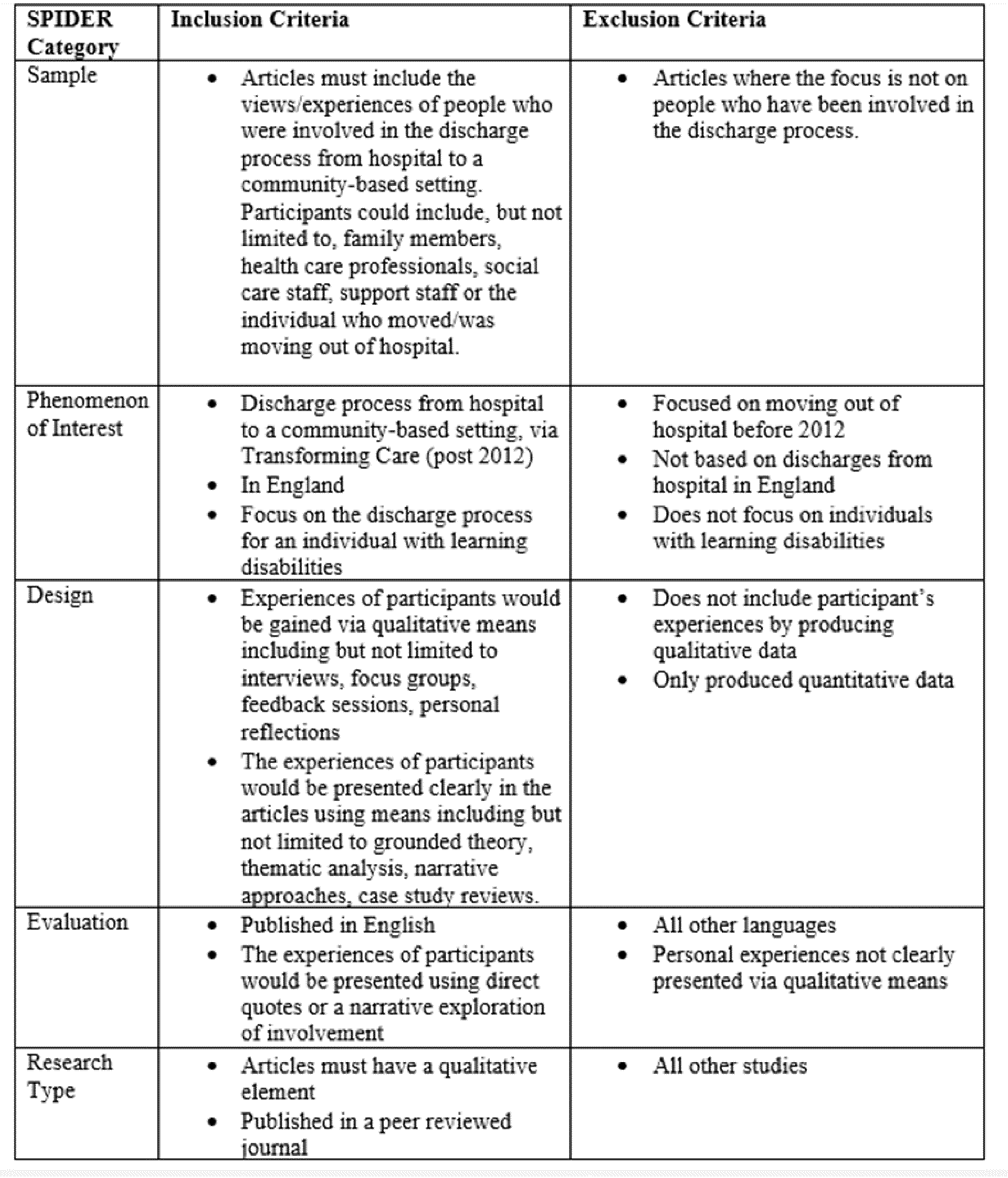
The present review aimed to systematically explore qualitative research to ensure the experiences of the participants would be captured in detail compared to quantitative data. This review involved a systematic search of the available literature using multiple databases, which was assessed against an inclusion and exclusion criteria. Once the final articles had been selected, the quality of each paper was reviewed using a quality appraisal tool, before identifying key themes through a thematic synthesis. A full description of the processes can be found below.

Inclusion and exclusion criteria

In July 2022, a search strategy was used based on the SPIDER framework (Cooke, Smith & Booth, 2012) to identify appropriate papers that fit the inclusion criteria. This framework was deemed the most appropriate when carrying out a systematic review for qualitative literature searches (Cooke, Smith & Booth, 2012) and was effective when reviewing the inclusion and exclusion criteria. The review consisted of identifying articles that met the following criteria (Table 1).

Table 1

Inclusion/exclusion criteria



SPIDER Category	**Inclusion Criteria**	**Exclusion Criteria**
Sample	• Articles must include the views/experiences of people who were involved in the discharge process from hospital to a community-based setting. Participants could include, but not limited to, family members, health care professionals, social care staff, support staff or the individual who moved/was moving out of hospital.	• Articles where the focus is not on people who have been involved in the discharge process.
Phenomenon of Interest	• Discharge process from hospital to a community-based setting, via Transforming Care (post 2012) • In England • Focus on the discharge process for an individual with learning disabilities	• Focused on moving out of hospital before 2012 • Not based on discharges from hospital in England • Does not focus on individuals with learning disabilities
Design	• Experiences of participants would be gained via qualitative means including but not limited to interviews, focus groups, feedback sessions, personal reflections • The experiences of participants would be presented clearly in the articles using means including but not limited to grounded theory, thematic analysis, narrative approaches, case study reviews.	• Does not include participant's experiences by producing qualitative data • Only produced quantitative data
Evaluation	• Published in English • The experiences of participants would be presented using direct quotes or a narrative exploration of involvement	• All other languages • Personal experiences not clearly presented via qualitative means
Research Type	• Articles must have a qualitative element • Published in a peer reviewed journal	• All other studies

Search Strategy

The search terms used initially, were informed by previous systematic reviews that focused on a similar topic and were revised by adding search terms using the thesaurus on each database. An electronic database search was carried out using five databases. It was predicted that articles meeting the inclusion criteria would be published in journals relating to qualitative data, healthcare, and social care. Therefore, the following databases included were:

- ASSIA (via ProQuest)
- CINAHL
- Medline (via Web of Science)
- Psychinfo (via Ovid)
- PubMed

As the *Transforming Care* agenda was introduced in 2012, the databases were searched for papers from this date onwards. To conduct the search in each of the databases, the search terms were devised against the SPIDER criteria (table 2). However, slight variations to the search term were made dependent on the requirements of each database. The exact search term used for each data base can be found in table 3. The choice was made not to limit the search terms by design and research, as after an initial search this limited the articles available and did not capture relevant studies that met the inclusion criteria. The databases were filtered to include the search term in abstract and full-text to reduce the large number of texts available.

Table 2

Search terms against the SPIDER criteria

SPIDER Category	Search Term
Sample (AND)	“learning disabilit* OR intellectual disabilit* OR mental retardation OR learning difficulties OR special needs”
Phenomenon of Interest (AND)	“transforming care OR discharge OR moving”
Design	Not specified in search
Evaluation (AND)	“experiences OR perceptions OR attitudes OR views OR feelings OR perspectives”
Research	Not specified in search

Table 3

Search terms for each data base

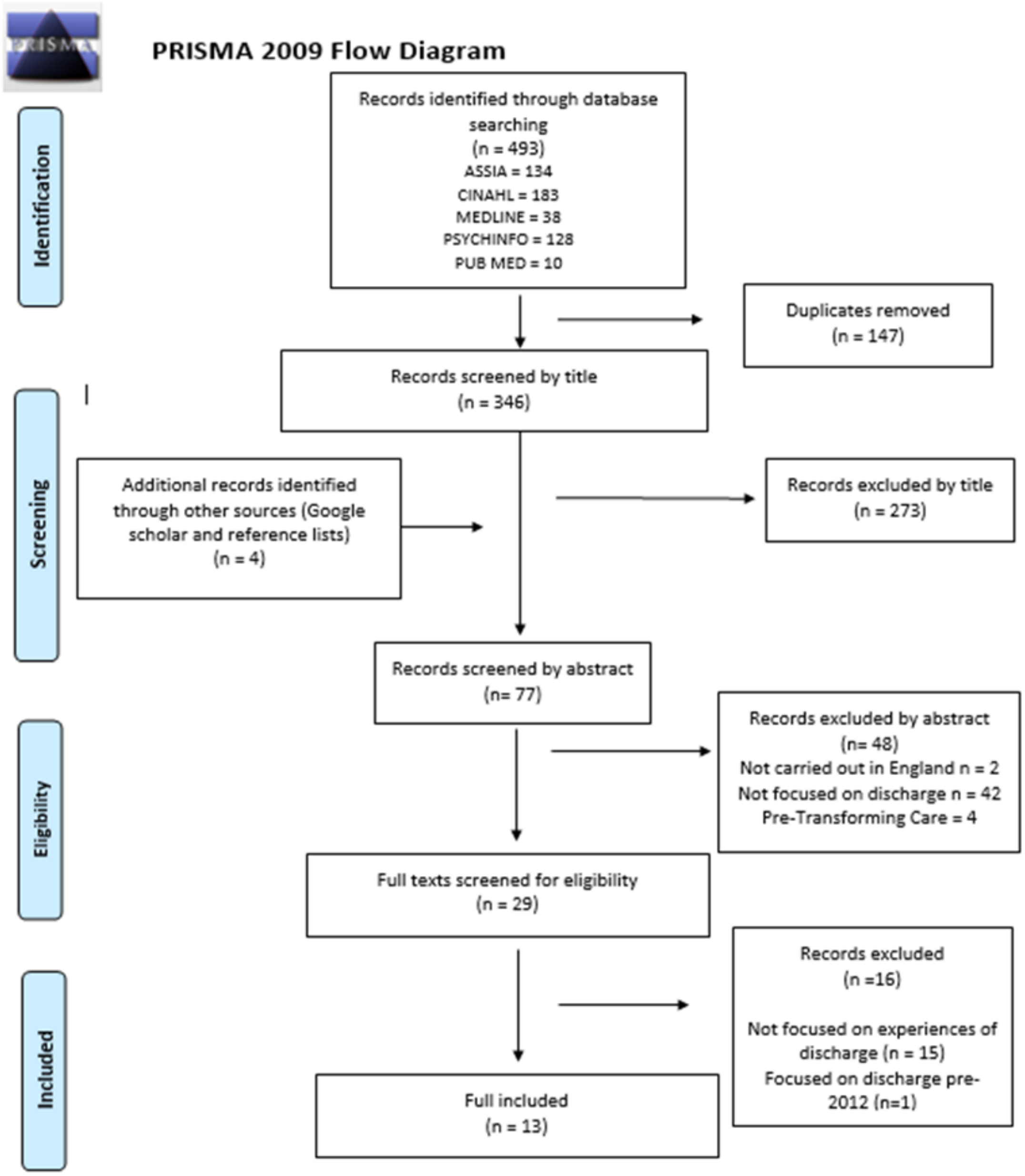
Database	Search term
ASSIA	(Transforming care or hospital discharge) AND (learning disability or intellectual disability) AND discharge AND (views OR perceptions OR experiences)
CINAHL	“learning disabilities OR intellectual disabilities OR mental retardation OR learning difficulties OR special needs AND transforming care OR discharge OR moving AND experiences OR perceptions OR attitudes OR views OR feelings OR perspectives AND nurses OR family OR community OR support”
Medline	(learning disabilit* or intellectual disabilit* or mental retardation or learning difficulties or special needs) AND (transforming care or discharge or moving) AND (experiences or perceptions or attitudes or views or feelings or perspectives)
PsychInfo	(Learning disabili* OR intellectual disabili* OR developmental Disabiliti*) AND (Transforming care OR moving OR discharge OR hospital) AND (experiences OR perceptions OR views)
PubMed	Transforming Care AND (learning disabili* OR intellectual Disabili* OR mental retardation) AND (experiences OR perceptions OR views OR attitudes)

Selection Process

An initial search on each of the five databases produced a total of 493 papers. These papers were exported into RefWorks and in the first instance duplicates were removed (n = 147). The inclusion criteria was used to screen the papers accordingly at different levels, title, abstract and full-text. The reference section of papers were hand searched, and a search on Google Scholar was also carried out, retrieving four further papers that were not found on the databases. At the title level, 273 papers were excluded, at the abstract level a further 48 papers were excluded due to not being carried out in England (n=2), not focusing on the discharge process (n=42) or being written about experiences prior to the *Transforming Care* agenda (n=4). The remaining 29 papers were screened at the full text level and 16 records were further excluded as they did not focus on the experiences of being part of the discharge process (n=15) or focused on being discharged before 2012 (n=1). The PRISMA diagram presented in Figure 1 (Moher et al., 2009), outlines the full systematic literature search process.

Figure 1

PRISMA Diagram



Literature review

Articles identified

The literature search strategy resulted in 13 papers that met the inclusion criteria for the final analysis. Key qualities of each paper can be found in table 4.

Overview of the studies

Data collection method

The research studies were published between 2016 and 2022 and were all based in England. Papers were included if they were published after 2012, when *Transforming Care* was first introduced. However, some papers published in 2012 were excluded as they included data that was collected before *Transforming Care*. The research papers included nine qualitative studies and four case studies. One paper, Hickman, Booth & Hoang (2018), also included quantitative measures alongside gaining qualitative feedback. Eight of the papers used semi-structured interviewing as their data collection method, three papers produced a narrative account of experiences, one paper used an online survey to gain qualitative feedback (Taylor et al., 2017) and one paper used a focus group (Hickman et al., 2018).

Samples

The sample sizes for the papers ranged between one and 33 participants, and the participants for each paper varied, with experiences collected from health professionals working in inpatient settings (n=3 papers), health professionals in community roles (n=5 papers), social workers (n=1 paper), support workers (n=1 paper), service users (n=6 papers) and family members (n=1 paper). Three papers included the views of both health professionals and service users (Hickman Booth & Hoang, 2018; Hollomotz, 2021; Turner, 2018), whilst the remainder of the studies only focused on one perspective. One paper (Turner, 2018) was written from the perspective of a health professional and included the views of other health professionals, however, the overall number of participants involved in the paper was not reported. Although the exact total number of participants included in the systematic review could not be determined, the known views of 80 people was achieved to gain their experiences of the discharge process via *Transforming Care.*

Table 4

Overview of papers

Authors and date	Title of paper	Research Aims	Participants	Location	Data collection	Data analysis
Chester, V., Brown, A. S., Devapriam, J., Axby, S., Hargreaves, C., & Shankar, R. (2017).	Discharging inpatients with intellectual disability from secure to community services: risk assessment and management considerations	To explore risk factors experienced by community teams when supporting an individual with intellectual disabilities who has been discharged from secure services.	Five staff members across two community teams that provided care for people with learning disabilities and who were involved in the discharge process from secure placements. (n=5)	Cornwall, UK	Semi-structured interviews	Thematic analysis
Clifford, A., Standen, P., & Jones, J. (2018).	"I don't want to take any risks even if it's gonna mean this service-user is gonna be happier": A thematic analysis of community support staff perspectives on delivering *Transforming Care*	To gain the views of community staff providing direct support for individuals who have moved to their service as part of Transforming Care	Support staff (n=6), team leaders (n=3), deputy managers (n=1) and managers (n=1), from three support providers for people with learning disabilities. (n=11)	Nottingham, UK	Semi-structured interviews	Thematic analysis

Head, A., Ellis, C. H., Rhodes, L., & Parkinson, K. (2018).	Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital	To explore how individuals with learning disabilities experienced the process of moving as part of Transforming Care	Adults with learning disabilities who had moved to the community following a hospital admission (n=11)	Hertfordshire, UK	Semi-structured interviews.	Grounded theory
Hickman, G., Booth, N., & Hoang, T. (2018)	Reflections on introducing a Leavers' Preparation Group in an intellectual disability secure service	To document the development of a group aimed at preparing individuals for a life after hospitalisation in Secure Services	Six men with learning disabilities who were currently residing in a low secure hospital and staff members reflecting on the facilitation of the group. (n=6)	Birmingham, UK	Qualitative feedback gained through an open discussion within a focus group and reflective sessions.	No clear method specified – general themes and quotes from the focus group provided.

Hollomotz, A. (2021).	Successful Community Resettlement of Men with Learning Disabilities Who Have Completed a Hospital-Based Treatment for Sexual Offending	Exploring how treatment for sexual offending assisted community resettlement for men with learning disabilities	11 men who had been an inpatient at a hospital and who had either been discharged from hospital (n=4), were in the transition of being discharged (n=3) or who had no active plans for discharge (n=4). 22 professionals identified as being involved in the men's care were also interviewed (n=33)	Leeds, UK	Semi-structured interviews	Thematic Analysis
Hudson, N., House, R., Robson, N., & Rayner-Smith, K. (2021)	'It's a good thing we are doing, we just need to be better at it'. Forensic Intellectual disability nursing experiences of Transforming Care: A multi-perspectival interpretive phenomenological analysis	To explore the experiences of inpatient and community forensic intellectual disability nursing staff working with individuals under Transforming Care.	Nursing staff who worked in either community or inpatient forensic teams (n=9)	Northumberland - UK	Semi-structured interviews	Interpretive Phenomenological analysis

Leaning & Adderley (2016).	From long-stay hospitals to community care: reconstructing the narratives of people with learning disabilities.	To explore the experiences of a clinical psychologist in supporting a man to move from long-stay hospital to the community	One clinical psychologist (n=1)	Ealing - UK	Narrative case study	No clear method specified – narrative case study explaining qualitative experiences
Read, M. (2022)	Transforming Care: supporting people with learning disabilities, autism and mental health issues to move out of long-stay hospitals	To explore the experiences of a dual-qualified social worker and mental health nurse working with in the Transforming Care Partnership.	One dual qualified social worker and mental health nurse (n=1)	North East London - UK	Narrative account of experiences	No clear method specified
Taylor, J. L., Breckon, S., Rosenbrier, C., & Cocker, P. (2017).	Development and implementation of a discharge pathway protocol for detained offenders with intellectual disabilities	To gain feedback from stakeholders on the development of a discharge pathway for individuals with intellectual disabilities in hospital.	13 stakeholders – community nurses, clinical psychologists, consultant psychiatrists, social workers, community service providers, solicitor and commissioner. (n=13)	Northumbria, UK	Email survey with the opportunity to provide qualitative feedback.	No clear method specified – themes were drawn from the survey.

Tearle, S., Sam, S., & Holt, R. R. (2020).	Collaborative case report: participatory action research into using EQUIP to support community discharge	To explore a service user's experience of completing the Equipping Youth to help One Another (EQUIP) programme as part of their transition into the community.	One service user with mild intellectual disability was supported to share their treatment experiences using participatory action research. (n=1)	Hertfordshire , UK	Semi-structured interview	No clear method specified – themes and quotes were drawn from the interview.
Turner, U. (2018).	North Cumbria and North East Transforming Care, transforming lives case study	To describe how Transforming Care is changing lives by helping people with a learning disability, autism or both to live more independent.	The support team involved in supporting the individual to move out of hospital and the individual themselves	North Cumbria, UK	Narrative account of experiences	No clear method specified – direct quotes included
Williams, E. M., Thrift, S., & Rose, J. (2018).	The subjective experiences of women with intellectual disabilities and offending behaviour: exploring their experiences of 'home'	To explore how women with intellectual disabilities and offending behaviour have experienced the places they have lived.	Seven participants recruited from a low secure women's hospital. (n=7)	Birmingham, UK	Semi-structured interviews	Interpretive Phenomenological Analysis

Williamson and Meddings (2018).	Exploring family members' experiences of the Assessment and Treatment Unit supporting their relative	To explore how family members experience their involvement with the ATU	Four participants – parents of service users (n=4)	Liverpool, UK	Semi-structured interviews	Thematic analysis

Settings

The setting which each study was carried out in varied. Two papers included the views of being discharged from hospital from service users who were currently residing in a secure hospital and awaiting to be discharged (Hickman, Booth & Hoang, 2018; Williams, Thrift & Rose, 2018). One paper included the views of service users who were both in hospital and who had been discharged into the community at the time of the research (Hollomotz, 2021). All the remaining studies were carried out in community settings by interviewing professionals, family members or service users regarding their experiences retrospectively.

All included studies focused on the discharge process from hospital to a community-based setting. Five studies focused on the experiences of discharge from a forensic hospital (Hollomotz, 2021; Hudson et al., 2021; Taylor et al., 2017; Tearle et al., 2020; Williams et al., 2018). Two articles captured the experiences of being discharged from long-stay hospitals (Leaning & Adderley, 2016; Read, 2022). Two papers focused on the discharge processes within an Assessment and Treatment Unit (ATU; Turner, 2018; Williamson & Meddings, 2018). Two papers focused on the experiences of being discharged from secure hospitals (Chester et al., 2017; Hickman et al., 2018). One paper focused on the perspectives of moving from various hospital environments (Head et al., 2018) and one paper did not specify the type of hospital the research was focused on (Clifford et al., 2018).

Data analysis method

The data analysis strategies used within the papers included, thematic analysis (n=4), Interpretive Phenomenological Analysis (n=2), grounded theory (n=1), and unspecified qualitative analysis method (n=6).

Quality Appraisal

Due to the different methodologies of the research papers, two different tools were used to assess the quality of the papers. Based on the results of the quality appraisal, the papers were not excluded from the review, but the results were used to inform critical thinking about the findings and conclusions. To ensure validity, 30% of the papers were double marked by a peer and any discrepancies were discussed.

Qualitative papers

The Critical Appraisal Skills Programme (CASP, 2018) was used to assess qualitative studies. The CASP tool consists of 10 questions to assess the quality of qualitative data by focusing on three areas: “are the results of the study valid?”, “what are the results?” and “will the results help us locally?”. The first two questions are screening questions, and the remaining eight questions focus on the methodology of the research, ethical considerations, the data analysis strategy employed and the future implications. The CASP tool typically has responses of either “yes”, “no” or “can’t tell” which are to be applied to each question. For this systematic review, the method adopted by Taylor (2019) was used to calculate an overall score for each paper. A score of one represented little or no reference to the CASP item, a score of two indicated some evidence was provided and a score of three indicated that the CASP question was fully addressed. Appendix A shows the overall scoring for each paper.

All studies scored highly for the use of qualitative methods as appropriate for answering the research question. Three papers received full marks for discussion over the choice of research design (Hollomotz, 2021; Hudson et al., 2021; Williams et al., 2018). Many of the papers received a moderate to high score for recruitment strategy, however, one paper (Clifford et al., 2018) did not explain clearly how the participants were recruited and the inclusion-exclusion criteria. With regards to the appropriateness of data collection all the studies received full marks, with the exception of Taylor et al. (2017) who received a moderate score and Hickman et al. (2018) who barely satisfied this criterion, due to not providing a clear explanation about how the feedback from the focus group was collected. Many of the papers scored highly for data analysis, however two papers (Hickman et al, 2018; Taylor et al., 2017) scored lowly for this criterion due to no clear method of analysis being stated. Finally, all studies scored highly for reporting a clear statement of findings, except for three studies who scored moderately (Chester et al., 2017; Head et al., 2018, Hudson et al., 2021).

Case studies

Case studies were assessed using the Centre for Evidence-Based Management (CEBM) Critical Appraisal of a Case Study (CACS) checklist (CEBM, 2014). This checklist consists of 10 questions which appraises the applicability, reliability and importance of the research. The checklist aims to establish: whether "the study addresses a clearly focused question", "uses valid methods to address the question", whether the "valid results are important" and whether the "results are applicable to the population". Similarly to the CASP tool, the responses for the CACS checklist are "yes", "no" and "can't tell". The same three-point scoring system that was applied to the CASP tool was also applied to the CACS checklist. Appendix B shows the overall scoring for each paper against the CACS checklist.

The studies reviewed by the CACS checklist were typically strong methodologically, with three out of four papers having a clearly focused question (Read, 2022; Tearle et al., 2020; Turner; 2018) and two papers receiving full marks for methodological design (Read, 2022; Tearle et al., 2020). However, the data analysis strategy was considered weak with all four papers barely satisfying this criterion. The data analysis method was not clearly specified within any of the papers and instead a narrative approach was taken exploring the experiences of one case-study and presenting the participants' experiences. The data analysis was not repeated in any of the studies, therefore all four papers scored low on this criterion also. The results of three of the four studies scored moderately for credibility and relevancy (Leaning & Adderley, 2016; Tearle et al., 2020; Turner, 2018). Finally, all four studies were rated as highly valuable as research.

Data synthesis

A meta-synthesis, using thematic synthesis (Thomas & Harden, 2008) was used to bring together the qualitative data across the research papers and provide new interpretations and meanings (Atkins et al., 2008). Extracting the data involved identifying all the study findings from the results and discussion sections, of each paper. The data used for developing themes was taken from the analysis provided by the researchers in each paper, therefore the codes and themes developed were linked closely to the data provided in the papers. Table 6 provides further information regarding the context of each paper and how the themes were developed. The reviewer read and re-read the papers generating initial codes which were written into an excel spreadsheet. Data was given two or more codes, indicated by further columns, if another code was also appropriate (Appendix C). The initial codes were then reviewed in collaboration with a supervisor, and potential themes were generated. Finally, the themes were organised into overarching themes and sub-themes (Thomas & Harden, 2008; Appendix D). When synthesising the data, it was difficult to differentiate the different professional perspectives in terms of their positioning and statements within the paper. Therefore, 'professionals' have been grouped together for the purpose of the synthesis.

Discussion of themes

The synthesis revealed four themes and nine sub-themes. These are summarised in the table below.

Table 5

Themes and sub-themes

Theme	Subtheme
Navigating within the system	• Working with families • Working with professionals • Working with the individual
Working within restrictions	• Policies and procedures • Resources
Preparing to move	• Practicalities • Uncertainty
Life after discharge	• Freedom of discharge • Identity

Table 6.

The development of themes and subthemes

Theme	Subtheme	Papers drawn upon and contextual information
Navigating the system	*Working with families*	**Read (2022)** – recognised how the family's perspective should be considered and they should be viewed as experts in the care of their loved ones. Also, regular contact should be encouraged between professionals and families to build trust and reassurance throughout the discharge process. **Williamson and Meddings (2018)** – highlighted in their analysis that families valued collaboration and being involved in their relatives care and that receiving a lack of information was difficult. However, families found it overwhelming attending meetings with multiple professionals and wished not to be present during discussions about finances, especially in moments of conflict. **Leaning & Adderley (2016)**– found in their analysis that families wanted to be included throughout the whole discharge process and this was important to them.
	Working with professionals	**Hudson et al. (2021)** – found in their analysis that discharges were delayed due to difficulties in communication between the different services involved and the lack of suitable services. **Clifford et al. (2018)** – found in their research that at times there were disagreements between external professionals and staff working on the ground. For example, recommendations being provided that do not hold the individual in mind or would not work in their setting. Staff felt devalued as every day experience was viewed as less important compared to expertise. **Read (2022)** – highlighted in their analysis that an MDT approach should be taken in order to provide support for the individual and that organisations need to work together. **Turner (2018)** – suggested from their analysis that multiple agencies need to be brought together to move a discharge forward. **Hollomotz (2021)** – found in their data that planning processes need to be well thought through in order to ensure the individual's needs are met. **Chester et al. (2017)** – highlighted in their analysis that professional roles should be well established, and people need to know the remits of their role. **Taylor et al. (2017)** – suggested that having clear roles and responsibilities of each professional helps with understanding what needs to be done and by whom.
	Working with the individual	**Turner (2018)** – their analysis highlighted the importance of listening to the individual and involving them in the discharge process. Also, ensuring properties were adapted to meet the individuals' needs. **Read (2022)** – found in their analysis that it was important to know the individual well and what was important to them, for example future goals to ensure an appropriate home was found. Creative and person-centred approaches are needed.

		Williams et al. (2017) – found that individuals felt they had no choice and other people were making decisions without their involvement. Individual's valued being involved and having their opinions listened to. **Leaning & Adderley (2016)** – highlighted in their analysis that it was important that the individual was prepared for discharge using adapted resources to aid understanding. **Tearle et al. (2020)** – found from their analysis that attending a pre-discharge group helped to prepare for the transition from hospital to community. **Hickman et al. (2018)** – highlighted in their analysis that individuals found it distressing when they received inconsistent information and placement options fell through. Also, when professionals changed which delayed the discharge process.
<u>Working within restrictions</u>	*Policies and Procedures*	**Hudson et al. (2021)** – found from their analysis that professionals felt under pressure to discharge an individual, even if they were not ready which made staff feel nervous. Also, decisions were made by people not involved in the direct care, and they lacked person-centred care due to policies and procedures that needed to be followed. **Clifford et al. (2018)** – found in their analysis that staff members felt restricted by the policies and procedures in place which resulted in a lack of positive risk taking. Staff did not want to risk their jobs for an individual and worried about being blamed by staff in a more powerful position. Staff felt decisions about discharge were rushed and there was a lack of planning. **Read (2022)** – highlighted in their analysis that staff in hospitals were often problem saturated and did not take positive risks. **Hollomotz (2021)** – found in their analysis that there had been a change in the meaning of 'ready for discharge' and there was more positive risk taking. **Chester et al. (2017)** – highlighted in their analysis the need for a comprehensive risk assessment before discharge and that a robust discharge plan is needed for a successful discharge – this should include a detailed assessment to really understand the individuals' needs. **Hickman et al. (2018)** – found that discharge planning should commence from admission to ensure this is carefully thought through and completed in a timely manner. **Leaning & Adderley (2016)** – highlighted from their analysis the importance of well-constructed PBS plans and risk assessments.
	Resources	**Read (2022)** – highlighted the challenge of finding appropriate placements that can be adapted to meet the needs of an individual and how this is the biggest barrier in the discharge process. **Head et al. (2018)** – found from their analysis that due to a lack of placements, individuals were being moved out of area, away from family and friends.

		Hudson et al. (2021) – found in their analysis that a big barrier to the discharge process was the lack of suitable placements available.
Preparing to move	*Practicalities*	**Head et al. (2018)** – highlighted in their analysis the importance of introducing the community staff members who would be working with the individual, whilst they were still in hospital to enable a gradual transition. **Turner (2018)** – found that it was helpful when individuals knew the staff members from the community before moving. **Read (2022)** – their analysis highlighted the importance of an extensive discharge process over a period of three months which allowed relationships between the individual and staff to be built. Also, sharing resources between hospital staff and community staff ensured a consistent approach which aided the transition. **Hollomotz (2021)** – found in their analysis that gradually building up the individuals' trust whilst in the hospital was helpful for the discharge e.g. by having leave and community outings. **Chester et al. (2017)** – highlighted the need for a gradual transition process such as visiting the community placement for short periods of time and to not rush the discharge process as this meant things were not in place to support the individual. **Taylor et al. (2017)** – suggested from their analysis that a clear plan of the discharge process and all the factors that needed to be completed was helpful to ensure everyone involved stayed on track. Also, this helped to bring together staff from the hospital and community placement for a good continuation of care and staff felt more knowledgeable and prepared to support the individual. **Leaning & Adderley (2016)** – highlighted how helpful it was for the community staff to spend time getting to know the individual on the hospital ward.
	Uncertainty	**Hickman et al. (2018)** – found in their analysis that service users felt anxious about changes that had happened in the community such as advanced technology. **Tearle et al. (2020)** – concluded from their analysis that the community can be difficult for individuals due to the faster pace of living compared to hospital and a lack of routine. This resulted in increased anxiety. **Leaning & Adderley (2016)** – highlighted how staff had fears and concerns about individuals living in the community as they were unsure how they would manage this change which led to a lack of positive risk taking. **Williamson and Meddings (2018)** – found families felt overwhelmed talking about their relative being discharged and living in the community when they did not feel ready. **Williams et al. (2017)** – highlighted how individuals felt safe in hospital and were uncertain about where they would live in the community. **Head et al. (2018)** – found in their analysis the individuals were unsure if staff in the community would meet their needs.

		Clifford et al. (2018) - highlighted how there was a lack of MDT involvement following discharge and were concerned about ongoing support.
Life after discharge	*Freedom of discharge*	**Clifford et al. (2018)** – found in their analysis that there was an overwhelming difference in between the restrictions in hospital compared to the community. **Head et al. (2018)** – concluded that individuals felt they had a lack of freedom whilst in hospital and were unable to do things for themselves that they were capable doing, due to the restrictions in place. Also, individuals felt they had to behave in a certain way for fear of returning to hospital. **Turner (2018)** – highlighted in their analysis the large difference in terms of freedom and flexibility in the community compared to the hospital and more opportunities for activities in the community. **Read (2022)** – highlighted the need for a homely environment to be created in the community placement, after experiencing a clinical setting within hospital. **Hollomotz (2021)** – highlighted in their paper that individuals valued making their placement more homely by buying furniture and home comforts. Individuals also recognised they wanted a space where they could have their own independence. However, it was recognised that individuals with a forensic history have ongoing restrictions due to court orders and are not always able to engage in activities due to these restrictions. **Williams et al. (2017)** – highlighted from their analysis that individuals longed for independence in the community (wanting their own space and employment opportunities) and creating a ‘home’ by having access to personal belongings. However, individuals recognised they may need support in some areas such as cleaning their home and finances. **Chester et al. (2017)** – highlighted the need for ongoing staff support in the community to manage risk and allow the individual to engage in community activities.
	Identity	**Head et al. (2018)** – concluded from their analysis that individuals felt their behaviour was seen as being ‘naughty’ and they had to behave in a certain way to be discharged. Individuals experienced a loss of identity whilst in hospital and felt like they could be themselves once discharged to the community. **Read (2022)** – found in their research that there was a need to shift the identity of the individual in order to build up their confidence about living in the community. **Hollomotz (2021)** – highlighted that individuals felt a sense of belonging in the community as they were able to engage in activities and seeing family. **Williams et al. (2017)** – highlighted how individuals felt they experienced a loss of identity whilst in hospital, however when the correct placement was found individuals felt a sense of belonging within the community.

Navigating the system

This theme captured the complex system around an individual with LD who was due to be moving from hospital to a community-based setting.

Working with families

Three studies discussed the importance of family involvement throughout the discharge process. Read (2022), interpreted their findings to suggest the family should be viewed as experts and their perspective to be highly valued during discussions. Furthermore, Leaning & Adderley (2016) interpreted that regular contact and involvement with families throughout the discharge process helped build reassurance and trust (Read, 2022), and contribute to a smoother discharge process. In line with the two other research papers, Williamson and Meddings (2018) highlighted in their analysis that families valued working in partnership with professionals and collaborating on decisions made surrounding their relatives. Some families reported the difficulty they experienced when receiving a lack of information from people in the system.

Furthermore, Williamson and Meddings (2018) interpreted that involvement could be an overwhelming experience. From their data they suggested families felt uncomfortable during discussions about funding, especially when this resulted in disagreements between professionals. Also, it felt overwhelming to be in the presence of multiple professionals. Some families requested to not be present during discussions of funding but still informed of outcomes. Families also shared their frustrations and disappointment when the whole system did not attend a meeting, and decisions could not be actioned due to the relevant people being absent.

Working with professionals

Seven studies considered the role health and social care professionals have in the discharge process. This resulted in discussions about the role and responsibilities of each professional (Chester et al., 2017; Taylor et al., 2017). The analysis of the researchers reflected that a lack of knowledge about the roles of other professionals, and not knowing the remit of one’s own role could result in actions not being completed. Also, a lack of communication between professionals was determined as a key factor in delaying discharges (Hudson et al., 2021). Clifford et al. (2018) also highlighted in their analysis the importance of professionals in the network linking in with staff who provided care at the community level. This paper’s analysis highlighted how a lack of communication resulted in care plans that did not meet the service user’s needs, resulting in staff teams feeling deskilled and devalued due to not being involved in discussions.

Studies suggested from their analysis the need for a joint multi-disciplinary approach (Read, 2022) to produce a well thought through care plan to meet the needs of an individual (Hollomotz, 2021). Turner’s (2018) interpretation of the data highlighted the importance of bringing together multi-agencies to ensure all parts of the discharge process were discussed and professionals worked together (Read, 2022).

Working with the individual

Across the reviewed papers, six studies discussed the involvement of the individual with LD during the discharge process. Most of the papers highlighted in their analysis, the importance of knowing the individual and listening to them when devising future care plans and making decisions regarding accommodation (Read, 2022; Turner, 2018, Williams et al., 2017). From the analysis it appeared individuals valued being able to advocate their preference for accommodation choices (Williams et al., 2017); and having adaptations made to property to meet their needs (Leaning & Adderley, 2016; Turner, 2018; Read, 2022). Also, being involved in choosing their staff team enabled the individuals to feel confident with the support they would receive (Turner, 2018; Williams et al., 2017). Across the papers, the analysis highlighted a focus on explaining the discharge process to the individuals using adapted methods of communication (Leaning & Adderley, 2016; Tearle et al., 2020) and educating on the types of accommodation available (Hickman et al., 2018).

Despite the research supporting the involvement of the individuals in their discharge process, Hickman et al. (2018), also interpreted how this process could be distressing for some, due to inconsistencies in information, placement options falling through, funding application delays and changes in leading professionals. Therefore, communication throughout the discharge process should be person-centred.

Working with restrictions

This theme captured the barriers of the discharge process and working within the system where restrictions were experienced.

Policy and procedures

Six research papers interpreted findings about working within the remits of policies and having to follow procedures. Clifford et al. (2018) and Hudson et al. (2021), interpreted in their findings that community support staff and inpatient nurses felt under pressure from *Transforming Care* to rush the discharge process and discharge individuals who they did not feel were ready. The focus on targets and deadlines resulted in staff feeling they were providing less person-centred care and positive risk taking to meet the targets (Clifford et al., 2018; Hudson et al., 2021; Read, 2022). Hollomotz (2021), Chester et al., (2017) and Leaning and Adderley (2016) also found in their analysis that there was a need for comprehensive risk assessments, full discharge plans and PBS plans to be completed before an individual can be discharged, again working within the remits of policies. However, Hollomotz (2021), highlighted how there had been a shift in the definition of ‘ready for discharge’ meaning not all behaviours had to be ‘gone’ and professionals work with the individual in a positive risk-taking way.

Resources

Three papers spoke about the limited resources available when thinking about placement options. Finding appropriate accommodation has become increasingly difficult due to private landlords not allowing adaptations to properties, therefore not meeting the needs of individuals (Read, 2022). Both Read (2022) and Hudson et al. (2021) identified in their analysis, that a lack of suitable services was a large barrier for individuals with LD to live in the community. Finally, Head et al. (2018), interpreted their findings to suggest that the limited placement options resulted in more people being moved out of area, therefore breaking down relationships with family and friends.

Preparing to move

This theme aimed to capture the processes and feelings involved with moving out of hospital and returning to the community.

Transition process

Across the papers, seven studies focused on the practicalities of the transition process. The analysis in many of the studies highlighted the importance of a gradual transition process. This allowed the new staff team to spend time on the hospital ward, getting to know the individual (Head et al., 2018; Turner, 2018; Read, 2022; Taylor et al., 2017; Leaning & Adderley, 2016) and for the individual to gradually spend time at their new placement (Read, 2022; Hollomotz, 2021). The studies also highlighted the importance of having a clear discharge plan (Chester et al., 2017; Taylor et al., 2017) which outlined what the process entailed and helped to stay on track (Chester et al., 2017). Taylor et al., (2017) and Hollomotz (2021) interpreted from their findings that the staff from the community placement valued having training around the individual moving to their service, as they felt more prepared and could continue using support strategies from hospital in the community setting to ensure consistency (Read, 2022).

Uncertainty

Across seven of the papers, the feeling of uncertainty was captured in the researcher’s analyses. Hickman et al., (2018) and Tearle et al., (2020) interpreted their findings to suggest individuals moving out of hospital had increased anxiety about the changes in the community since they had been in hospital, reflecting on the increase in technology and the fast pace of the community compared to the hospital environment. Also, some were unsure whether their new staff team would be able to support their needs appropriately (Head et al., 2018), and worried about where they were going live and moving away from the safe environment of hospital (Williams et al., 2018). Leaning and Adderley (2016), identified in their analysis that health and social care professionals expressed fears and concerns about discharging an individual due to not knowing what they will be like in the community (Williams et al., 2018), therefore resulting in a lack of positive risk taking (Leaning & Adderley, 2016). Clifford et al. (2018), found in their analysis that support workers expressed uncertainty regarding the lack of multi-disciplinary team input once the individual was discharged to their service, and were concerned about ongoing support (Clifford et al., 2018). Finally, families who had relatives moving out of hospital often felt overwhelmed talking about the discharge process if they did not feel ready to be thinking about their relative back in the community (Williamson & Meddings, 2018).

Life after discharge

This theme captured the ideas and realities of living in the community after being discharged from a hospital setting.

Freedom

Seven of the papers captured within their analysis the feeling of freedom associated with living in the community and life after hospital. The papers interpreted that individuals longed for enhanced freedom and flexibility in the community (Clifford et al., 2018; Turner 2018; Williams et al., 2018), following the restrictions placed upon them in hospital (Head et al., 2018). Individuals wanted independence in the community (Hollomotz, 2021) but also acknowledged the need for support from staff in certain areas, such as finances (Williams et al., 2018). The papers also captured in their analysis how people were focused on creating a 'home' for themselves by buying furniture and having personal belongings, following the clinical setting of the hospital (Read, 2022; Hollomotz, 2021; Williams et al., 2018). They also spoke about future goals in the community such as work opportunities and new activities that they could be part of (Turner, 2018; Williams et al., 2018).

Despite the positive focus of discharge and having more independence, the papers also referred in their analysis to the ongoing restrictions an individual experienced post-discharge. Hollomotz (2021) interpreted their data to highlight that individuals who had a forensic background, court-ordered restrictions were often in place following discharge, meaning activities were limited, even with direct support from staff who could mitigate the risks. Chester et al. (2017) also interpreted that the involvement of staff support was required for the individual to partake in activities and manage the level of risk whilst in the community. The individuals themselves spoke about fearing bad behaviour would result in readmission (Head et al., 2018) and the risk of negative attention from others (Chester et al., 2017) which felt like a restriction in their lives.

Identity

Four papers recognised in their analysis that there were changes in identity for individuals throughout the discharge process. Whilst in hospital, William et al. (2018) interpreted that individuals felt they lost their identity as a person and viewed themselves as a patient rather than someone capable of doing things for themselves (Head et al., 2018). Also, Head et al. (2018) captured in their analysis how individuals felt challenging behaviour was seen as ‘being naughty,’ and there was a need to prove they were ‘being good’ to be discharged. It was also interpreted from the data that health and social care professionals needed to shift the individual’s identity before being discharged, to develop self-confidence about residing in the community and to view this as a realistic option (Read, 2022). Post-discharge, researchers felt individuals spoke about belonging to the community by being close to family and friends and engaging in community activities (Williams et al., 2018; Hollomotz, 2021) and feeling more like themselves (Head et al., 2018).

Discussion

This report sought to critically review and synthesise the qualitative literature with the aim of exploring the experiences of the discharge process from hospital to the community via *Transforming Care*. The search returned 13 papers consisting of case-studies and qualitative methods. Eight of the thirteen papers included the experiences from health professionals; one focused on the views of support workers; six papers included the views of service users; and one paper highlighted the views of family members. The meta-synthesis consisted of carrying out a thematic analysis which revealed four over-arching themes: *Navigating within the system; Working within restrictions; Preparing to move; and Life after discharge.*

Overall, the synthesis highlighted the complexity of the discharge process for individuals with LD and the network around the individual. Having a cohesive network to coordinate a discharge was viewed as an important factor, however this appeared to be difficult at times due to encountering barriers and pressures working under *Transforming Care*. The synthesis also highlighted the number of practical processes that need to be undertaken before a discharge can occur. However, the new life an individual could have in the community was recognised, and the impact this had on a person's identity.

The theme "navigating within the system" was devised based on the large amount of data produced from 12 out of 13 papers. Three papers discussed the importance of involving families in the discharge process, especially when making decisions about their relative's care (Williamson & Meddings, 2018). This is in line with previous research which highlighted satisfaction was reached when families felt listened to, professionals completed accurate assessments and an agreement was made between professionals and family members about the ideal care for their relative (Barton, 1998).

Another theme, "life after discharge," highlighted the freedom and flexibility an individual had in the community compared to hospital, which was also found to be associated with a change in identity. The development of *Transforming Care* and the deinstitutionalisation process was to widen the opportunities for individuals with LD with the aim of improving their quality of life. The 12 papers associated with this theme highlighted that individuals valued their independence and reduced restrictions in the community, therefore leading a life like anyone else. This finding suggests that people prefer to live in the community rather than restricted environments, which is in line with previous research (Bond

& Hurst, 2010; Chowdhury & Benson, 2011; Kozma et al., 2009). Despite the increased freedom, the individuals acknowledged the need for support in areas of their lives such as finances (Williams et al., 2018) and engaging in community activities (Chester et al., 2017). This is in line with previous research which found individuals with LD experience difficulties with managing more complex tasks when living independently, despite being independent with other household tasks (Bond & Hurst, 2010). Despite the positive aspects with living independently in the community, it was also found in the current review that individuals were fearful about negative attention in the community (Chester et al., 2017). Previous research has highlighted the vulnerability of individuals with LD and the increased risk of victimisation (Bond & Hurst, 2010; Wiseman & Watson, 2022; Whittell & Ramcharan, 2000).

Community living was also associated with a change in identity, moving from ‘patient’ to an individual (Head et al., 2018). Community living was associated with more connection to family and friends and engagement with the community (Williams et al., 2018; Hollomotz, 2021). The current findings are in line with previous research which highlighted individuals with LD living in the community valued the increased social connections, feeling involved and having reciprocal relationships (Barr, McConkey & McConaghie, 2003).

A further theme, “preparing to move,” highlighted the practical processes which contributed to a successful transition from hospital to the community, whilst also capturing the feelings associated with transitioning. Seven papers highlighted the importance of a gradual transition process, which involved the new community staff team getting to know the individual well before they moved into the new placement and allowing the individual to familiarise themselves with their new home. Having these processes in place is supported by previous research which highlighted that families felt the most important aspect of a staff team was learning how to appropriately support their relative and communicate using suitable means (Mansell, 2010).

Finally, the theme "working with restrictions" highlighted the restrictions and barriers experienced throughout the discharge process. Health and social care professionals spoke about the pressure from *Transforming Care* to discharge individuals and working within a system to meet targets which led to less person-centred care. Furthermore, due to the limited placement options available this delayed discharges for individuals or resulted in moving away from their families. These concerns have also been raised in a report by The National Autistic Society (2017) highlighting the reason for delayed discharge was due to the lack of community social care and mental health housing.

Overall, this review emphasises the complexity of the discharge process via *Transforming Care* and the multiple layers involved. This review highlights the limited research into *Transforming Care* and recognises the ongoing barriers of fulfilling discharges. There is the need for further research to focus on the processes involved, for those facilitating the discharge process.

Clinical implications

The results of the current review are in line with the *Valuing People* principles (DoH, 2001) which states that individuals with LD should have greater choice, independence, and rights to improve the quality of their lives. The results highlight important factors to support an individual to move successfully from hospital to a community-based setting.

Firstly, the results from the current review demonstrate the importance of the whole system working together to support the discharge process. The professionals involved should communicate regularly to ensure everyone is aware of the ongoing process and structure regular meetings to guarantee the discharge process continues. Also, actions should be defined and clearly allocated for completion. It is also important for the individual and family members to be included to determine what is important for the individual when searching for a placement.

It may be beneficial for health and social care professionals to receive training to ensure a better understanding of *Transforming Care* and the principles they are working in line with. This would allow staff to feel more confident making decisions about an individual’s care and supporting people to move to the community, without feeling they are risking their own careers by making decisions.

Accessible resources should be provided to the individual, to outline the different stages of the discharge process. This could include information on what finding a placement and staff entails, as well as being open and honest about the timings of each stage. This would help the individual to have more awareness about what happens behind the scenes to help reduce anxiety. Also, by preparing the individual for discharge this could help them to think about their identity. It would be helpful for a member of psychology to complete life story work with the individual to understand their identity, as they move from hospital to the community.

Finally, staff from the community-based setting should get to know the individual before they are discharged. This would involve community staff visiting the individual whilst in hospital and support them on the ward with activities. This will help to build relationships and for the staff team to feel confident providing care.

Strengths and limitations of the review

All the research papers included in this review were qualitative studies or case studies resulting in relatively small sample sizes. Although these choices of methodologies were suitable for the research questions in each paper, this may reduce the generalisability of the results in this review.

Also, the papers for the meta-synthesis were not excluded due to their quality appraisal score, to prevent the removal of valuable data. The focus of the CASP and CACS tools were to review the paper's methodology and analysis rather than focusing on strength of the qualitative data and experiences captured. It has been debated whether the use of quality appraisal tools is a useful way to evaluate qualitative data, due to the subjective nature of using the tool and the lack of guidance of how to use the tool against different methodological approaches (Williams, Boylan & Nunan, 2019). Despite this, if a paper was rated extremely low, this would have been carefully considered before including in the review.

The search strategy employed for the review only included the use of published peer-reviewed papers. This was to ensure the papers included in the review were of a certain standard. However, this may have excluded other useful qualitative data such as magazine articles, books and government papers which also report on the experiences of people with LD and the system around them.

Thematic analysis was the chosen method of synthesising the data. However, this method has been criticised as it can be data or theory driven, leading to inconsistencies when developing themes (Snilstveit et al., 2012; Holloway & Todres, 2003). However, the strengths of this methodology include the ability to have a structure to arrange the data and highlight the key themes, which was appropriate for this review.

Overall, the papers included provided an overview of the experiences of moving out of hospital under *Transforming Care* and enough information was provided to understand what helps and hinders this process.

Limitations of the papers

As the *Transforming Care* agenda has been committed to by NHS England (2015), the research papers included in this review were all carried out in England. Therefore, this limits the generalisability of the results to other parts of the UK, however the clinical implications of this meta-synthesis may be of use in these areas.

Also, looking at the CASP and CACS scores, all the papers have a low score for ‘relationship between researcher and participant’. It would be helpful to have more reflexivity throughout the papers, to understand more about the researcher’s stance.

Future research

The review revealed a limited number of papers looking at the experiences of support workers within the community placements, therefore this could be a focus of future research. Also, the papers which used health and social care professionals as participants focused mainly on the aspect of using a discharge protocol or assessing risk, rather than focussing on the processes involved in coordinating a successful discharge and the personal experiences involved. Those papers that captured the experiences of health and social care professionals in the community either consisted of case study data or was completed in only one geographical area, therefore lacking generalisability. Community health and social care professionals have a large role within the discharge process; therefore, it would be helpful to gain a multi-disciplinary perspective to understand more about their experiences and the processes involved, in order to improve discharges and ensure these are successful for individuals with LD.

Conclusion

The findings highlight that the discharge process can be complex and involves communicating with a large system around the individual moving. However, by having a clear discharge plan which includes the views of the individual moving, this ensures the discharge process continues and a suitable placement is found for the individual. Moving out of hospital was associated with a more positive identity and sense of freedom due to living more independently, for the individual. Despite this, the limited number of placements available and the difficulty communicating between teams can result in a delayed discharge process and longer time spent in hospital.

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Major Research Project: Section B

Word Count: 8000 (424)

Abstract

Background: The BBC panorama "Winterbourne View", uncovered the mistreatment of people with learning disabilities residing in long stay hospitals, resulting in the introduction of the *Transforming Care* agenda. The current research aimed to explore the experiences of community health and social care professionals who work under *Transforming Care*, to understand what contributes to successfully discharging someone with learning disabilities and/or autism from hospital to a community-based setting.

Method: A qualitative research design was used to gather information from participants. Twelve health professionals and three social workers took part in semi-structured interviews. A social constructionist grounded theory approach was used to analyse the data.

Results: The concept model highlighted 12 categories which derived from four concepts. Participants highlighted the importance of "Balancing the different levels of the system" and having the whole system aligned. Participants felt they had a responsibility to ensure the transition process was manageable for the individual and therefore "Providing the 'opportunity to thrive again'". Participants recognised the barriers that impacted their work and "Feeling stuck working within the system". Finally, participants recognised the emotional toll of working under *Transforming Care*, expressing "It's not easy work".

Conclusion: The findings indicate the importance of a joined-up approach amongst the system, and the emotional impact the role has on staff. Clinical implications include focussing on the wellbeing of community health and social care professionals and allowing a space for supervision to be provided to the network.

***Key words**: learning disability, autism, Transforming Care, health, social care.*

Introduction

The term ‘learning disability’ is defined as a significant impairment in intellectual and adaptive functioning, with an age onset before adulthood (British Psychological Society [BPS], 2014). In the early twentieth century, people with learning disabilities (LD) resided in large-scale institutions, isolated from the public (Walmsley, 2008). Wolfensberger (1972) highlighted the impact of ‘normalisation’ and how individuals with LD are made to feel powerless and devalued due to society structures.

In the late twentieth century, the process of deinstitutionalisation began (Barron et al., 2011), to reduce inappropriate admissions to hospital and focus on developing a community infrastructure that was accessible for individuals with LD (Bachrach & Lamb, 1989). This reduced the number of people with LD residing in hospitals (NHS England, 2020). However, community placements were not always equipped to support individuals with complex presentations, resulting in placement breakdowns (Beadle-Brown et al., 2007), and limited suitable placements (Hudson & Cox, 1991). This highlighted the difficulties of individuals moving from hospitals to community-based settings, and the risk of re-admission (Simpson & Price, 2010).

Winterbourne View and Development of *Transforming Care*

The 2011 BBC Panorama investigation “Winterbourne View” uncovered mistreatment and abuse towards individuals with LD who were residing at the hospital (BBC, 2011). This resulted in the development of the *Transforming Care* programme. The outcome of the *Transforming Care Report* (Department of Health, 2012) was to set up a programme to reduce the number of people with LD and/or autism residing in hospital or long-stay institutions. *Transforming Care* was a national programme with funding to support people with LD to live more independently (Local Government Association, 2021) and receive person-centred care in the community (Department of Health, 2015).

Staff experience of supporting moves from hospital to the community

Health and Social Care (HaSC) professionals provide a large amount of support for people with LD and/or autism, and co-ordinate many of the discharges from hospital to the community. However, these professionals are often missing from conversations about how this cohort of people with complex needs are supported to move to a community provision (Hudson et al., 2021). Hudson et al. (2021) investigated the experiences of inpatient nursing staff involved in *Transforming Care* discharges. Some of the nursing staff found the system's expectations of them difficult to achieve. Participants commented on the difficulties of meeting targets whilst balancing the needs of the patients, and as a result felt forced into premature discharges. However, other nurses in the same study disagreed, and felt the rate of discharge was delayed due to communication difficulties between the coordinating network. Read (2022) provided the experience of a dual-qualified mental health nurse and social worker within their role coordinating *Transforming Care* discharges. They concluded that the transition process from hospital to the community was complex due to the number of services required to coordinate for the individual. Both Read (2022) and Hudson et al. (2021) suggested that more focus should be on the community organisation to ensure successful discharges are achieved.

Workplace demands and challenges to staff wellbeing

Research has demonstrated the demands placed upon healthcare professionals and social workers, and the impact this has on staff wellbeing and health (Niedhammer et al., 2020; Ravalier, 2019; Van der Heijden et al., 2019; Bakker & Demerouti, 2017). Social workers reported feeling frustrated that their skill set was not understood or valued by healthcare staff (Travis et al., 2016) and acknowledged having to manage high caseloads with limited supervision (Barak et al., 2006) and working long hours (Ravalier, 2019). As a result, social workers had an increased level of stress (Ravalier, 2018), burnout and job dissatisfaction (Kim et al., 2017; McFadden et al., 2017).

Working within health or social care supporting complex individuals involves a continued use of empathy and compassion (Rothschild & Rand, 2006). The prolonged use of empathy, combined with workplace stressors outlined above, can result in "compassion fatigue" (Figley, 2002b; Cavanagh et al., 2020). Compassion fatigue occurs when professionals take on the trauma or stress others have experienced and this has been linked to work impairment (Perez-Garcia et al., 2021) and staff turnover (Wells-English et al., 2019). If community HaSC professionals do not feel able to support individuals with LD and/or autism successfully, there is potential for the risk of the 'revolving door' phenomena of discharge then re-admission (Royal College of Nursing, 2016).

Rationale for the present study

Systemic theory suggests that no person lives in isolation from the systems and contexts which influence their lives (Von Bertalanffy, 1973). For people with LD and/or autism, the systems in which they live are likely to exert a huge influence on the quality of their lives. HaSC professionals exert a large amount of power over the decisions made about living arrangements and have an enormous impact on the quality of care for people with LD and/or autism (NHS England, 2015). These same professionals may also be constrained by managerial decision making, policies and procedures, which are a consequence of the context of society, politics, and power (Reynolds, 2009; 2011). Managing such tensions in their professional role can take a toll on staff's wellbeing (Quirk et al., 2018).

Research surrounding the experiences of the hospital discharge process, via *Transforming Care*, has been systematically reviewed in section A. This review highlighted a larger emphasis on the experiences of nursing staff, rather than a broader focus on the processes involved in the wider multi-disciplinary team (MDT). There was also more research gathered from inpatient staff compared to community staff and the voice of social workers was extremely limited. Therefore, it would be helpful to gain the perspectives of community HaSC professionals, to allow for a theory that can be generalised to MDT's.

Read (2022) and Hudson et al. (2021) produced useful research which provided an insight into the HaSC professionals perspective. However, Read's (2022) was a single-case study therefore lacked generalisability; and Hudson et al. (2021) focussed on solely the experiences of one professional group, nursing.

Aims

A review of the literature identified the limited empirical research into the processes involved in supporting individuals with LD and/or autism to move from hospital to a community-based setting. By understanding what factors contribute to a perceived successful transition, recommendations can be made for future discharges, which may have significant real-world implications. Professional networks may have a better understanding of what is involved in supporting a transition and how to overcome some of the barriers that have been previously experienced by the participants. Therefore, this project aimed to explore the processes community HaSC professionals undertake when working within the remits of *Transforming Care*.

This investigation involved interviewing a range of community HaSC professionals within different services, regarding their involvement of supporting an individual with LD and/or autism who had been discharged from a mental health or forensic hospital setting from 2012 onwards. The interviews were analysed using grounded theory, from a social constructionist approach. This approach allowed for reflexivity throughout the analysis, to consider the relationship the researcher had with the data. This investigation was in line with the NHS values ‘working together for patients’, and ‘commitment to quality of care’ (Health Education England, 2021).

Methodology

Design

A qualitative research design was chosen for the current study, as this is valuable when exploring individuals’ experiences and developing meaning (Willig, 2013). Semi-structured interviews were used to explore the experiences of community HaSC professionals who had been involved in supporting people with LD and/or autism to move from hospital to a community-based placement, via *Transforming Care*.

Grounded theory (GT)

A GT approach, taking a social constructionist epistemological design (Charmaz, 2008) was employed for the current research. Table 7 outlines this approach:

Table 7.

Outline of social constructionist approach.

Outline of social constructionist approach
• The social constructionist GT technique (Charmaz, 2008) allows for data to be analysed using a bottom-up approach, to generate a new theory inductively from the data.
• This approach focuses on how knowledge is created and understood, considering culture, time, and language from the participants’ perspective (Willig, 2013).
• Taking a social constructionist approach considers the relationship the researcher has with the data and holds in mind the impact of potential bias (Charmaz, 2008).
• This approach is valuable in areas of research where there is limited knowledge.

The literature review revealed a lack of understanding regarding the experiences of community HaSC professionals working under *Transforming Care*. Therefore, the use of GT seemed appropriate for the current study to develop a theoretical model, which in the future could be used with professionals who are supporting individuals with LD and/or autism to transition out of hospital and back to a community placement. The GT process will be described in more detail in the data analysis section.

Consideration of other methodologies

During the initial planning stages of the current research project, discussions were had about the appropriateness of GT compared to other methodologies, such as Interpretative Phenomenological Analysis (IPA).

Working under the *Transforming Care* agenda is a difficult role and there continues to be challenges when supporting individuals out of hospital (Hudson et al., 2021). Therefore, the current study intended to understand the underlying processes involved in supporting an individual to move under the *Transforming Care* agenda, to construct a theory that can be used for future discharges (Mills et al., 2008) and provide meaningful recommendations.

Based on this description, using IPA as a methodology would have allowed for individual experiences to be explored, however this approach requires homogeneity of participants, and therefore lacks generalisability. The current project aimed to understand a range of experiences, from participants working in different roles, to make sense of a process rather than individual experiences. Therefore, GT was deemed a more appropriate methodology compared to IPA.

Recruitment

Participants were recruited using purposive sampling, an effective strategy when there are limited resources (Patton, 2014). A leaflet for the research (appendix E) was distributed to the professional network of the researcher and supervisors involved in the project. Participants were requested to contact the lead researcher if they were interested in taking part.

Theoretical sampling (Charmaz, 2014) was used to ensure data was collected from a diverse sample to achieve the GT aim of theoretical sufficiency and enough meaningful data was collected to develop a GT (Dey, 1999). In the present study, as data collection and analysis occurred successively, this allowed the researcher to identify a gap in the data. Many of the health care professionals interviewed in the early stages of the project spoke about the importance of social care throughout the discharge process. Therefore, it felt important to ensure this voice was captured. Theoretical sampling was used to seek out participants from a social care background, this involved the research advert being sent to the professional network, requesting the advert was forwarded to social workers who fitted the inclusion criteria and who may have been interested in participating. Recruitment continued alongside data analysis until data saturation was met (Charmaz, 2014). The participant inclusion criteria is outlined in Table 8.

Table 8.

Inclusion Criteria

Inclusion Criteria
A community health or social care professional
Had an active involvement in supporting an individual(s) with learning disabilities and/or autism move from hospital to the community via *Transforming Care* agenda.
A minimum of three months' experience of supporting an individual with learning disabilities and/or autism who has transitioned from hospital to the community

Participants

Fifteen participants were involved in the research study. All the interviews took place using Microsoft Teams, a secure platform. The participants consisted of 12 community health professionals and three social workers, across areas of England. Details of the participants can be found in Table 9.

Table 9.

Outline of participant details.

Pseudonym	**Gender**	**Profession**	**Service**	**How many people supported out of hospital**	**Length of time since last person they supported**
Charlotte	Female	Learning Disability Nurse	Transforming Care team, NHS	10	Two months before interview
Laura	Female	Speech and Language Therapist	Learning disability, Intensive Support Team, NHS	10	Nine months before interview
Sarah	Female	Clinical Psychologist	Learning disability, Intensive Support Team, NHS	3	Less than a year before interview
Jane	Female	Clinical Psychologist	Learning disability, Intensive Support Team, NHS	15	Nine months before interview
Catherine	Female	Occupational Therapist	Learning disability mental health team, NHS	3	Five months before interview
Linda	Female	Nurse Practitioner	Forensic Learning Disability Team, NHS	7	Current involvement at time of interview
Alison	Female	Occupational Therapist	Learning disability mental health team, NHS	10	One month before interview

Carol	Female	Clinical Psychologist	Learning disability, Intensive support team, NHS	4	Current involvement at time of interview
Thomas	Male	Behaviour Specialist	Learning disability mental health team, NHS	1	Current involvement at time of interview
Kevin	Male	Learning Disability Nurse	Transforming Care team, NHS	5	Current involvement at time of interview
Amelia	Female	Clinical Psychologist	Learning disability mental health team, NHS	4	Nine months before interview
Isabelle	Female	Speech and Language Therapist	Transforming Care team, NHS	2	Four months before interview
Samuel	Male	Social Worker	Adult social care, Local government	2	Eight months before interview
Katie	Female	Social Worker	Adult social care, Local government	10	Six months before interview
Michelle	Female	Social Worker	Adult social care, Local government	4	Sixteen months before interview

Data Collection

Individual semi-structured interviews were conducted. The length of interview ranged from 46 minutes to 76 minutes, and these were audio recorded and transcribed using a secure platform.

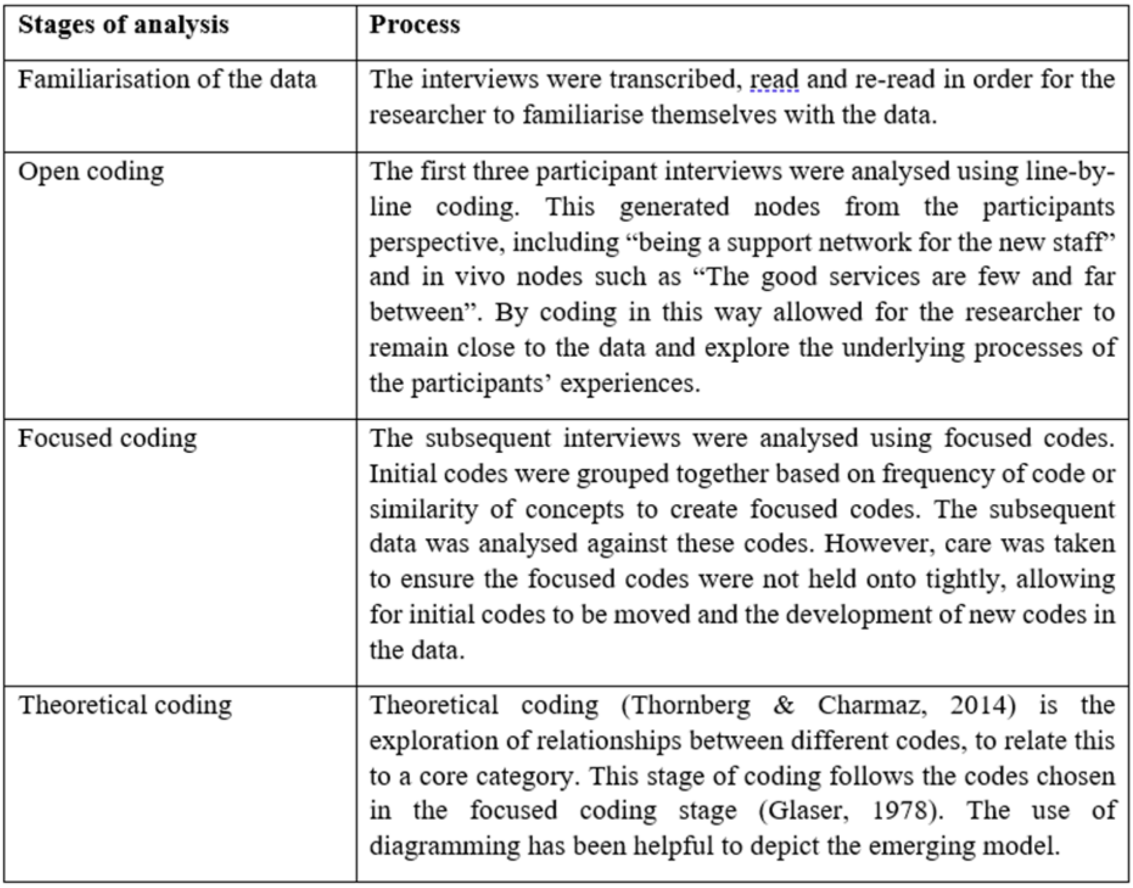
Interview guides displayed in appendix F provided prompts for the interview to help guide the participants to share their experiences (Willig, 2013). In line with the GT data analysis process (Charmaz, 2014), the interview guide was adapted following the initial analysis of the data to develop and refine areas of interest (see appendix F).

Data analysis

The data collected from interviews was transcribed and analysed using NVivo 12, using the GT structure outlined by Charmaz (2014). The data analysis process is outlined below in table 10.

Table 10.

Outline of the GT process.



Stages of analysis	**Process**
Familiarisation of the data	The interviews were transcribed, read and re-read in order for the researcher to familiarise themselves with the data.
Open coding	The first three participant interviews were analysed using line-by-line coding. This generated nodes from the participants perspective, including “being a support network for the new staff” and in vivo nodes such as “The good services are few and far between”. By coding in this way allowed for the researcher to remain close to the data and explore the underlying processes of the participants’ experiences.
Focused coding	The subsequent interviews were analysed using focused codes. Initial codes were grouped together based on frequency of code or similarity of concepts to create focused codes. The subsequent data was analysed against these codes. However, care was taken to ensure the focused codes were not held onto tightly, allowing for initial codes to be moved and the development of new codes in the data.
Theoretical coding	Theoretical coding (Thornberg & Charmaz, 2014) is the exploration of relationships between different codes, to relate this to a core category. This stage of coding follows the codes chosen in the focused coding stage (Glaser, 1978). The use of diagramming has been helpful to depict the emerging model.

In line with the social constructionist epistemological stance (Charmaz, 2008), memos were written (appendix G) and a reflexive diary (appendix H) was kept ensuring there was a mindfulness of how the researcher's personal perspectives may have impacted the coding process. This helped acknowledge the relationship I had to the data and reduce the risk of bias. Further examples of the coding process are demonstrated in appendices I and J.

Quality of the research

The Big Tent Criteria (Tracy & Hinrichs, 2017) was applied during data collection, data analysis and the write up of the project to ensure the quality criteria was being met (see appendix K). Supervision was also used during the data analysis stage which helped to refine the open and focused codes and ensure the researcher remained reflexive.

Ethical considerations

Ethical approval was granted by Salomon's University ethics board on 28th June 2022 (appendix L).

Consent

Before taking part, an information sheet was sent via email for the participant to read (appendix M). Participants had the option to ask questions via email or a phone call. Once participants were happy to take part they were required to read, sign and return a consent form (appendix N). Verbal consent was also gained before starting the interview to confirm participation.

Maintaining confidentiality

It was explained to participants that their data will remain confidential unless there is evidence of risk to self or others, in which there was duty of care to share this information with relevant others. The participants were asked to maintain anonymity of the individual(s) they had supported and were reminded not to disclose any identifiable information. As interviews were conducted online, participants were asked to move to a private room to maintain confidentiality.

Table 11 outlines how the data was used securely.

Table 11.

Data security

1. Interviews were audio recorded using a Dictaphone and transcription was recorded using Microsoft Teams.
2. The data was saved securely on to an encrypted USB and secure OneDrive and accessed on a password protected computer.
3. During the transcription stage, all identifiable information was altered to maintain anonymity.
4. Once the interviews were transferred to the encrypted USB and secure OneDrive and transcribed, they were deleted off the Dictaphone.

Debrief

Participants were informed they could withdraw from the research at any point. After the interview, participants had two weeks to inform the lead researcher if they wished to withdraw their data. At the end of the interview, participants were debriefed by having the opportunity to ask questions and were provided contact details of the lead researcher if they had any concerns. Participants were asked if they would like to receive a copy of the research following completion. All participants received a £10 amazon voucher for their participation.

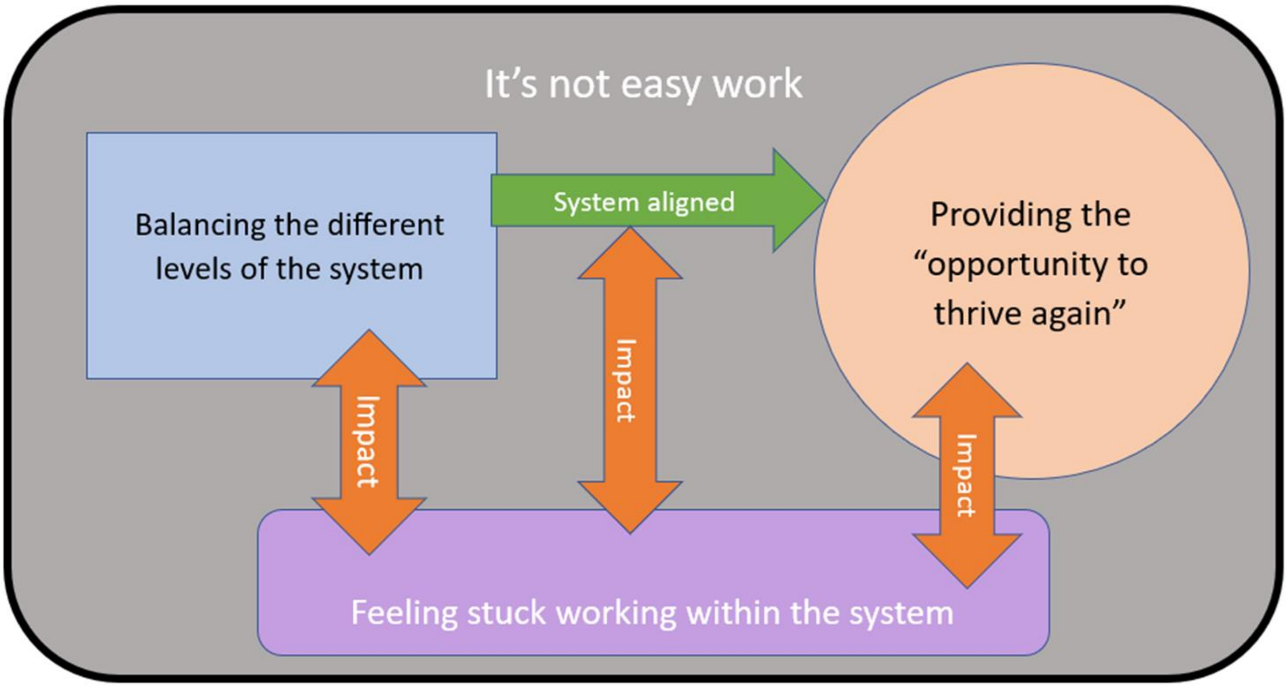
Results

The results of the current study presented a GT model to understand the views of community HaSC professionals, regarding what contributes to a perceived successful transition from hospital to a home within the community for people with LD and/or autism. The model presented in figure 2 outlines the processes which community HaSC professionals use to support a discharge from hospital to a community-based setting, via *Transforming Care*. The model highlights four concepts: “Balancing the different levels of the system”, “Providing the ‘opportunity to thrive again’”, “Feeling stuck working within the system” and “It’s not easy work”, comprising of 12 categories.

The interactions between the concepts are described in further detail, using descriptive quotes from participants and visual diagrams. Initial drawings of the theory development can be found in appendix O and further quotes for each concept can be found in appendix P.

Figure 2.

Grounded theory model.



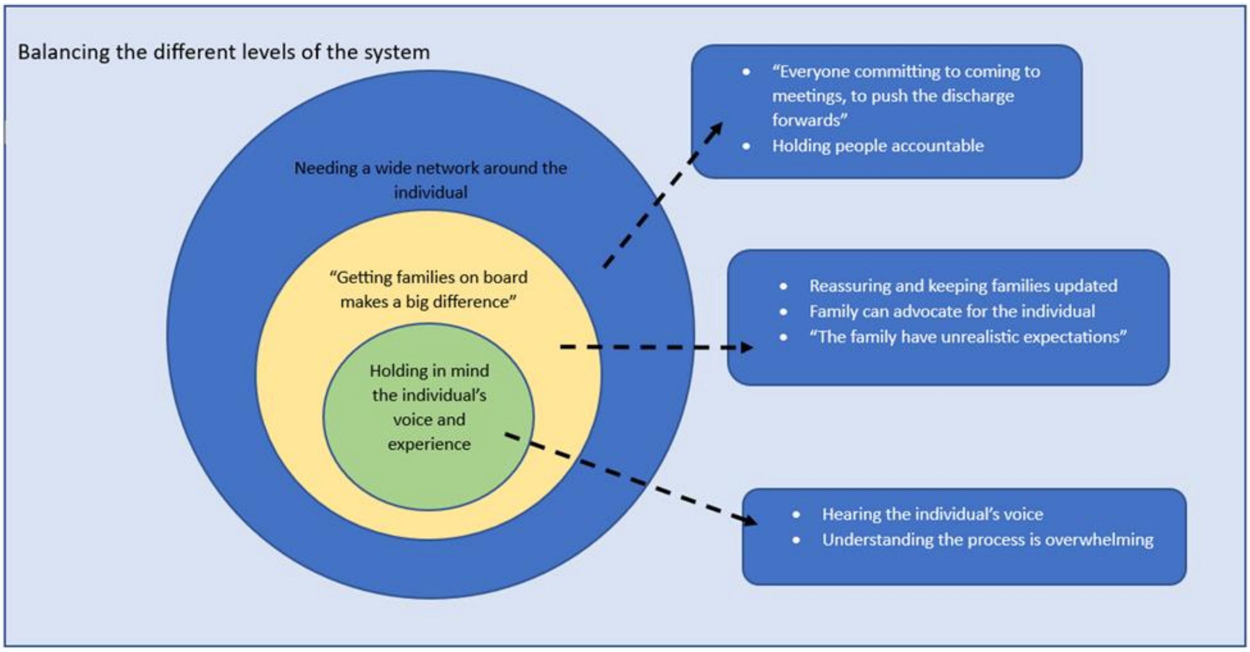
Overall, the model highlighted four interconnecting concepts. The participants described the importance of “Balancing different levels of the system” to ensure the system aligned and the discharge process could progress. The participants felt they had a responsibility in “providing the ‘opportunity to thrive again’” by ensuring the discharge process was smooth and manageable for the individual. However, often the participants would face barriers which left them “feeling stuck working within the system”, impacting on the different processes involved. Finally, participants highlighted that the whole discharge process was challenging, with many professionals reflecting “it’s not easy work”, which affected all parts of the process.

Balancing the different levels of the system

This concept captures the different processes involved when working as part of a system that included the professional network, family members and the person moving, to ensure a successful discharge process. The categories “Holding in mind the individual’s voice and experience”, “Getting families on board makes a big difference” and “Needing a wide network around the individual” were constructed within this concept.

Figure 3

“Balancing the different levels of the system” concept.



Holding in mind the individual’s voice and experience.

Participants spoke about finding the balance as to when the individual should be involved in the discharge process. The subcategories represent the feelings of push and pull experienced by the participants.

Hearing the individual’s voice. Participants described the importance of involving the individual in choices about where they should live and how knowing the individual helped to find the correct placement:

“Umm we've done it where we've done…like what would you want your house to look like? What's important to you?” (Amelia).

"Knowing that person really well, making sure I understand their formulation of their needs and then pointing out what's you know, good or not good about a potential service" (Amelia).

Understanding the process is overwhelming. Participants described that in their experience, providing too much information to an individual could be overwhelming for them:

"Some of our clients, especially our people who may have ASD who really struggle with any prior information. So, we make, make a decision to actually withhold information" (Kevin).

This category positions the experience of transition as one of fragility and highlights the need for a shared perspective. The quotes emphasise how transition is an emotionally demanding process, which contrasts with the perhaps anticipated sense that transition from hospital can be an act of freedom and positive emotion.

"Getting families on board makes a big difference."

The participants acknowledged the importance of including families, but also the difficulty of managing their expectations. This is reflected in the conflicting subcategories.

Reassuring and keeping families updated. Throughout the interviews, participants described the importance of involving family members in the decisions made:

"It was just really important to….give family a chance to kind of express, like their concerns and hopes" (Carol).

"For the new placement to work, the family has to be happy with it and they have to have met the provider and kind of have confidence that they'll be supporting their relative in good way" (Jane).

Family can advocate for the individual. Participants also reflected on the importance of the family voice in advocating for the individual, especially when the individual did not have capacity to make decisions:

"If it wasn't for his mum, I am not sure that drive would have been there for him to return back" (Katie).

"The family have unrealistic expectations". Despite valuing the importance of family members being involved, participants also recognised how sometimes "*parent expectations are not realistic, and they expect too much from the provider" (Sarah),* which could lead to a breakdown in relationships:

"So, if the family have unrealistic expectations….the provider might say early on we didn't sign up for this" (Jane).

Participants also highlighted that families did not always follow the recommended plans, and the need for professionals to manage this with boundaries:

"They need to be held accountable as well, sometimes they're not always following recommendations and boundaries" (Laura).

This category positions the family as an expert involved in the individual's care. These quotes highlight the importance of the family voice and their role within the professional network, which may contrast with the view that HaSC professionals lead on the discharge process and are seen as holding the power.

Needing a wide network around the individual

Participants spoke about working with the professional network to coordinate discharges and the need for *"an MDT around someone" (Katie)*. However, participants recognised the difficulty with communication at times.

"Everyone committing to coming to meetings, to push the discharge forwards". Participants described the need for clear communication amongst all professionals involved in the discharge process and ensuring roles were well-established:

"So just really clear, succinct…actions for each person. Everybody knows where they're at and making sure that we're all meeting…together as a team" (Amelia).

It was important for the network to be committed and prioritise attending regular meetings to ensure the discharge process moved forward.

"A team that are willing to commit to attending regular meetings as well to keep everyone up to date, to keep those actions moving" (Isabelle).

Holding people accountable. Some participants described feeling responsible for chasing up the network:

"And other times it feels like we have to do a lot of pushing" (Jane).

"And sometimes I am the unwelcome voice saying, you're not actually doing what we commission you to do" (Charlotte).

This category describes the motivation and commitment required to drive the discharge process forward. The quotes highlight the feelings of disappointment felt by the professionals when meeting attendance was not prioritised, and the frustration with having to be the person that chases other members of the system. This category suggests that no one person takes a lead in the discharge process, which contrasts with other structures within HaSC settings.

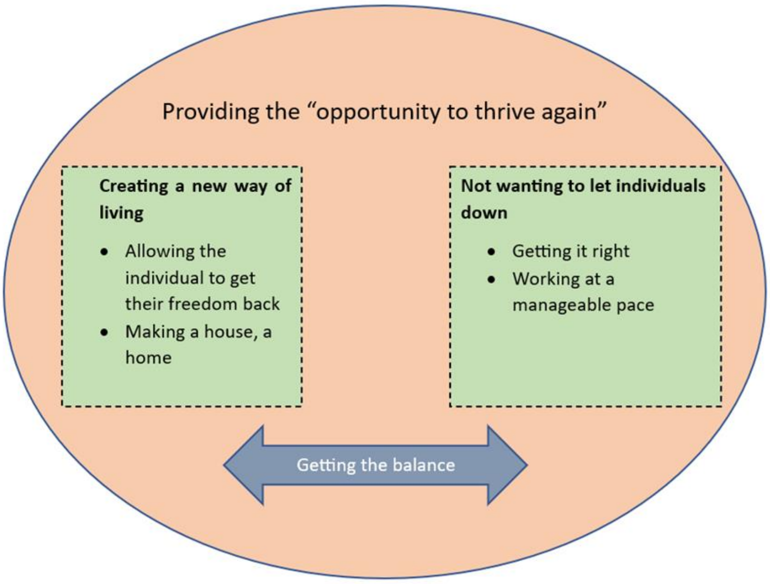
This concept captured the multi-layered system involved in supporting an individual with LD and/or autism and ensuring the system is aligned for a successful discharge to be facilitated. Participants described their experiences of conflict amongst the subcategories at each level of the system, which resulted in them feeling stuck and their role became challenging to navigate.

Providing “the opportunity to thrive again”

This concept covered the processes participants experienced when supporting someone to thrive in their new home. Participants described their experiences of wanting to support individuals to have a meaningful life in the community but felt this had to be balanced with making the right decisions for the individual to ensure a successful transition happened.

Figure 4

“Providing the ‘opportunity to thrive again’” concept.



Creating a new way of living

The participant's hoped for individuals to have a good quality of life in the community and recognised that *"this is someone's life" (Laura).* Participants felt they had a responsibility to work in person-centred ways to ensure they supported the individual to connect with the community.

Allowing the individual to get their freedom back. The data implied that the participants recognised the life they lead in the community with limited restrictions and wanted participants to experience a similar level of freedom:

"Not that when they come out, they have to stick rigidly to like lunchtime at this time, because in hospital, they do. And you know when you're…living in your own home, you don't necessarily do that" (Catherine).

Participants also described needing to know the individual well-enough to organise community activities they would enjoy:

"Going to an art class because that's what they wanted to do" (Linda).

Making a house, a home. Participants described the importance of individuals having an element of choice over their room to create a homely environment:

"We do try and make it bespoke. We do try and make it very person centred. We will request for colours of rooms. We will look at furnishing. So we support on that level as well" (Linda).

This category highlights the act of transition as one of increased freedom and opportunity for the individual. The quotes capture the positive feelings of the transition, and the hopes that professionals held for the individuals to flourish. This contrasts with feelings of anticipation and worry that may be expected during a significant life change.

Not wanting to let individuals down

Participants described their feelings of aspiring to support an individual to transition successfully back to the community *"we really have aspirations for them, and we want them to do well" (Laura).* Participants described experiencing a level of responsibility to ensure they did not set individuals up to fail.

Getting it right. Participants reflected on how some individuals had been in hospital for long periods of time and *"hospital has been a safe place" (Linda)*. Therefore, participants felt it was their responsibility to check the community setting was suitable for the individual, to prevent placement breakdown:

> *"I was happy that it was gonna be good enough for them rather than just being chucked out anywhere and then it not working and them ending up potentially back in hospital" (Amelia).*

Also, participants described the importance of having a well thought-through transition plan:

> *"A successful and carefully thought-out transition plan…is definitely kind of key to that transition" (Amelia).*

Participants outlined their role in holding the risk for individuals and feeling responsible for sharing risk assessments to ensure placements can meet the individuals' needs and prevent hospital readmission:

> *"I think people get a bit blasé and the risks aren't really taken seriously. And unfortunately for this person because the risks were not managed, there was an incident and he ended up back in hospital" (Catherine).*

Working at a manageable pace. Participants highlighted working in person-centred ways to ensure that an individual transitioned to their community placement at a manageable pace:

"They could spend the whole day going to this place and then sleeping back at the unit" (Laura).

And expressed working in ways to ensure the individual settled at their own pace into the community placement:

"I mean obviously on moving day, we wouldn't suggest taking people out in the community. They need to settle in" (Jane)

However, participants described the importance of structure and routine in the community:

"But we do feel structure to someone's day is really important when they're coming from structure, a structured, environment" (Catherine).

This category captured the personal impact a transition had on the professionals involved. The quotes highlight the personal responsibility that the participants felt to support the individual successfully, and to provide them with a good quality of life in the community. An alternative interpretation may be that the quotes reflected the participants' anxiety about discharging the individual, and how they would no longer be under their care.

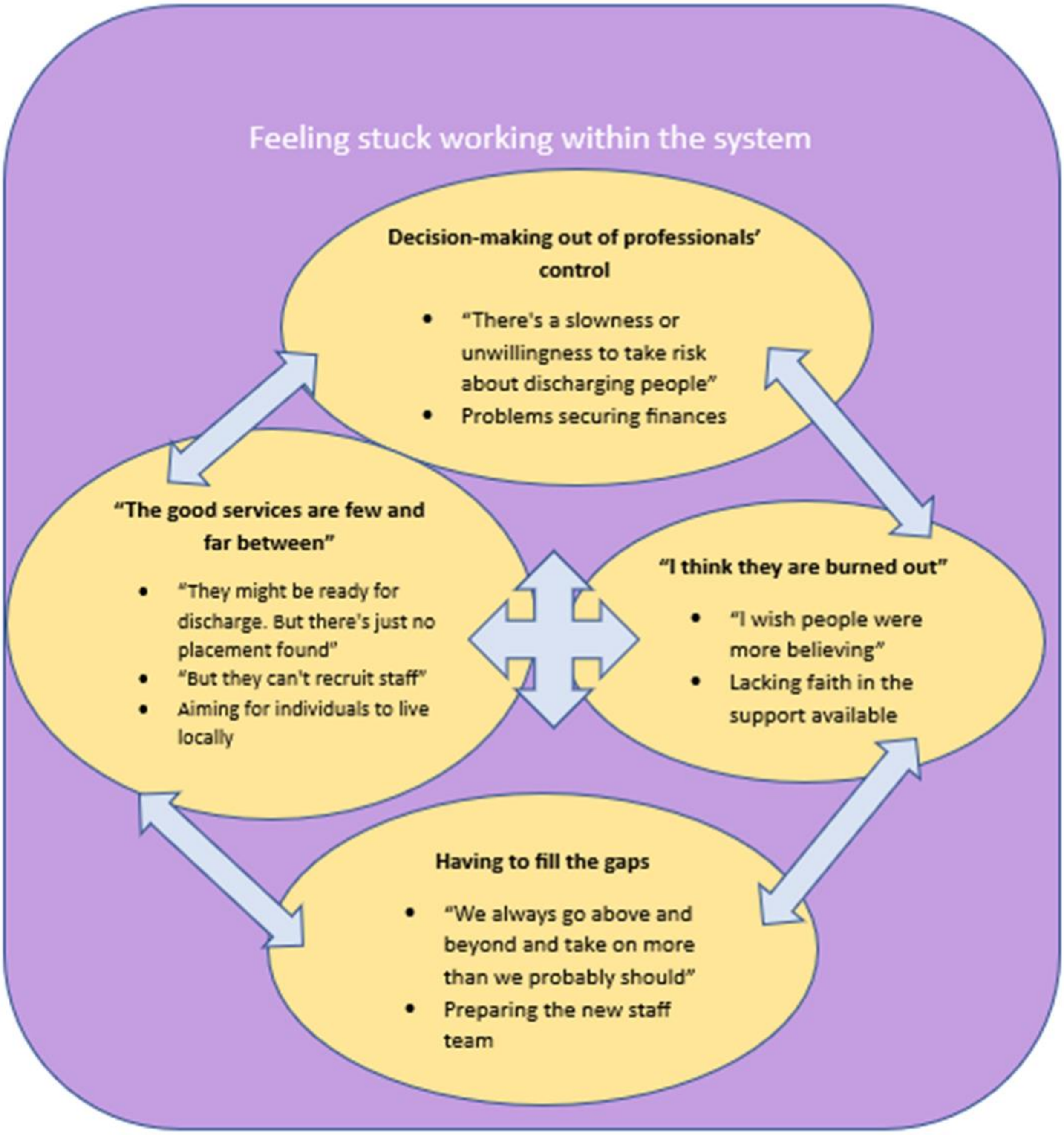
Overall, in this concept if the balance was not achieved between the categories, the participants would find themselves 'feeling stuck' within their job roles.

Feeling stuck working within the system

Within this concept, four interacting categories were devised which resulted in professionals feeling stuck within the system. These barriers impacted on the other processes and delayed the discharge for an individual. The overall model (figure 2) highlights the interaction this concept has with the other processes.

Figure 5

“Feeling stuck working within the system” concept.



“The good services are few and far between”

Many of the participants described the challenges faced with *"locating appropriate placements" (Alison)* and the frustration this created, due to a long discharge process *"we go into it knowing that it's gonna be quite a long slog and it's really frustrating" (Laura).*

"They might be ready for discharge. But there's just no placement found". Participants shared their difficulties with finding appropriate placements to meet the needs of the individual and the lack of choice available:

"There isn't the providers out there…able to meet her needs" (Carol).

This meant individuals remained in hospitals for longer than necessary, which impacted on their mental health:

"If they're waiting too long to leave hospital, they might start regressing and kind of relapsing a bit because they get frustrated" (Jane).

"But they can't recruit staff". Participants also highlighted the difficulties with recruiting care staff, even if a setting was found:

"So there was a building there and a provider that said we're ready to go. You know, we just need to build up our team and then we'll have him. They could not recruit" (Jane).

And expressed their frustrations surrounding the delays of discharge:

"So he's been in transition for about a year. It's ridiculous. Absolutely ridiculous" (Laura).

Aiming for individuals to live locally. Participants reflected they would like individuals to be placed within the locality, close to their families and community services. However, this was not always possible and out-of-area placements had to be sourced:

"But these really are people that you want to keep local" (Charlotte).

Which resulted in difficulties and frustrations for the professionals trying to navigate the discharge process out of area:

"How do you arrange a transition in an area that's more than 370 miles away, you know it's just not manageable, really, is it?" (Samuel)

This category positions the transition process as one full of difficulty and restriction. The quotes highlighted the frustration when faced with barriers, as well as the longing for individuals to be discharged from hospital. Alternatively, these quotes could also reflect the determination of the participants to persevere with the process, despite the impact this may have had on motivation, knowing that the lengthy discharge process was ahead.

Having to fill the gaps

Participants highlighted the need to step into roles outside of their professional capacity to ensure the discharge continued.

"We always go above and beyond and take on more than we probably should". Participants spoke about the strain placed on other professionals within the network and therefore, felt the need to take on tasks outside the remit of their professional role:

"It's absolutely horrendous locally. And so, because we know them well, leave it with me. I'll write it up. I'll do it. Don't worry" (Charlotte).

Preparing the new staff team. Some participants felt they stepped into a role which helped train up new staff teams to ensure the placement knew the individual and how to best support them:

"Before moving to the placement when we usually create a, what we call a placement profile, which is a document that describes all the person's needs" (Sarah).

Supporting the staff team after discharge. Participants also spoke about their roles continuing after the individual had been discharged, to be a support network for the new staff teams:

"And once they have moved, having that good link in terms of then being able to go out and see the person and the staff kind of knowing what we're there, what we're doing" (Catherine).

The quotes in this category capture the caring nature of the professionals and the need to support colleagues, as well as the individual, throughout the transition process. This was interpreted in a way that suggested that the professionals were happy with supporting their colleagues rather than feeling resentful for having to do the work of others.

"I think they are burned out"

Participants described across the interviews the impact of supporting an individual with LD and/or autism for the care staff within a placement setting, *"sometimes it just feels like carers are under so much pressure in these placements" (Samuel).*

"I wish people were more believing". Some of the participants described feeling they had to step into advocacy roles for the individuals and were "*constantly trying to persuade" (Laura)* placements to see the individual as a person which was *"stressful" (Laura)*:

"So, it feels a bit like we have to fight for them and stand up for them and present them in a way that is really positive" (Laura).

Participants also described some frustration towards placements, as it was felt they used an individual's hospital admission as a reason to refuse the individual back:

"*Then they get a breather when the person comes into hospital and they use that breather to go actually we shouldn't have ever had them in the first place" (Jane).*

Participants described longing for placements to see the individual as the person they had previously supported before the hospital admission:

"You think, well, you, you spent ten years looking after them with no problem so you could go another 10 years" (Laura)

And were developing ways to encourage staff teams to believe in the individual more:

"We've started thinking about doing video PBS plans. As a way of like, hey, this is me and here I am and this is what I'm like and you can hear it from me myself instead of hearing it from my reports" (Laura).

Lacking faith in the support available. Participants highlighted their concerns of inconsistent staff teams and the impact this had on the support an individual received in the community:

"So even the best service is a staff leaving distance away from it becoming not such a good service" (Charlotte).

Participants also spoke to their experiences of feeling let down by services as they did not fulfil what they promised:

"You have lots of providers that will say that they are specialist PBS trained or specialist attachment or trauma trained. But actually when you look at what they provide, umm they don't have the expertise or training that they often say they do" (Amelia).

Participants also shared their frustrations when staff members did not follow recommendations, which then impacted the individual:

"I know we can't prevent everything from happening, but I think when it's something silly like things being left… it's just not really acceptable" (Catherine)

The quotes in this category capture the empathy that HaSC professionals held for the staff working within the community providers and acknowledged the difficult role and challenges they faced. This contrasts with feelings of frustration and anger that may have been anticipated by HaSC professionals when an individual was let down by a provider in the community.

Decision-making out of professionals' control

Participants voiced their frustrations with the decision-making process which delayed discharges. Participants spoke about challenging these choices but also a sense of hopelessness about these decisions being out of their control *"I haven't got any ability to say yes do this or no do that" (Laura)*.

"There's a slowness or unwillingness to take risk about discharging people". Participants shared their feelings around the hesitancy of discharge and wanting community placements and wider networks to have *"some of that positive risk taking" (Isabelle).*

> *"You know, I was always sort of thinking well do they really want this person to be discharged or you know cause it…there did seem to be a little bit of a barrier sometimes in terms of the ohh everything needs to be perfect for this person to be discharged there" (Samuel).*

Problems securing finances. Participants highlighted their frustrations with securing funding for placements *"it's really frustrating because we always hit a roadblock with funding" (Laura)"* and the impact this had on an individual by delaying their discharge:

> *"There's always a tussle with money and who's gonna pay for what" (Charlotte)*

This category positions the discharge process as one full of barriers, frustrations and feelings of hopelessness. The quotes reflect the passion that HaSC professionals have when supporting an individual, and the need to fight for the individual to have a life in the community. This contrasts with expected feelings that everyone would want the individual to be out of hospital as quickly and as safely as possible.

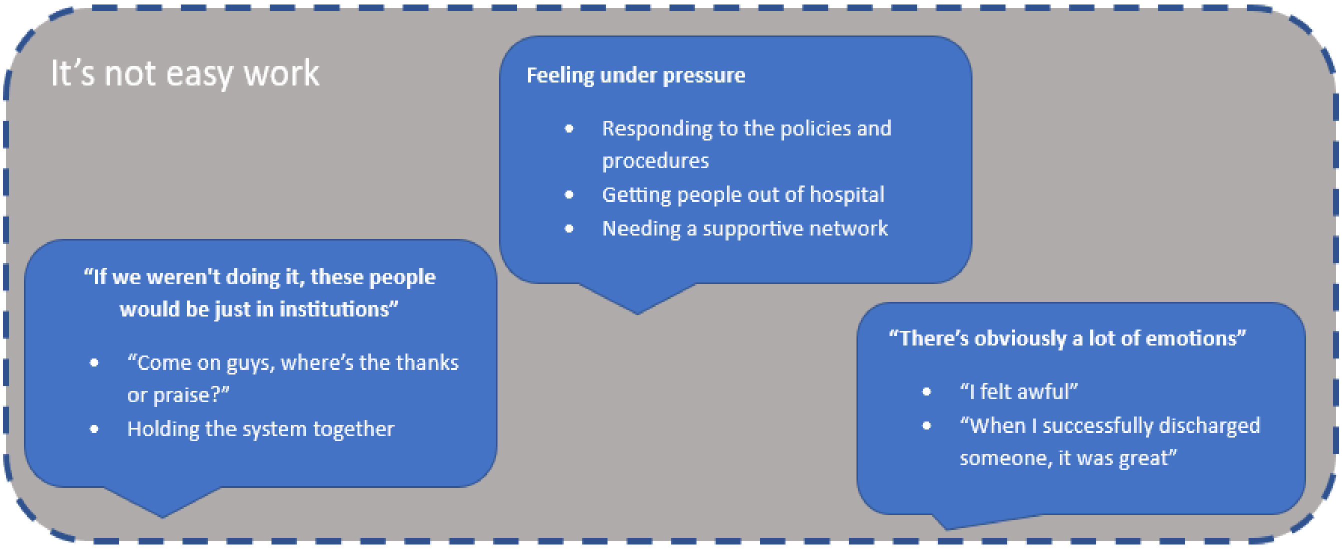
If community HaSC professionals could not overcome barriers within the process, this resulted in a feeling of 'stuckness', which impacted on "balancing different levels of the system" and "providing the 'opportunity to thrive again'".

It's not easy work

This concept reflected the participants' personal experiences of working as part of the *Transforming Care* agenda and facilitating all the other processes highlighted in the concept model (figure 2).

Figure 6

"It's not easy work" concept.



It's not easy work

Feeling under pressure

- Responding to the policies and procedures
- Getting people out of hospital
- Needing a supportive network

"If we weren't doing it, these people would be just in institutions"

- "Come on guys, where's the thanks or praise?"
- Holding the system together

"There's obviously a lot of emotions"

- "I felt awful"
- "When I successfully discharged someone, it was great"

“If we weren't doing it, these people would be just in institutions”.

Participants valued the importance of their job roles within the professional network. *“I'm not saying for instance, before I joined this team, it never happened. But the feedback we've got…the discharges were down…we've almost halved it” (Kevin).* However, participants felt underappreciated for their hard work.

“Come on guys, where’s the thanks or praise?”. Some participants recognised the importance of praise and wanted more formal recognition when successfully discharging individuals:

> *“I think having praise and having the really good discharges, not just like, Oh well done, guys, that was really good. Having a clear record somewhere of …which we do have. But having like, praise and recognition for actually getting someone out of hospital” (Laura).*

Holding the system together. Some participants spoke about being the glue in the system that brings everyone together to resolve issues stopping a discharge:

> *“It’s very challenging and time consuming, but I think one of the things that we can usually offer is…coordinating those people together” (Carol).*

This category captures the hard work that HaSC professionals put in to making a discharge process successful. The quotes reflect the feelings of disappointment experienced by the participants, due to the lack of recognition they received. This could also reflect the participants becoming burnt out within their professional role, suggesting that praise and recognition maintained their motivation.

Feeling under pressure.

Participants expressed they felt pressurised working under the policies of *Transforming Care*, alongside trying to ensure discharges happened in a timely manner. However, participants valued the support from teams and colleagues.

Responding to the policies and procedures. Participants experienced a sense of pressure to meet deadlines and performance quotas.

"I feel like there was a lot of pressure just to move people out of hospital. Um, and I think that probably came from, you know probably the targets like KPIs" (Samuel).

Getting people out of hospital. Participants felt working under the *Transforming Care* agenda meant they were put under a large amount of pressure to "*get people out of hospital" (Samuel).*

"I had transforming care phoning my manager up saying why have you not moved him yet?" (Michelle).

Needing a supportive network. Participants recognised feeling supported and protected by other colleagues and managers within the team.

"I've got really good support within the team" (Thomas).

This category demonstrates the pressures of working within the HaSC system. The quotes highlight the worry that participants experienced when being monitored by *Transforming Care*. However, rather than this feeling accusatory towards HaSC professionals, this may be interpreted as positive action taken by *Transforming Care* by ensuring the discharge process was moving forward and looking for ways to support the network involved.

"There's obviously a lot of emotions".

Participants expressed the emotional response working under *Transforming Care* evoked**.** *"I think when you move anybody it's quite intense. There is obviously a lot of emotions" (Katie).*

"I felt awful". Some participants described the negative emotions associated with working in a difficult system and feeling responsible when situations went wrong:

"It does make me quite sad to be working in this role quite a lot and. I don't really like being part of a system that's keeping people in the hospital for 5 1/2 years on average. It doesn't feel very nice" (Isabelle).

"When I successfully discharged someone, it was great". However, participants also held onto the positive aspects of the role:

"But I love the job I'm doing. I love. I can't tell you how it feels when you, you know, even now, when I think about the first person that transitioned and the fact that he's still in the community" (Linda).

This category positions the discharge process as an emotive experience that impacts on HaSC professionals. The quotes used highlight how the success of the transition takes its toll personally on the participants and the need for regular support. Much of the focus of the discharge process is on supporting the individual and their family, however these quotes highlight the need to also support the professionals involved. This contrasts with the possible view that professionals do not carry the weight of their responsibilities into their personal lives.

Overall, this concept aligns with the culture of the work being extremely tough, which is expressed within each stage of the concept model (figure 2).

Discussion

The current study aimed to develop a GT of community professionals' experiences of what contributes to a perceived successful discharge process for individuals with LD and/or autism, moving from hospital to a community setting. The model highlighted four interrelated processes: "Balancing the different levels of the system", "Providing the 'opportunity to thrive again'", "Feeling stuck working within the system" and "It's not easy work".

Relating the model to existing literature

The current model highlighted that community HaSC professionals are part of the system involved in *Transforming Care,* but are also responsible for coordinating families, the individual and working as an MDT. A key factor in this process was to ensure everyone's voice was heard and that each part of the system was aligned. Participants shared the challenges and the complexity of having multiple perspectives. However, having a wide system involved was recognised as being valuable for support and expertise. This is in line with the results of Read (2022) who deemed it necessary to have a full MDT approach when coordinating a discharge and acknowledged the difficulty of this due to professional boundaries and differing opinions (Stevens, 2013).

Tuckman's model of group processes (1965) outlined different stages of group development. The forming stage involves establishing roles and personalities, whereas the storming stage occurs when the group starts to deviate from the plan, actions are not completed, and people do not prioritise attending meetings. The norming and performing stages are when the group begins to feel more cohesive to work towards a plan. The current research study spoke to these different stages when working as an MDT. The results highlighted that when the system was well aligned in the norming stage, the network can be proactive to coordinate a discharge. However, this is a dated model that does not consider the role of systems theory (Tubbs, 2004) and the impact of other outside influences on group processes (Hurt & Trombley, 2007), which is often likely within professional groups. Therefore, this model may not be fully applicable to an MDT.

When the system was well balanced and aligned, participants felt they were responsible for ensuring the individual had a meaningful life in the community. Participants recognised the life of flexibility they have and worked in ways to encourage individuals to also increase their freedom. This is in line with Dunn et al., (2010) who highlighted that support workers caring for people with LD, often draw on their own life experiences and moral values to make decisions on behalf of the people they care for. However, participants also acknowledged the need for clear transition plans, at a manageable pace for the individual, to prevent placement breakdown. The model is in line with previous findings of Clifford et al., (2018). Care staff felt conflicted as they wanted to provide service-users with the freedom of choice but observed that too much choice overwhelmed the individual.

The community HaSC professionals encountered occasions where they felt stuck within their role and the system. A major barrier to supporting a discharge was the lack of appropriate placements and staff. This has also been recognised as a major barrier to discharges in other research (Taylor et al., 2017; Read, 2022; Evans, 2018). Participants also felt that they were required to take on roles outside of their job description to move a discharge process forward and support the network. In other research, changes to job roles were associated with feeling a lack of control and burnout (Gemine et al., 2021).

Working under *Transforming Care* was emotive. Participants reflected on the pressure they felt to meet targets and to work in line with policies and procedures. Participants from Hudson et al. (2021) also acknowledged the pressure of working under

Transforming Care and the need to discharge individuals within a timely manner, which at times felt rushed due to working to targets. This is a contradiction to the results of the current study which found that community professionals wished people took more positive risks to discharge individuals. The current study emphasised the emotional difficulties the role can evoke. Reynolds (2011) highlighted the impact of social structures which forced clinicians to work outside of their ethical stance and the spiritual pain this resulted in. Reynolds (2011) highlighted the difficulty of working within a role where “working harder isn’t working” and the isolation this creates amongst professionals (Reynolds, 2009), which reflects the experiences in the current research.

The current study also highlighted the lack of praise and recognition the participants received after successfully discharging an individual to a community placement. However, having a good support structure allowed for participants to feel supported. Maslow’s hierarchy of needs (Maslow, 1970) highlights the importance of motivational factors to increase job satisfaction and performance. Within the workplace, the needs of employers must be met, including esteem needs such as feeling valuable and recognising achievements (Greenberg & Baron, 2003).

Finally, the results of the current study can be linked to Bronfenbrenner’s Ecological Systems Theory (1989) in the health-care setting (Dobbs et al., 2012). This theory highlights the complex interactions between different levels of the system, which need to be compatible for processes to happen smoothly (Bronfenbrenner 1979, 1986). The participant experiences in the current study demonstrate how difficulties in the wider macrosystem, such as staff burnout, lack of placements and difficulties with finance, alongside working within the exosystem of policy and procedure, has an impact on the interactions between a professional network (mesosystem). This can also affect the professional themselves, the care the individual receives and other people in the system (microsystem). However, it is important to recognise that Bronfenbrenner's Ecological System's theory (1989) was first introduced to understand child development and has since been applied to work-place settings, therefore it may not be fully applicable to a HaSC setting.

Clinical Implications

Participants in the current study spoke about providing support to other professionals and staff. This is in line with research which has found that staff within HaSC roles valued peer and professional supervision (Billings et al., 2021). It would be important for psychologists working within *Transforming Care* to provide supervision and consultation to the wider network. Research has suggested that community support workers benefit from the support of clinicians, if this is provided in a way that acknowledges the difficult role of a support worker and good relationships are built (Clifford et al., 2018; Bradshaw & Goldbart, 2013). Without looking after the well-being of the professionals working within *Transforming Care*, it is likely staff burnout will result in further delays, as there would not be a network coordinating the discharge. The role of clinical psychology could support professionals involved in the discharge process by ensuring key roles are defined and the network is aware of each other's responsibilities. Clinical psychologists could support with organising regular review meetings to ensure the discharge process progresses.

Low job satisfaction within the NHS has shown to be a key factor in staff leaving and low productivity (Bimpong et al., 2020; Jessen, 2010). Managerial appreciation was a factor identified to increase staff retention (Chamanga et al., 2020). Therefore, it is important staff members working under *Transforming Care* are recognised for their work.

Research Implications

The current study was from the perspective of community HaSC professionals, however many of the participants spoke about the challenging role of support workers. Future research to understand the experiences of community care staff when supporting an individual from hospital to their residential placement, would be beneficial. This would be relevant as breakdowns in placement can result in a revolving door phenomenon of the individual returning to hospital (Royal College of Nursing, 2016). It may also be helpful to gain the perspectives of family members who are also heavily involved in the discharge process and part of the individual's wider system.

This research focussed solely on the discharge process for adults with LD and/or autism, however *Transforming Care* extends to children and young people (NHS England, 2015). Further research into whether the current theory can be applied to discharges involving children and young people with LD and/or autism would be beneficial.

Limitations

The participants were all working within their professional role at the point of interview. Despite being reassured that their information would be anonymised, this still may have impacted on the ability to be open and honest in the interview, due to concerns about information being disclosed to their service.

Throughout the interviews, I was aware I was a colleague working for the NHS and had experienced the frustrations of working within a professional network and under the strains of policy and procedure. These experiences may have impacted on the coding and analysis of the data. However, the use of supervision, memoing and reflexive diary keeping, was used to be aware of these biases and prevent them impacting on the research process.

Although the participants involved both HaSC professionals, an equal balance of each sector was not established. Therefore, the overall model may speak more to the experiences of health professionals rather than social care professionals. Also, 80% of the participants were female. However, this reflects the staffing ratios within the NHS, with over three-quarters of the staff force being female (NHS England, 2018).

A key part of the system spoken about within the process model were the support staff in community placements. However, this voice was missing from the current research. The voice of individuals with LD was captured by Head et al., (2018), however, it may have been helpful to have gained service-user feedback in relation to the concept model that was developed from the HaSC perspective, to see if this resonated with the service-users.

Conclusion

The current project aimed to develop a theoretical model to understand what contributes to a successful discharge process from hospital to a community-based setting, for people with LD and/or autism, from the perspective of community HaSC professionals. The participants highlighted the need for the whole system to be well coordinated, and access to appropriate resources. The results highlighted the personal feelings the role evoked and the impact of barriers on the discharge process. This project has contributed to the limited research exploring the impact of the *Transforming Care* agenda and suggest helpful clinical and research implications for the future, which are in line with wider available research.

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SECTION C: APPENDICES

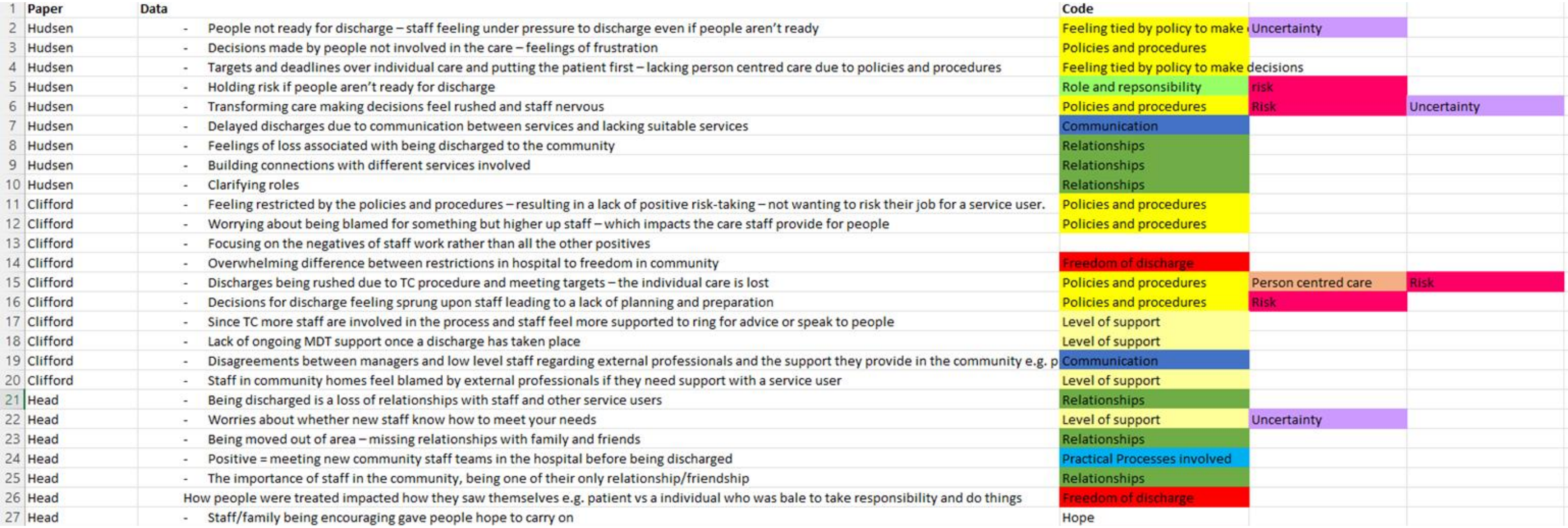
Appendix A: CASP Ratings

CASP questions	**Chester et al. (2017)**	**Clifford et al. (2018)**	**Head et al. (2018)**	**Hickman et al. (2018)**	**Hollomotz. (2021)**	**Hudson et al. (2021)**	**Taylor et al. (2017)**	**Williams et al. (2018)**	**Williamson & Meddings. (2018)**
Clear statement of the aims?	3	3	3	3	3	3	3	3	3
Qualitative method appropriate?	3	3	3	3	3	3	3	3	3
Research design appropriate?	2	2	2	1	3	3	1	3	2
Recruitment strategy appropriate?	2	1	2	2	2	3	2	3	3
Data collection appropriate?	3	3	3	1	3	3	2	3	3
Relationship between researcher and participants considered?	1	1	1	1	1	2	1	1	3
Ethical issues considered?	2	2	2	1	1	3	1	2	3
Rigorous data analysis?	3	3	3	1	2	2	1	3	2
Clear statement of findings?	2	3	2	3	3	2	3	3	3
Is the research valuable?	3	3	3	3	2	3	3	3	2
Total score	***24***	***24***	***24***	***19***	***23***	***27***	***20***	***27***	***27***

Appendix B: CACS Ratings

CACS questions	**Leaning & Adderley. (2016)**	**Read (2022)**	**Tearle et al., (2020)**	**Turner (2018)**
Study addresses a clearly focused question/issue?	2	3	3	3
Method design appropriate?	2	3	3	1
Setting and subjects representative?	3	2	2	2
Researcher’s perspective described?	1	3	2	1
Method for data collection clearly described?	1	1	3	2
Data analysis valid and reliable?	1	1	1	1
Analysis repeated another researcher?	1	1	1	1
Results credible and relevant?	2	1	2	2
Findings transferable?	2	2	2	2
Is the research valuable?	3	3	3	2
Total score	***18***	***20***	***22***	***17***

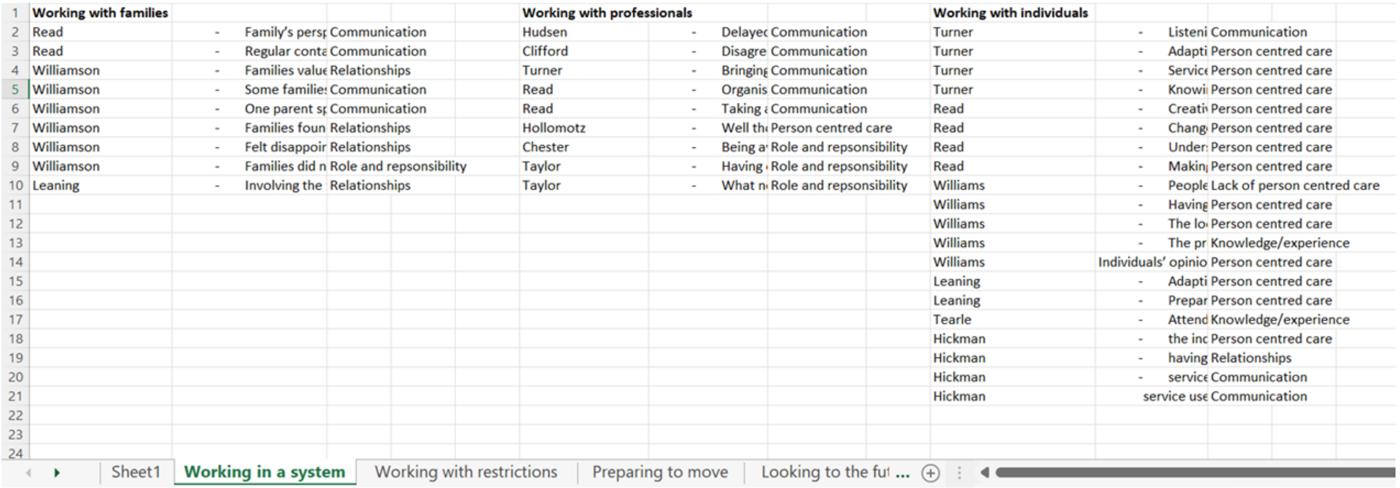
Appendix C: Examples of initial coding process



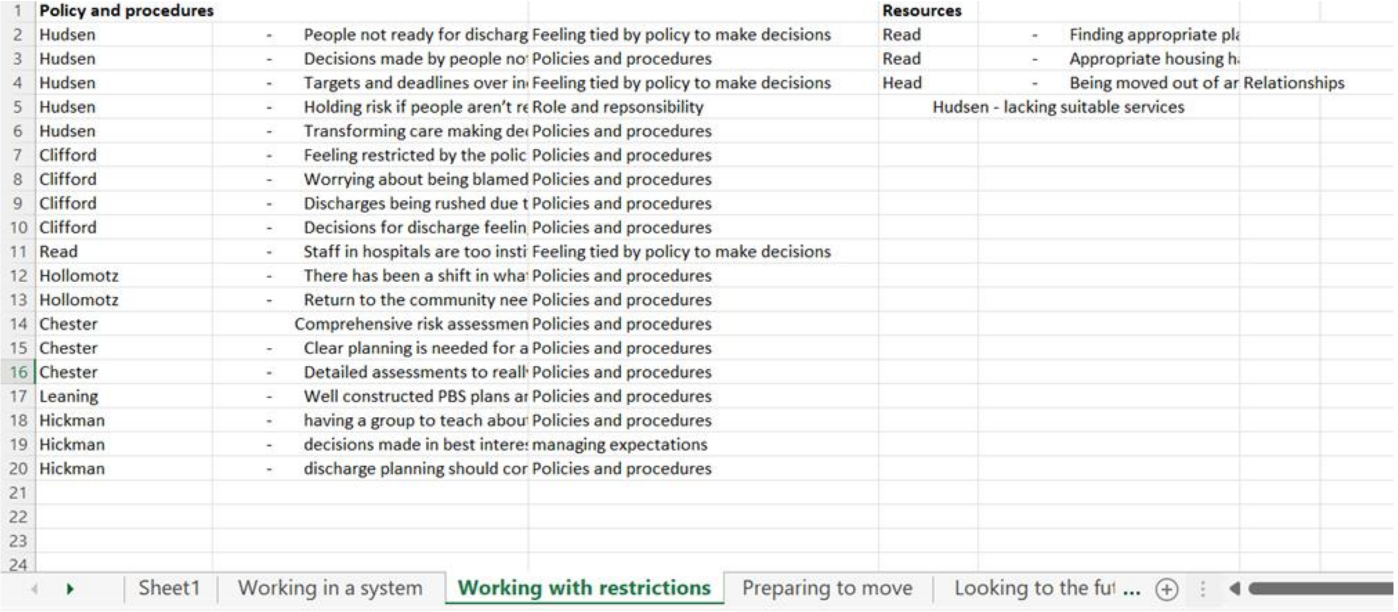
1	Paper	Data	Code		
2	Hudsen	- People not ready for discharge – staff feeling under pressure to discharge even if people aren't ready	Feeling tied by policy to make	Uncertainty	
3	Hudsen	- Decisions made by people not involved in the care – feelings of frustration	Policies and procedures		
4	Hudsen	- Targets and deadlines over individual care and putting the patient first – lacking person centred care due to policies and procedures	Feeling tied by policy to make decisions		
5	Hudsen	- Holding risk if people aren't ready for discharge	Role and repsonsibility	risk	
6	Hudsen	- Transforming care making decisions feel rushed and staff nervous	Policies and procedures	Risk	Uncertainty
7	Hudsen	- Delayed discharges due to communication between services and lacking suitable services	Communication		
8	Hudsen	- Feelings of loss associated with being discharged to the community	Relationships		
9	Hudsen	- Building connections with different services involved	Relationships		
10	Hudsen	- Clarifying roles	Relationships		
11	Clifford	- Feeling restricted by the policies and procedures – resulting in a lack of positive risk-taking – not wanting to risk their job for a service user.	Policies and procedures		
12	Clifford	- Worrying about being blamed for something but higher up staff – which impacts the care staff provide for people	Policies and procedures		
13	Clifford	- Focusing on the negatives of staff work rather than all the other positives			
14	Clifford	- Overwhelming difference between restrictions in hospital to freedom in community	Freedom of discharge		
15	Clifford	- Discharges being rushed due to TC procedure and meeting targets – the individual care is lost	Policies and procedures	Person centred care	Risk
16	Clifford	- Decisions for discharge feeling sprung upon staff leading to a lack of planning and preparation	Policies and procedures	Risk	
17	Clifford	- Since TC more staff are involved in the process and staff feel more supported to ring for advice or speak to people	Level of support		
18	Clifford	- Lack of ongoing MDT support once a discharge has taken place	Level of support		
19	Clifford	- Disagreements between managers and low level staff regarding external professionals and the support they provide in the community e.g. p	Communication		
20	Clifford	- Staff in community homes feel blamed by external professionals if they need support with a service user	Level of support		
21	Head	- Being discharged is a loss of relationships with staff and other service users	Relationships		
22	Head	- Worries about whether new staff know how to meet your needs	Level of support	Uncertainty	
23	Head	- Being moved out of area – missing relationships with family and friends	Relationships		
24	Head	- Positive = meeting new community staff teams in the hospital before being discharged	Practical Processes involved		
25	Head	- The importance of staff in the community, being one of their only relationship/friendship	Relationships		
26	Head	How people were treated impacted how they saw themselves e.g. patient vs a individual who was bale to take responsibility and do things	Freedom of discharge		
27	Head	- Staff/family being encouraging gave people hope to carry on	Hope		

28	Head	-	Restricted in hospital – not being able to do things for themselves which they could do– lack of freedom	Freedom of discharge	
29	Head	-	In hospital, challenging behaviour seen as 'being naughty' or 'being bad'. Having to 'be good' to be discharged from hospital – loss of identity	Identity	
30	Head	-	Able to be themselves once discharged from hospital	Identity	
31	Head	-	Fearful that bad behaviour would lead back to hospital	Ongoing restrictions	Uncertainty
32	Head	-	Narrative work in the community to change the narrative of the person from hospital to community	Identity	
33	Head	Staff need to have a greater understanding of a person's behaviour and how to respond to prevent the person internalising a negative narrative about th		Knowledge/experience	
34	Turner	-	Careful planning around an individual's needs	Person centred care	
35	Turner	-	The freedom and flexibility in the community compared to hospital	Freedom of discharge	quality of life
36	Turner	-	Listening to people to find the right support and accommodation	Communication	Person centred care
37	Turner	-	Bringing together multiple agencies	Communication	
38	Turner	-	Support people to be safe	Risk	
39	Turner	-	Professionals focus is on support in the community not hospital	Quality of life	
40	Turner	-	Adapting properties to fit the individual's needs	Person centred care	
41	Turner	-	Good relationships with support staff	Relationships	
42	Turner	-	Service user being involved in choosing staff members	Person centred care	
43	Turner	-	Knowing staff before the transition	Practical Processes involved	
44	Turner	-	Staff knowing the individual and their family well	Relationships	
45	Turner	-	Skilled staff workforce	Knowledge/experience	
46	Turner	-	Knowing the individual well and how to support changes in mental health – through PBS	Person centred care	Knowledge/experience
47	Turner	-	Regular review of care	Level of support	
48	Turner	-	Providing extra support to an individual when needed	Level of support	
49	Turner	-	Including all family and the network in appointments	Communication	Relationships
50	Turner	-	Staff supporting to new activities and opportunities e.g. work	Quality of life	
51	Turner	-	Right planning and support	Practical Processes involved	
52	Read	-	Living in the community is seen as unrealistic option by service users	Loss of identity	Uncertainty
53	Read	-	Having to shift identity of a service user to develop confidence to think about living in the community is possible	Loss of identity	Uncertainty
54	Read	In hospital there is the narrative that individuals are 'too complex' to live in the community		Ongoing restrictions	

Appendix D: Over-arching themes and sub-themes



	Working with families				Working with professionals				Working with individuals			
2	Read	-	Family’s persp	Communication	Hudsen	-	Delayec	Communication	Turner	-	Listeni	Communication
3	Read	-	Regular conta	Communication	Clifford	-	Disagre	Communication	Turner	-	Adapti	Person centred care
4	Williamson	-	Families value	Relationships	Turner	-	Bringing	Communication	Turner	-	Service	Person centred care
5	Williamson	-	Some families	Communication	Read	-	Organis	Communication	Turner	-	Knowi	Person centred care
6	Williamson	-	One parent sp	Communication	Read	-	Taking a	Communication	Read	-	Creati	Person centred care
7	Williamson	-	Families foun	Relationships	Hollomotz	-	Well th	Person centred care	Read	-	Chang	Person centred care
8	Williamson	-	Felt disappoir	Relationships	Chester	-	Being a	Role and repsonsibility	Read	-	Under	Person centred care
9	Williamson	-	Families did n	Role and repsonsibility	Taylor	-	Having	Role and repsonsibility	Read	-	Makin	Person centred care
10	Leaning	-	Involving the	Relationships	Taylor	-	What n	Role and repsonsibility	Williams	-	People	Lack of person centred care
11									Williams	-	Having	Person centred care
12									Williams	-	The lo	Person centred care
13									Williams	-	The pr	Knowledge/experience
14									Williams	Individuals’	opinio	Person centred care
15									Leaning	-	Adapti	Person centred care
16									Leaning	-	Prepar	Person centred care
17									Tearle	-	Attend	Knowledge/experience
18									Hickman	-	the inc	Person centred care
19									Hickman	-	having	Relationships
20									Hickman	-	service	Communication
21									Hickman		service use	Communication
22												
23												
24												



	Policy and procedures				Resources			
2	Hudsen	-	People not ready for discharg	Feeling tied by policy to make decisions	Read	-	Finding appropriate pla	
3	Hudsen	-	Decisions made by people no	Policies and procedures	Read	-	Appropriate housing ha	
4	Hudsen	-	Targets and deadlines over in	Feeling tied by policy to make decisions	Head	-	Being moved out of ar	Relationships
5	Hudsen	-	Holding risk if people aren’t re	Role and repsonsibility		Hudsen - lacking suitable services		
6	Hudsen	-	Transforming care making de	Policies and procedures				
7	Clifford	-	Feeling restricted by the polic	Policies and procedures				
8	Clifford	-	Worrying about being blamed	Policies and procedures				
9	Clifford	-	Discharges being rushed due t	Policies and procedures				
10	Clifford	-	Decisions for discharge feelin	Policies and procedures				
11	Read	-	Staff in hospitals are too insti	Feeling tied by policy to make decisions				
12	Hollomotz	-	There has been a shift in wha	Policies and procedures				
13	Hollomotz	-	Return to the community nee	Policies and procedures				
14	Chester		Comprehensive risk assessmen	Policies and procedures				
15	Chester	-	Clear planning is needed for a	Policies and procedures				
16	Chester	-	Detailed assessments to reall	Policies and procedures				
17	Leaning	-	Well constructed PBS plans ar	Policies and procedures				
18	Hickman	-	having a group to teach abou	Policies and procedures				
19	Hickman	-	decisions made in best intere	managing expectations				
20	Hickman	-	discharge planning should cor	Policies and procedures				
21								
22								
23								
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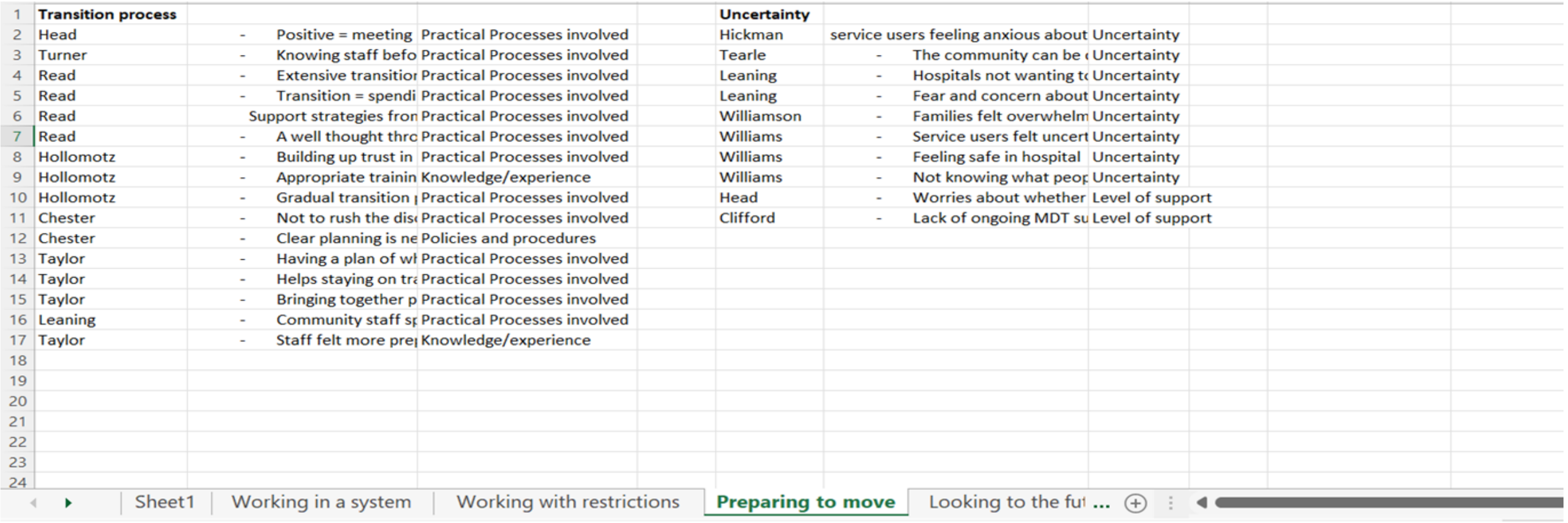
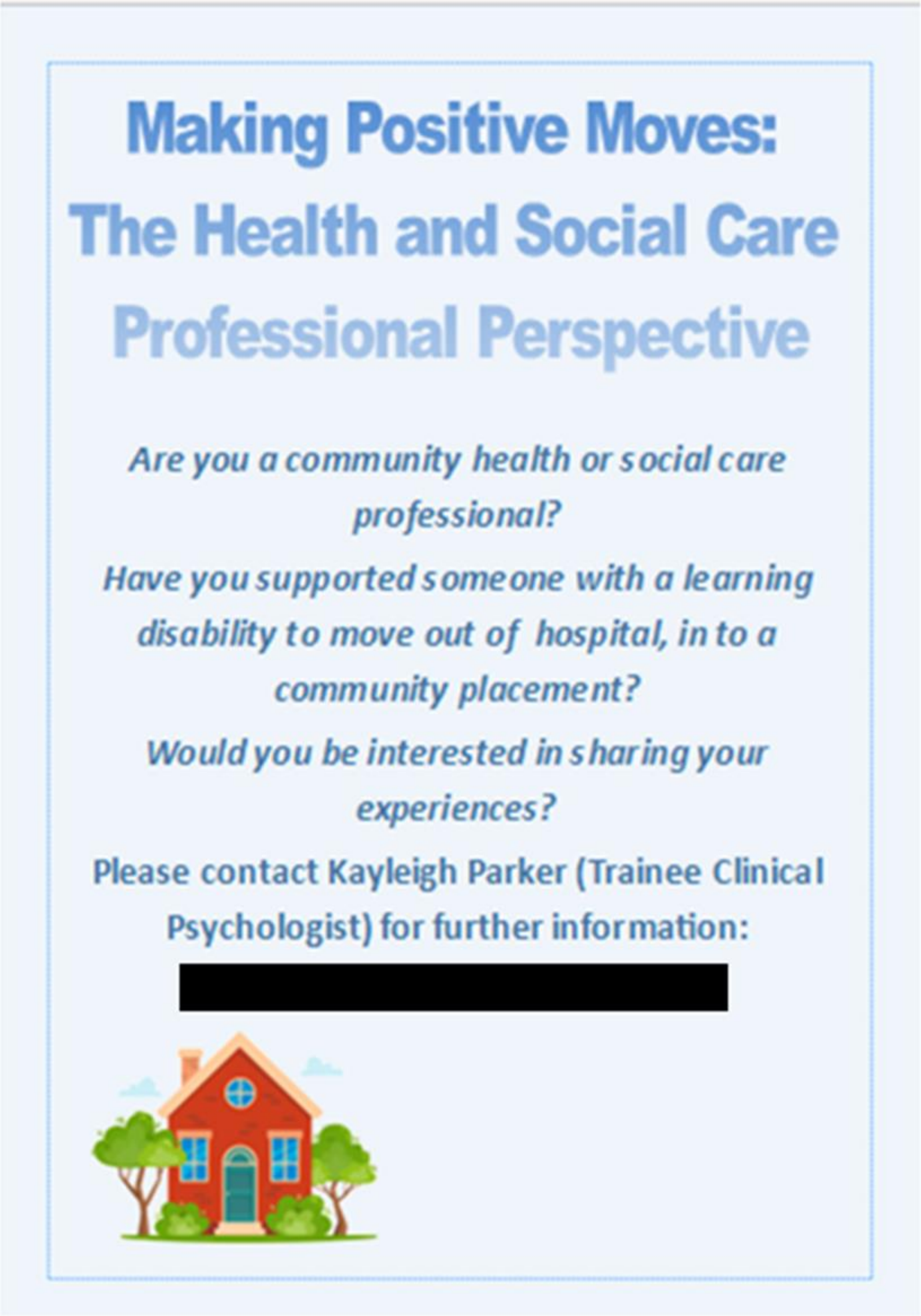


1	**Transition process**			**Uncertainty**		
2	Head	- Positive = meeting	Practical Processes involved	Hickman	service users feeling anxious about	Uncertainty
3	Turner	- Knowing staff befo	Practical Processes involved	Tearle	- The community can be (	Uncertainty
4	Read	- Extensive transitior	Practical Processes involved	Leaning	- Hospitals not wanting t(	Uncertainty
5	Read	- Transition = spendi	Practical Processes involved	Leaning	- Fear and concern about	Uncertainty
6	Read	Support strategies fron	Practical Processes involved	Williamson	- Families felt overwhelm	Uncertainty
7	Read	- A well thought thro	Practical Processes involved	Williams	- Service users felt uncert	Uncertainty
8	Hollomotz	- Building up trust in	Practical Processes involved	Williams	- Feeling safe in hospital	Uncertainty
9	Hollomotz	- Appropriate trainin	Knowledge/experience	Williams	- Not knowing what peop	Uncertainty
10	Hollomotz	- Gradual transition	Practical Processes involved	Head	- Worries about whether	Level of support
11	Chester	- Not to rush the dis(	Practical Processes involved	Clifford	- Lack of ongoing MDT su	Level of support
12	Chester	- Clear planning is ne	Policies and procedures			
13	Taylor	- Having a plan of wl	Practical Processes involved			
14	Taylor	- Helps staying on tra	Practical Processes involved			
15	Taylor	- Bringing together p	Practical Processes involved			
16	Leaning	- Community staff sp	Practical Processes involved			
17	Taylor	- Staff felt more pre|	Knowledge/experience			
18						
19						
20						
21						
22						
23						
24						

1	**Freedom**			**Identity**		
2	Clifford	- Overwhelming	Freedom of discharge	Head	- In hospital, challengin	Identity
3				Head	- Able to be themselve	Identity
4	Head	- Restricted in h	Freedom of discharge	Head	- Narrative work in the	Identity
5	Turner	- The freedom a	Freedom of discharge	Read	- Living in the commun	Loss of identity
6	Turner	- Staff supportir	Quality of life	Read	- Having to shift identit	Loss of identity
7	Read	- Making the en	Quality of life	Hollomotz	- Being in the communi	Quality of life
8	Hollomotz	- People value n	Quality of life	Williams	- Loss of identity when	Identity
9	Hollomotz	- Providing a spa	Quality of life	Williams	- Sense of belonging –	Identity
10	Williams	- Service users l(	Freedom of discharge	Williams	- Service users wanted	Identity
11	Williams	- Longing for ow	Quality of life	Head	How people were treated	Freedom of discharge
12	Williams	- What 'home' n	Quality of life			
13	Williams	- Su's wanted tc	Freedom of discharge			
14	Williams	- SU's felt capak	Freedom of discharge			
15	Williams	- Wanting to do	Freedom of discharge			
16	Williams	- SU's wanted tl	Quality of life			
17	Head	- Fearful that ba	Ongoing restrictions			
18	Hollomotz	not allowing activiti	Ongoing restrictions			
19	Hollomotz	Having to mana	Ongoing restrictions			
20	Chester	- Risk of negativ	Identity			
21	Chester	- Putting proces	Ongoing restrictions			
22						
23						
24						

Appendix E: Recruitment Advert



Making Positive Moves: The Health and Social Care Professional Perspective

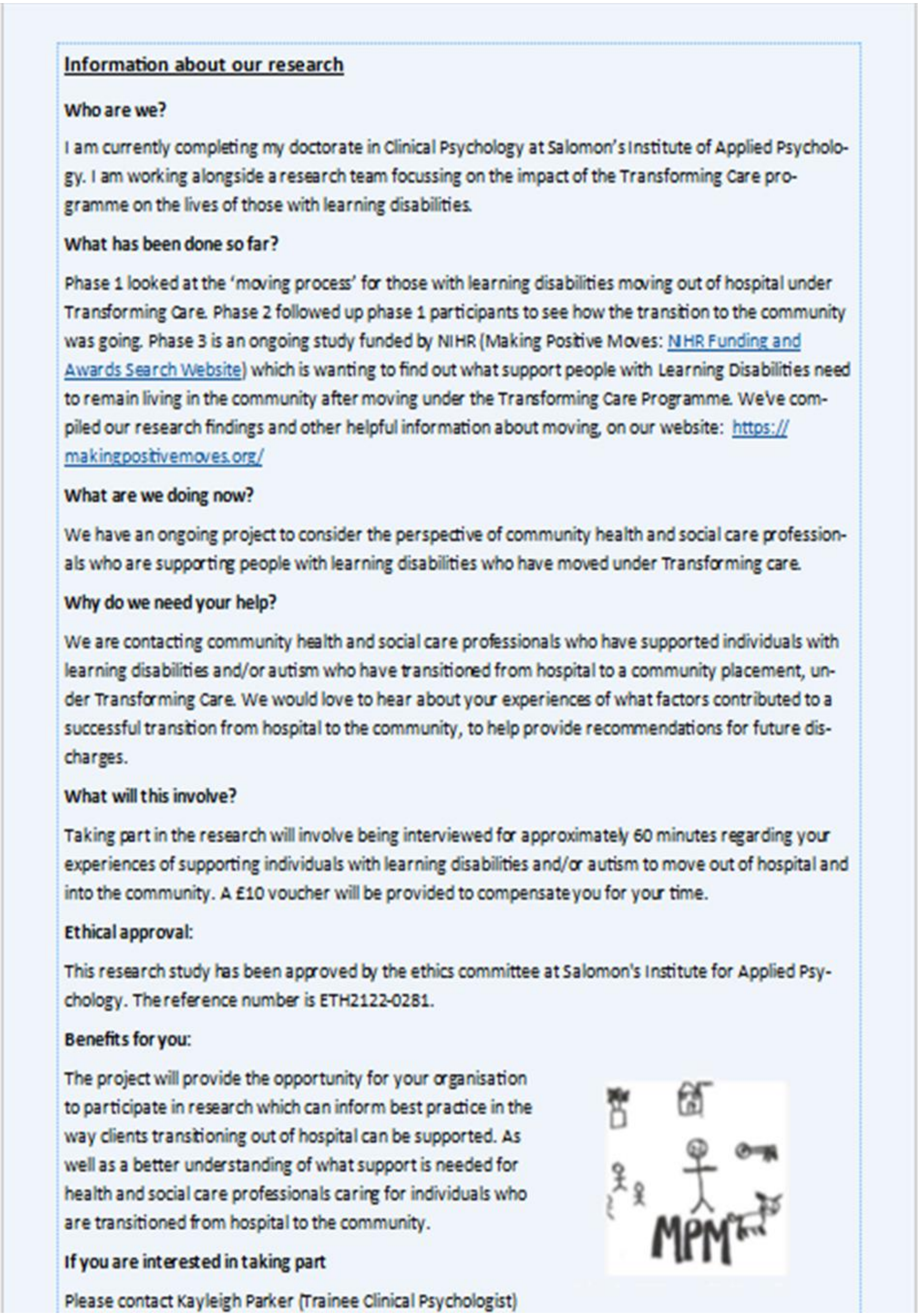
Are you a community health or social care professional?

Have you supported someone with a learning disability to move out of hospital, in to a community placement?

Would you be interested in sharing your experiences?

Please contact Kayleigh Parker (Trainee Clinical Psychologist) for further information:

[redacted]



Information about our research

Who are we?

I am currently completing my doctorate in Clinical Psychology at Salomon's Institute of Applied Psychology. I am working alongside a research team focussing on the impact of the Transforming Care programme on the lives of those with learning disabilities.

What has been done so far?

Phase 1 looked at the 'moving process' for those with learning disabilities moving out of hospital under Transforming Care. Phase 2 followed up phase 1 participants to see how the transition to the community was going. Phase 3 is an ongoing study funded by NIHR (Making Positive Moves: NIHR Funding and Awards Search Website) which is wanting to find out what support people with Learning Disabilities need to remain living in the community after moving under the Transforming Care Programme. We've compiled our research findings and other helpful information about moving, on our website: https://makingpositivemoves.org/

What are we doing now?

We have an ongoing project to consider the perspective of community health and social care professionals who are supporting people with learning disabilities who have moved under Transforming care.

Why do we need your help?

We are contacting community health and social care professionals who have supported individuals with learning disabilities and/or autism who have transitioned from hospital to a community placement, under Transforming Care. We would love to hear about your experiences of what factors contributed to a successful transition from hospital to the community, to help provide recommendations for future discharges.

What will this involve?

Taking part in the research will involve being interviewed for approximately 60 minutes regarding your experiences of supporting individuals with learning disabilities and/or autism to move out of hospital and into the community. A £10 voucher will be provided to compensate you for your time.

Ethical approval:

This research study has been approved by the ethics committee at Salomon's Institute for Applied Psychology. The reference number is ETH2122-0281.

Benefits for you:

The project will provide the opportunity for your organisation to participate in research which can inform best practice in the way clients transitioning out of hospital can be supported. As well as a better understanding of what support is needed for health and social care professionals caring for individuals who are transitioned from hospital to the community.

If you are interested in taking part

Please contact Kayleigh Parker (Trainee Clinical Psychologist)

Appendix F: Interview Schedules

Topic Guide

Confirm happy with the information sheet and consent form. Happy to record and then get verbal consent on recording. Remember to choose transcription option.

Firstly, demographic information will be collected from the participants. This will include:

Demographic information:
- Age: age brackets as prompts - 18-25, 26-35, 36-45, 45 and over?
- Ethnicity:
- Gender:

Other information:
- Role:
- Length of time in the role:
- Number of people supported to move out of hospital:
- Length of involvement (include dates):
- Geographical area in which they supported moves out of hospital (not trust name):

Broad topics are outlined below, with some example questions and prompts provided. Other questions or prompts may be used as the grounded theory analysis develops or according to participant responses.

Topic areas:

Preparation for the move:
When did you first get involved with the care of an individual who was identified as moving out of hospital?
Was that when they were in hospital?
What did you do whilst they were in hospital?
What was the experience of preparing for the move like for you, as a professional?
Prompt: what did you think about the individual coming to service
What supported and what barriers were there to this process?

During the move
What was your role during the move?
Prompt: what did that involve?
Take us through the steps of the move
How did you liaise with the team around the individual?
What was the experience during the move like for you, as a professional?
What supported and what barriers were there to this process?

After the move
What was your role after the move?
Is your role ongoing? *Prompt: How long were you involved?*
What was the experience after the move like for you, as a professional?
What supported and what barriers were there to this process?

The challenges of supporting someone under transforming care and what has been helpful:
What support did you get?
What challenges were there supporting someone who moved via Transforming Care?
What was the impact of this?
What helped?
What support did you want?
What support did you get?
Prompt: training, support from managers?

Final comments:
Thank you for taking the time to participate.

Have you got any other comments about anything you feel would be important to ask but I haven't asked?

Explain their email address will be passed on to the university and their voucher will be sent to their email address if they are happy for this?

Debrief: have you got any questions about the research or what you have been asked today?

Topic Guide - refocus for social workers

Confirm happy with the information sheet and consent form. Happy to record and then get verbal consent on recording. Remember to choose transcription option.

Firstly, demographic information will be collected from the participants. This will include:

Demographic information:
- Age: 18-25, 26-35, 36-45, 45 and over?
- Ethnicity:
- Gender:

Other information:

- Role:
- Length of time in the role:
- Number of people supported to move out of hospital:
- Length of involvement (include dates):
- Geographical area in which they supported moves out of hospital (not trust name):

Broad topics are outlined below, with some example questions and prompts provided. Other questions or prompts may be used as the grounded theory analysis develops or according to participant responses.

Topic areas:

Preparation for the move:
When did you first get involved with the care of an individual who was identified as moving out of hospital?
Was that when they were in hospital?
What did you do whilst they were in hospital?
What was the experience of preparing for the move like for you, as a professional?
It is a difficult process finding a suitable placement for someone, how do you find this process?
Do you ever feel pressurised to find a suitable placement? E.g. from the network, family members, the individual? How do you navigate this?
Prompt: what did you think about the individual coming to service
What supported and what barriers were there to this process?

During the move
What was your role during the move?
Prompt: what did that involve?
Take us through the steps of the move
How did you liaise with the team around the individual?
What was the experience during the move like for you, as a professional?
What supported and what barriers were there to this process?

After the move
What was your role after the move?
Is your role ongoing? *Prompt: How long were you involved?*
What was the experience after the move like for you, as a professional?
What supported and what barriers were there to this process?

The challenges of supporting someone under transforming care and what has been helpful:
What support did you get?
What challenges were there supporting someone who moved via Transforming Care?
What was the impact of this?
What helped?
What support did you want?
What support did you get?
Prompt: training, support from managers?

BRING IN MORE ABOUT PERSONAL EXPERIENCES THROUGHOUT THE INTERVIEW – GAIN MORE OF AN UNDERSTANDING OF WHAT THEY WERE PERSONALLY EXPERIENCING AT EACH STAGE.

Final comments:
Thank you for taking the time to participate.

Have you got any other comments about anything you feel would be important to ask but I haven’t asked?

Explain their email address will be passed on to the university and their voucher will be sent to their email address if they are happy for this?

Check if they have any questions - debrief

Appendix G: Excerpts of memos throughout the open coding and theoretical coding stages.

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Appendix H: Reflexive diary across the process

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Appendix I: Example of open coding transcript:

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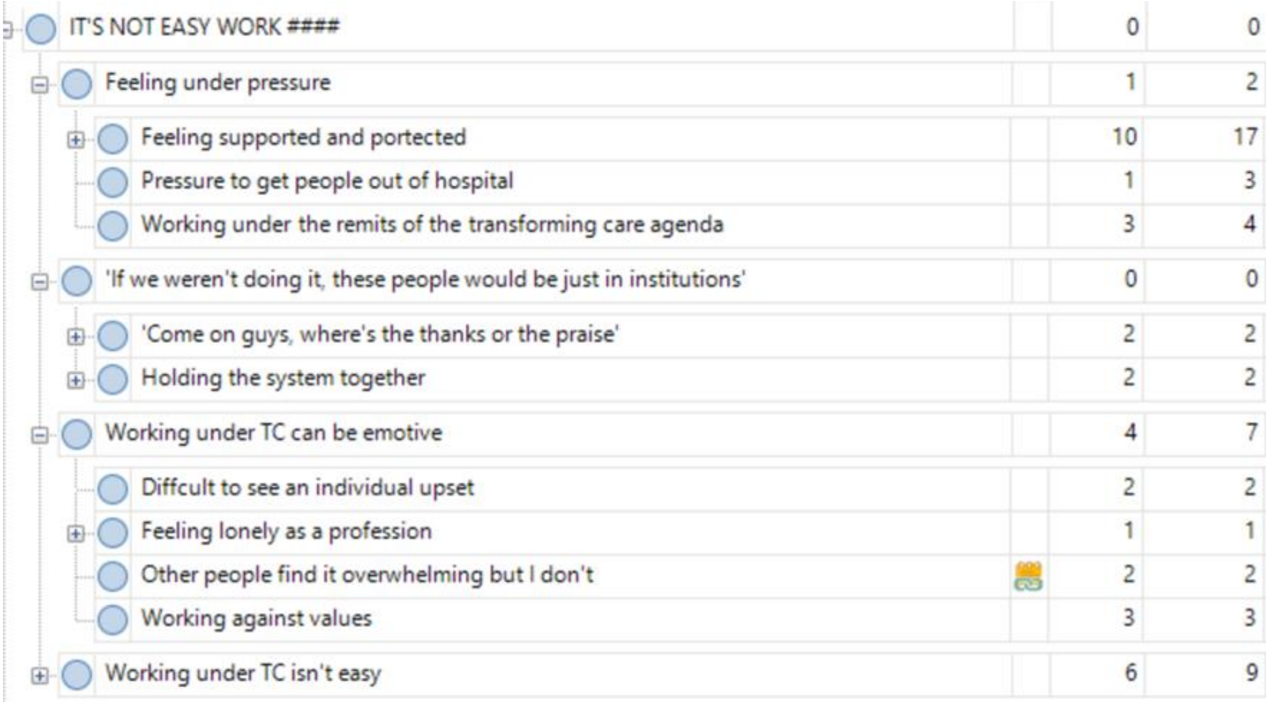
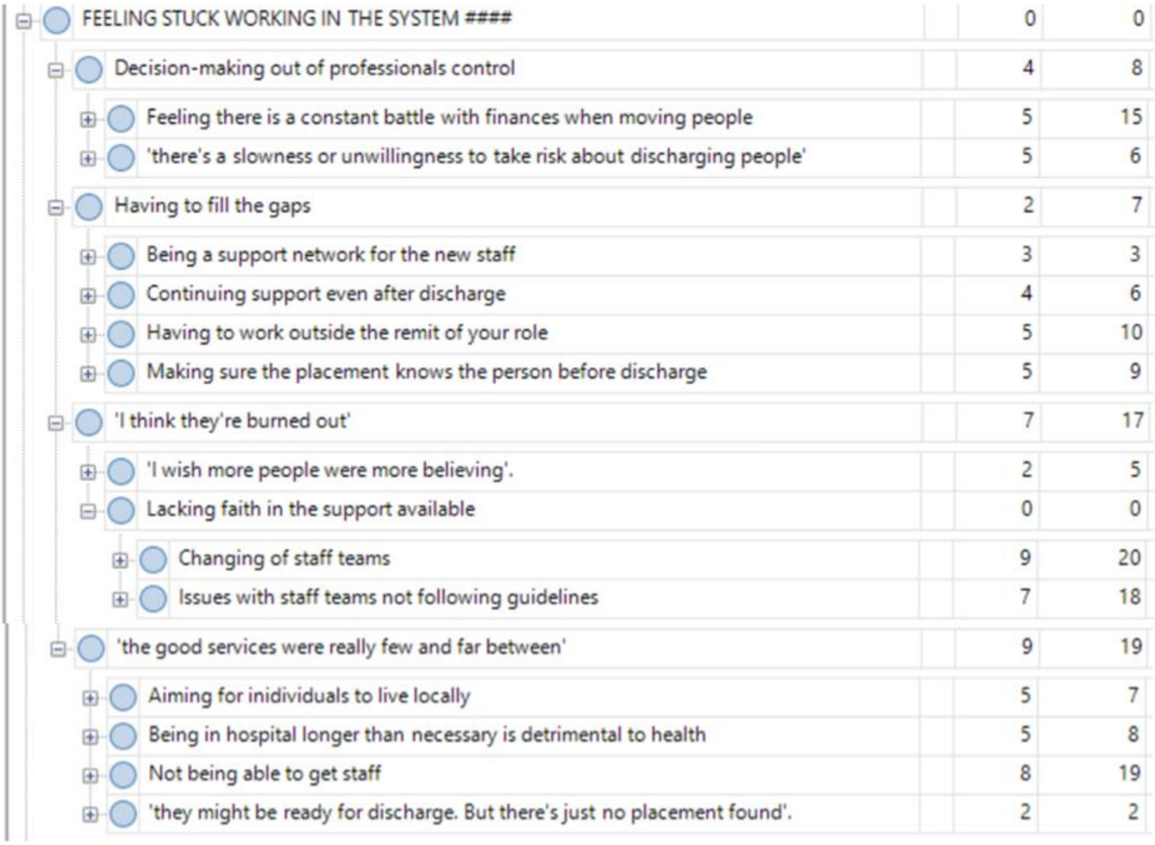
Appendix J: Nvivo coding example

Concept – “It’s not easy work”



IT'S NOT EASY WORK ####	0	0
Feeling under pressure	1	2
Feeling supported and portected	10	17
Pressure to get people out of hospital	1	3
Working under the remits of the transforming care agenda	3	4
'If we weren't doing it, these people would be just in institutions'	0	0
'Come on guys, where's the thanks or the praise'	2	2
Holding the system together	2	2
Working under TC can be emotive	4	7
Diffcult to see an individual upset	2	2
Feeling lonely as a profession	1	1
Other people find it overwhelming but I don't	2	2
Working against values	3	3
Working under TC isn't easy	6	9

Concept – “Feeling stuck working within the system”



FEELING STUCK WORKING IN THE SYSTEM ####	0	0
Decision-making out of professionals control	4	8
Feeling there is a constant battle with finances when moving people	5	15
'there's a slowness or unwillingness to take risk about discharging people'	5	6
Having to fill the gaps	2	7
Being a support network for the new staff	3	3
Continuing support even after discharge	4	6
Having to work outside the remit of your role	5	10
Making sure the placement knows the person before discharge	5	9
'I think they're burned out'	7	17
'I wish more people were more believing'.	2	5
Lacking faith in the support available	0	0
Changing of staff teams	9	20
Issues with staff teams not following guidelines	7	18
'the good services were really few and far between'	9	19
Aiming for inidividuals to live locally	5	7
Being in hospital longer than necessary is detrimental to health	5	8
Not being able to get staff	8	19
'they might be ready for discharge. But there's just no placement found'.	2	2

Appendix K: Big tent criteria.

Criteria	**How this criteria has been achieved through the research**
Worthy topic	The topic of the research is: *Relevant* – the marked phenomena of the 'revolving door' has a large impact on the lives of individuals with learning disabilities and/or autism. *Timely* – there continues to be a strain on care settings. *Significant* – there is limited research into the views of health and social care professionals on their experience of working under transforming care. *Interesting* – The *Transforming Care* agenda has an important impact on lives of people with learning disabilities and/or autism. It is an interesting perspective looking at the experiences of health and social care professionals who are responsible for coordinating discharges and making significant decisions for these individuals.
Rich rigor	This research uses a sufficient, abundant, appropriate and complex: - Theoretical constructs - Sample from a range of health and social care professionals - Research sites – data has been collected from different UK locations - Data analysis processes Further details can be found in the method section of the research report.
Sincerity	Self-reflexivity has been documented throughout the research project to be aware of subjective values, biases and inclinations about the research. An exert of this can be found in appendix H. Transparency about the research methods and challenges has been documented throughout this write-up.
Credibility	The credibility of this research has been demonstrated by: - Richness - providing direct quotes from participants and using in-depth descriptions. - Triangulation – the choice of methodology has been explained in the method section and other methodologies considered. - Member reflections- once the theory had been developed, one further interview was arranged to discuss the model and whether the participant agreed with this. Also, it has been arranged for the results to be disseminated to a stakeholder conference.

Resonance	This research influences readers through: - Personal experiences, by providing direct quotes from participant interviews. - This model can be applied to future discharges under *Transforming Care*. - Feeding back to expert by experience groups and stakeholder events.
Significant contribution	This research provides a significant contribution to understanding the processes of working under *Transforming Care* and helps to address the gap of research into community health and social care professionals perspectives.
Ethics	Ethical consideration has been carefully considered throughout the project. This has been clearly outlined in the method section and confirmation of ethical approval has been provided in the appendices.
Meaningful coherence	The study: - Achieves what it intended by answering the aims set out in the introduction. - Uses methods and procedures that are in line with the stated goals for the project. - Meaningfully uses literature to understanding findings and draw interpretations.

Appendix L: Ethical approval confirmation

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Appendix M: information sheet

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

Information about the research

Making Positive Moves: The Health and Social Care Professional Perspective

Understanding the views of community health and social care professionals regarding what contributes to a successful transition from hospital to the community, for people with learning disabilities and/or autism.

Hello. My name is Kayleigh Parker and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.
(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?

There is little research into understanding the views and experiences of community health and social care professionals when supporting an individual with learning disabilities, who has moved from hospital to a home within the community, via Transforming Care. By gaining feedback from health and social care professionals this will help to understand what factors lead to a successful transition from hospital to the community for people with learning disabilities and/or autism. This will provide useful information for future discharges and an insight into health and social care professionals roles and responsibilities.

Why have I been invited?

You have been invited to take part in this investigation as you were identified as a health or social care professional who has provided support to an individual with learning disabilities and/or autism who has moved into the community, from hospital from 2012 onwards. It is hoped approximately 10-15 people will be interviewed as part of this investigation.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part in the study, this will involve completing an interview lasting approximately 60 minutes and a possible follow-up interview if required. The questions will be focused on your own personal views of working within a service provision that has supported an individual with learning disabilities and/or autism who moved into the community from hospital. The interview will be audio recorded and transcribed as part of the data analysis, however no identifiable will be used.

Expenses and payments
As a thank you for taking part in the interview, you will be offered a £10 voucher.

What will I be asked to do?
As part of the interview, you will be asked a number of questions regarding your own personal views and experiences of working within a service provision that supported an individual with learning disabilities and/or autism who transitioned to the community from hospital, within approximately the last year.

What are the possible disadvantages and risks of taking part?
The questions will involve asking about your personal experiences of supporting an individual with learning disabilities and/or autism, therefore this could be emotive.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study will help to inform what support is needed for health and social care professionals who are involved in supporting people with learning disabilities and/or autism who have been discharged from hospital.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don’t want to carry on with the study?
You are free to withdraw at any point of the research without a reason. However, if you wish to withdraw your data from the study you will have two weeks from your interview to contact the researcher and request your data is removed. Should you decide to withdraw at a later stage once data analysis has commenced it may not be possible for data to be extracted or destroyed as this would already have been used for data analysis purposes. If you chose to withdraw from the study, we would like to use the data collected up to the point of withdrawal.

Concerns and Complaints
If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by email [removed for confidentiality]. Please leave a contact number and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons

Institute for Applied Psychology [removed for confidentiality].

Will information from or about me from taking part in the study be kept confidential?
All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised. Data will be collected in the form of an interview which will be audio recorded using a Dictaphone or online recording platform and then transcribed as part of the data analysis procedure. This data will be stored securely on an encrypted USB or secure OneDrive and accessed only on a password protected computer. Once the audio file has been transferred to the encrypted USB or secure OneDrive, this will be deleted off the Dictaphone device or online recording platform. When the audio recording is transcribed, all identifiable information will be altered in order to keep anonymity. Direct quotes may be used as part of the report but any identifiable information will be changed. Only authorised persons such as myself and my supervisors [Dr Annabel Head, Dr Louisa Rhodes, Dr Helen Ellis-Caird and Dr Simon Powell] will have access to your data which may include identifiable information. Should an external transcriber be used to transcribe the interview, they will be required to sign a confidentiality agreement before any data is sent. All information will be sent to the transcriber using a secure method. The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else, this will be reviewed in line with the adult safeguarding policy.
Once the information has been used as part of the study, this shall be retained for up to 10 years in the Institute's office in a locked cupboard. We ask for consent for your anonymised data to be used in further research studies. For example, research studies conducted by members of the same research team in the same area.

What will happen to the results of the research study?
It is hoped that the results from the research study will be published. A copy of the publication will be sent to all participants involved once this is available. The report or publication may include direct quotes from your interview, but no identifiable information will be used and any quotes will be anonymised to maintain confidentiality.

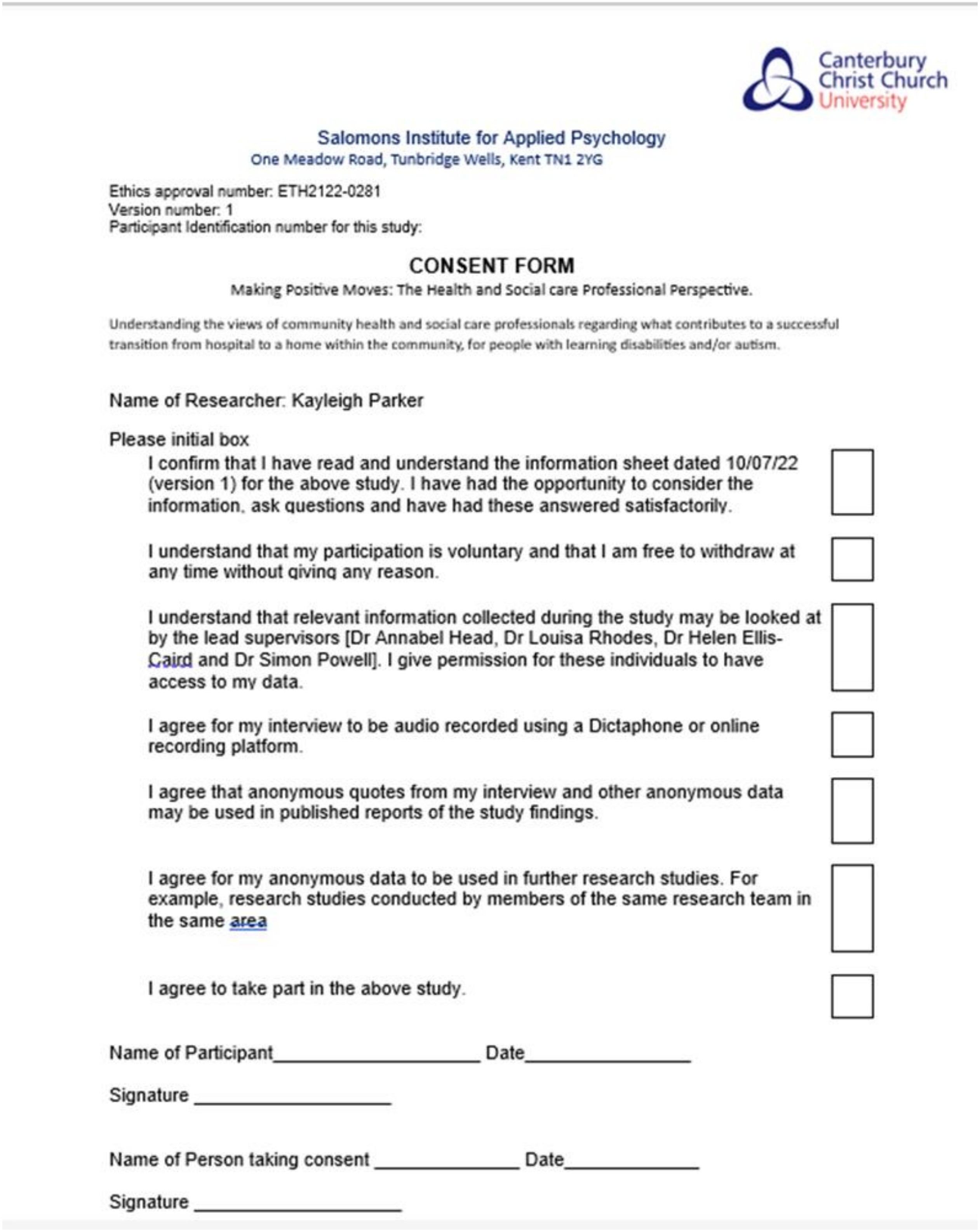
Who is sponsoring and funding the research?
The research is sponsored and funded by Canterbury Christ Church University.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University. For further information please visit the university's research privacy notice
https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx

If you would like to speak to me and find out more about the study or have questions about it answered, you can email [removed for confidentiality]. Please provide a contact number so that I can get back to you.

You will be given a copy of your signed information sheet for your records.

Appendix N: Consent form



Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: ETH2122-0281
Version number: 1
Participant Identification number for this study:

CONSENT FORM

Making Positive Moves: The Health and Social care Professional Perspective.

Understanding the views of community health and social care professionals regarding what contributes to a successful transition from hospital to a home within the community, for people with learning disabilities and/or autism.

Name of Researcher: Kayleigh Parker

Please initial box

- I confirm that I have read and understand the information sheet dated 10/07/22 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
- I understand that relevant information collected during the study may be looked at by the lead supervisors [Dr Annabel Head, Dr Louisa Rhodes, Dr Helen Ellis-Caird and Dr Simon Powell]. I give permission for these individuals to have access to my data. ☐
- I agree for my interview to be audio recorded using a Dictaphone or online recording platform. ☐
- I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings. ☐
- I agree for my anonymous data to be used in further research studies. For example, research studies conducted by members of the same research team in the same area ☐
- I agree to take part in the above study. ☐

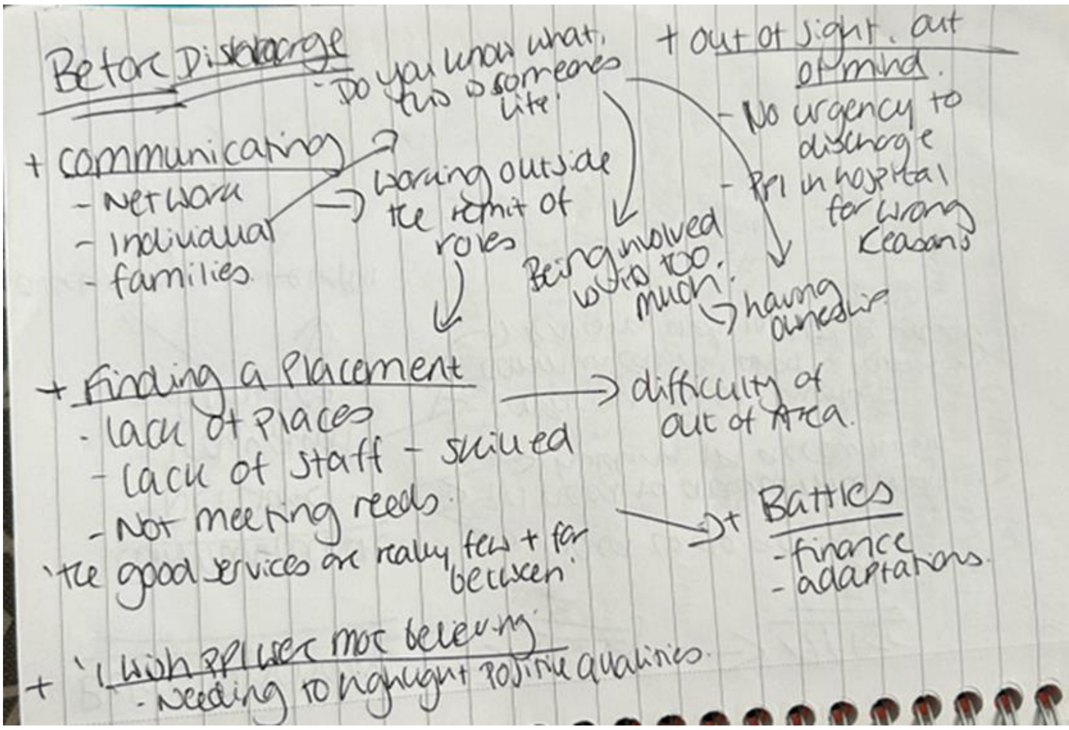
Name of Participant____________________ Date________________

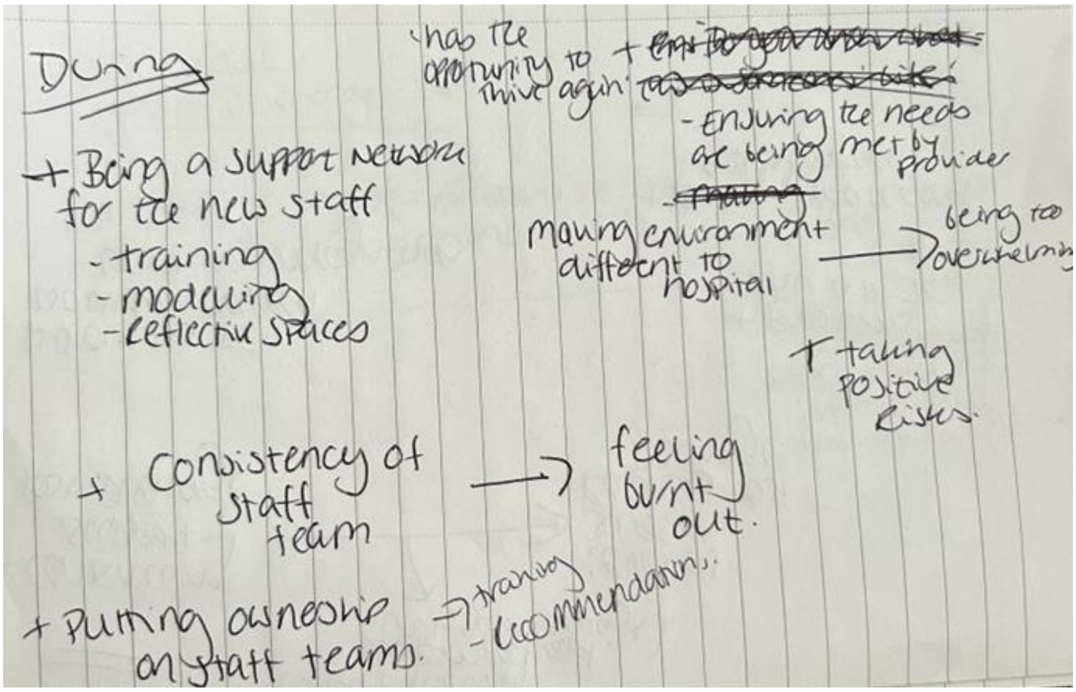
Signature ___________________

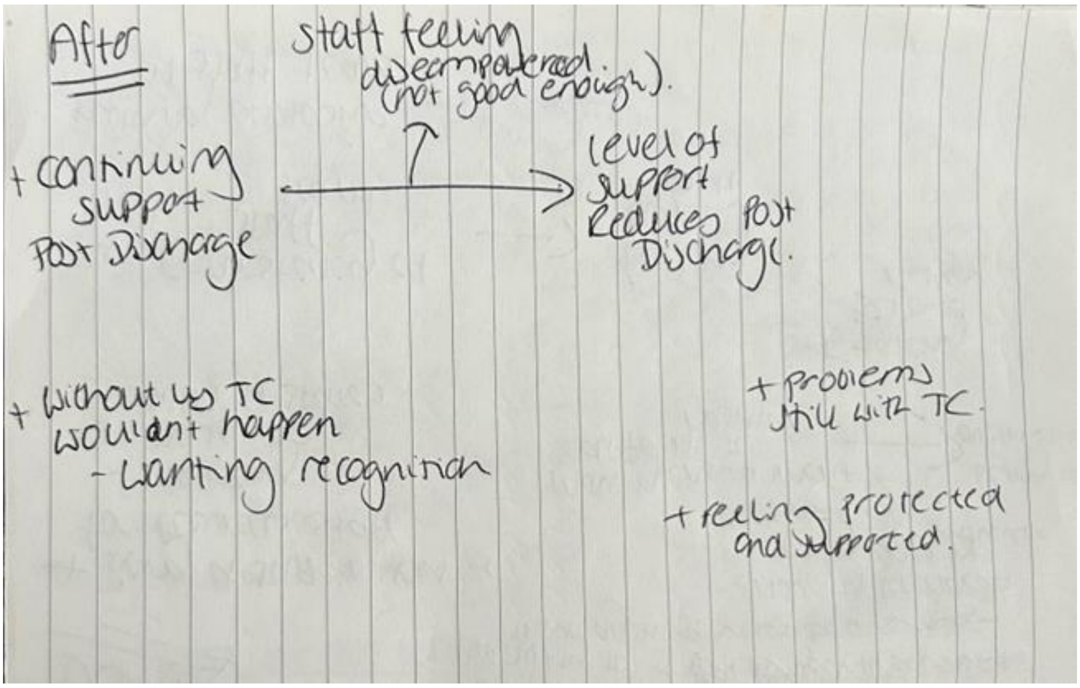
Name of Person taking consent ______________ Date_____________

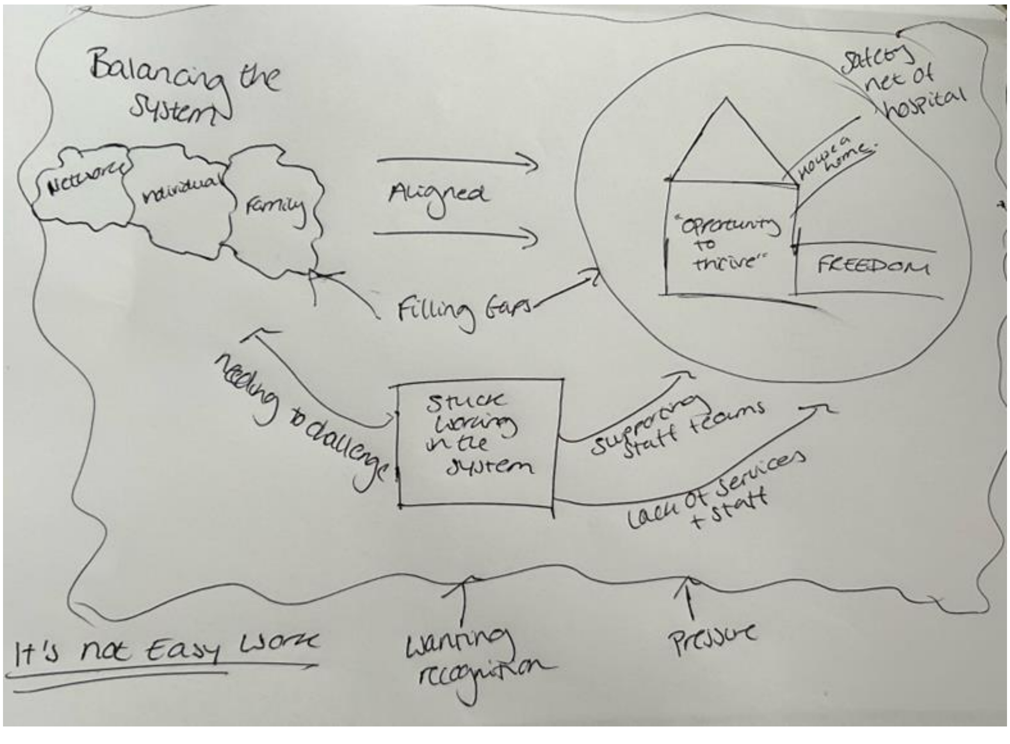
Signature ____________________

Appendix O: Examples of initial drawings of theory development






After
Staff feeling disempowered (not good enough).
+ continuing support post discharge
level of support reduces post discharge.
+ without us TC wouldn't happen
- wanting recognition
+ problems still with TC.
+ feeling protected and supported.


Balancing the system
Network
Individual
Family
Aligned
Filling Gaps
Safety net of hospital
house a home.
"Opportunity to thrive"
FREEDOM
Needing to challenge
Stuck working in the system
Supporting staff teams
Lack of services + staff
It's not Easy Work
Wanting recognition
Pressure

Appendix P: Further quotes for each concept

Balancing different levels of the system

Holding in mind the individual's voice and experience

Hearing the individual's voice:

"We'd kind of give the person accessible information tailored to their needs so they know the process" (Jane).

"Really, really put in the effort into knowing the person" (Charlotte).

"What, what did they want?" (Samuel).

Understanding the process is overwhelming:

"Some patients I work with wouldn't be able to handle the anxiety of maybe helping an interview" (Isabelle).

"I think only one of them was able to kind of tolerate coming into a CTR meeting or into a network meeting" (Carol).

"But some of these people, those choices are too big to make for them and it would actually cause them more harm than good" (Michelle).

"Getting families on board makes a big difference."

Reassuring and keeping families updated:

"But I have to say like having a regular ward round where families involved is really, really important" (Sarah).

"What I think works for me, is I communicate with the families" (Katie).

"They'd (family) always be seen as team members as well in terms of getting the right place for someone" (Amelia).

"If you've got the trust of the family, then it's so much easier" (Michelle).

Family can advocate for the individual:

"But where there is no capacity to make that decision, we usually liaise with family, so family are usually maybe more involved" (Sarah).

"The family have unrealistic expectations":

"The family sometimes, they intentionally or not intentionally, are not being that supportive for the person. So it's better to to put some boundaries in place" (Sarah).

"We had to sit down with the family and have some very, very difficult conversations" (Michelle)

Needing a wide network around the individual

"Everyone committing to coming to meetings, to push the discharge forwards";

"It was well attended and if didn't, if we missed it was a one off, it was something we all tended to prioritise" (Thomas).

"I think there's things like having, having all the right people in the room for certain meetings" (Alison).

"We were having weekly meetings, even from the very beginning that there was weekly meetings with the hospital" (Michelle).

Holding people accountable:

"When they know who's going to do that, when they're gonna do it by?" (Alison)

"I think sometimes it can be actions can kind of go a little bit into the ether" (Alison).

"We have to push every agency, I think" (Kevin).

Providing "the opportunity to thrive again"

Creating a new way of living

Allowing the individual to get their freedom back.

"Going to an art class because that's what they wanted to do" (Linda).

"It's just nice to see that liberty and that level of freedom" (Sarah).

"Giving us the opportunity to build towards the goals and objectives, to community participation and, and improve quality of life" (Thomas).

Making a house, a home.

"There was stuff about umm his bedroom being just as he likes it and and kind of preparing his bedroom in advance" (Carol).

"Ordering furniture so that they feel that's, that it is their home" (Isabelle).

"They can make their room homely and things like that 'cause, possibly in hospital, they couldn't really do that so much" (Catherine).

Not wanting to let individuals down

Getting it right.

"So I think having a good transition" (Catherine).

"I think the transition, the transition went OK, because there was like a clear transition plan in place and he felt comfortable with leaving the hospital and moving to this new placement" (Sarah)

"I think sometimes people kind of think ohh no, it will be fine. They are gonna come out to community, they're gonna be happy and they're not…looking at potential risks" (Catherine).

Working at a manageable pace.

"It is preventing another placement breakdown, it's going to promote a positive discharge experience for everyone" (Laura).

"Structure and routine in helping the person to actually be a meaningful part of their community" (Isabelle).

"I know that they were trying swimming with him. He was going shopping, so they really are pushing the boundaries very gently with him" (Michelle).

Feeling stuck working within the system

"The good services are few and far between"

"They might be ready for discharge. But there's just no placement found".

"we've had people stuck in hospital for such a long period of time" (Laura).

"I think the impact is that people stay in hospital longer than they need to, so there's a risk of institutionalisation. I think people get a bit stuck. I don't think it helps people's Wellness" (Alison).

"If you don't have any choice. How are we gonna empower our people?" (Linda)

"I think for some people there's a real challenge in locating the right physical environment" (Alison).

"But they can't recruit staff".

"You know we we have someone whose house is ready to go, painted, filled with furniture, PBS plans, care plans in place, fundings in place, can't recruit, can't recruit staff" (Isabelle).

Aiming for individuals to live locally.

"Yeah, umm we try very hard not to move people out of area, obviously for obvious reasons, and so I don't think any of mine have moved out of area" (Amelia)

"The idea obviously of Transforming Care is to bring them back to… their local place. That's the aim, really" (Kevin)

"The big push for transforming care seems to be around moving people back to their local area into their local communities" (Samuel)

"It was out of county, but not far out of county" (Michelle).

"We've had to go back out of the area for for one, for one person because there was nothing suitable" (Linda).

"Trying to find a placement which is equally miles away and you're like I don't even know where to start" (Isabelle).

Having to fill the gaps

"We always go above and beyond and take on more than we probably should".

"So we do pick up a bit of work to help them out. Help our colleagues out really" (Kevin).

"It ends up being us going a little bit off piste and approaching providers directly that we know of" (Isabelle).

"It's not our job to do, but it's it's about what's best for that person" (Michelle).

"There are elements of the discharge process that we can do and we can manage even though we shouldn't be doing it" (Laura).

"And I don't know if this is our role, but we always end up doing it" (Laura).

"We pick up a lot of [service name] work.....because we know [they] are so stretched" (Kevin)

Preparing the new staff team.

"We put together the presentation and and we deliver that as a kind of handover session to the people that are gonna be providing the direct support" (Jane).

"So everybody has a good understanding. We don't want. We don't want individuals coming out into the community and being labelled" (Linda).

"We actually did training with the staff. We did provide training with them" (Michelle).

Supporting the staff team after discharge.

"We mainly support staff to support the person" (Sarah).

"But also is the provider? Are they struggling as well? Any additional services that you need?" (Kevin).

"I think they are burned out"

"I wish people were more believing".

"I will advocate for those individuals all the time, because at the end of the day I will pass them over to someone else and they've gotta live that life. And I am quite passionate about that" (Michelle).

"They're very unreceptive to the idea of, yeah, but they're better now. So they are back to that person that you assessed. So you can take them" (Laura).

"We offer some staff consultations when we can reflect with staff on how the person is at their best" (Sarah).

"You know we try and make sure that someone else is there championing their cause to say, come on, this person needs to…. start living their life (Jane)"

Lacking faith in the support available.

"Some of the problems that I have seen with some discharges have been where there's a high staff turnover" (Isabelle).

"If they've got that consistent staff team, it tends to work because everybody gets to know each other" (Michelle).

"I think the problem there was just the fact that there was no, not a consistent staff team" (Carol).

"They can't you know, provide that support ongoing to everyone, unless they have a specialist team and there isn't really any specialist teams" (Samuel).

"And there are a number of providers who might suggest that they are specialist or highly specialist, but actually when you look at the care on the ground, there isn't that specialism" (Alison).

"Now you've told me you can do this and that's why one of my other placements broke down because we wouldn't increase their hours because we didn't think that they were needed" (Michelle).

"The leadership, I mean you can't keep track of who the leaders are. They change like each month" (Amelia).

"I think it's difficult to find a placement that has got a good solid staff team in it" (Amelia)

Decision-making out of professionals' control

"There's a slowness or unwillingness to take risk about discharging people".

"You know if people are ready for discharge, sometimes there has to be an acceptable risk in the Community, and we'll accept that risk.... So we have to try and support providers to take the kind of leap of faith sometimes with us" (Kevin).

Problems securing finances.

"So why are we arguing about is it mental health or social care? It comes down to money, and that's really annoying" (Jane).

"So someone was due to be discharged Monday and hasn't because the fundings changed. Now that's got to be re-done…and if that's not approved, then we're a bit stuck" (Isabelle).

It’s not easy work

“If we weren't doing it, these people would be just in institutions”.

“Come on guys, where’s the thanks or praise?”.

“We need some congratulations and you know, well done. I've seen you work so hard on that” (Laura).

“The other thing that keeps, that helps is when you do get good outcomes for people and you get good, good feedback…that keeps you going through the like, the frustrating parts of the job” (Carol).

“I'm going to go somewhere else cause I've had enough” (Michelle).

“So it wasn't about the money. It was literally about the recognition” (Michelle).

Holding the system together.

“We would almost like helicopter in to try and push that discharge and try and unblock things as well” (Kevin).

“So a partner to all of the, all of the working parts of the system. Oiling everyone's parts, if you like” (Charlotte).

Feeling under pressure.

Responding to the policies and procedures.

“There's probably some pressure after the six week review if everything's going really well, to close” (Katie).

"You have to learn to manage lots of spinning plates" (Kevin)

"It became a real battle where I ended up having to bring my colleague in" (Michelle)

"The pressure I guess has more been from the transforming care agenda that people shouldn't be in hospital" (Katie).

Getting people out of hospital.

"There's this big push to move people out of hospital, but there isn't the emergency *resource"* (Samuel).

"Yeah, there's this real move to get people out" (Catherine).

Needing a supportive network.

"Managers above me are always really supportive" (Kevin).

"So yeah, no, I've never felt unsupported in my role" (Catherine).

"I do have that back up and support and she will back me up" (Michelle).

"There's obviously a lot of emotions".

"I felt awful".

"When it all went wrong.... You know it wasn't a nice feeling" (Samuel).

"At the time it can be really tiring and hard working" (Michelle).

"When I successfully discharged someone, it was great".

"Then seeing them settle and blossom and bloom and family saying ohh my goodness. I didn't realise [insert name] could do that" (Michelle).

Appendix Q: Summary report for ethics panel and participants

Dear ethics panel members [and participants]

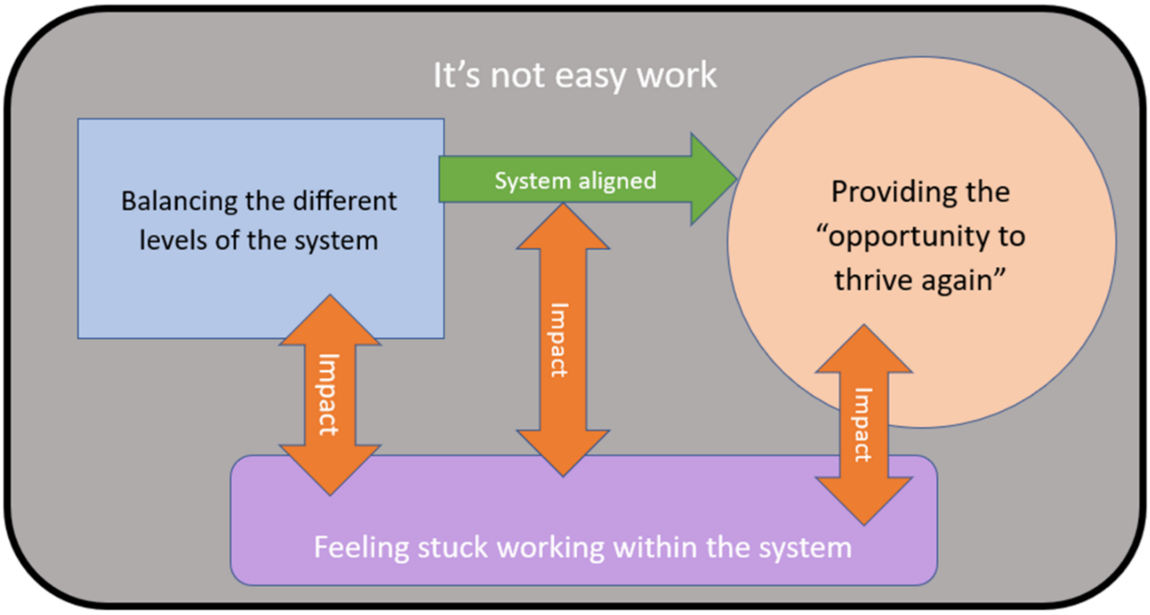
Re: "*It's not easy work*". A grounded theory of community health and social care professionals' experiences of what contributes to a successful transition under *Transforming Care*.

I am writing to update you that the above research study has now been completed and submitted in partial fulfilment of the requirements of Canterbury Christ Church University Doctorate in Clinical Psychology. I have outlined the results of the project below.

Overview of the research: The grounded theory model aimed to highlight the processes community health and social care professionals engage with when supporting an individual with learning disabilities and/or autism to move from hospital to a community-based setting. Twelve health professionals and three social workers were interviewed about their experiences using semi-structured interviews. A grounded theory methodology was adopted from the social constructionist epistemology.

Figure 1

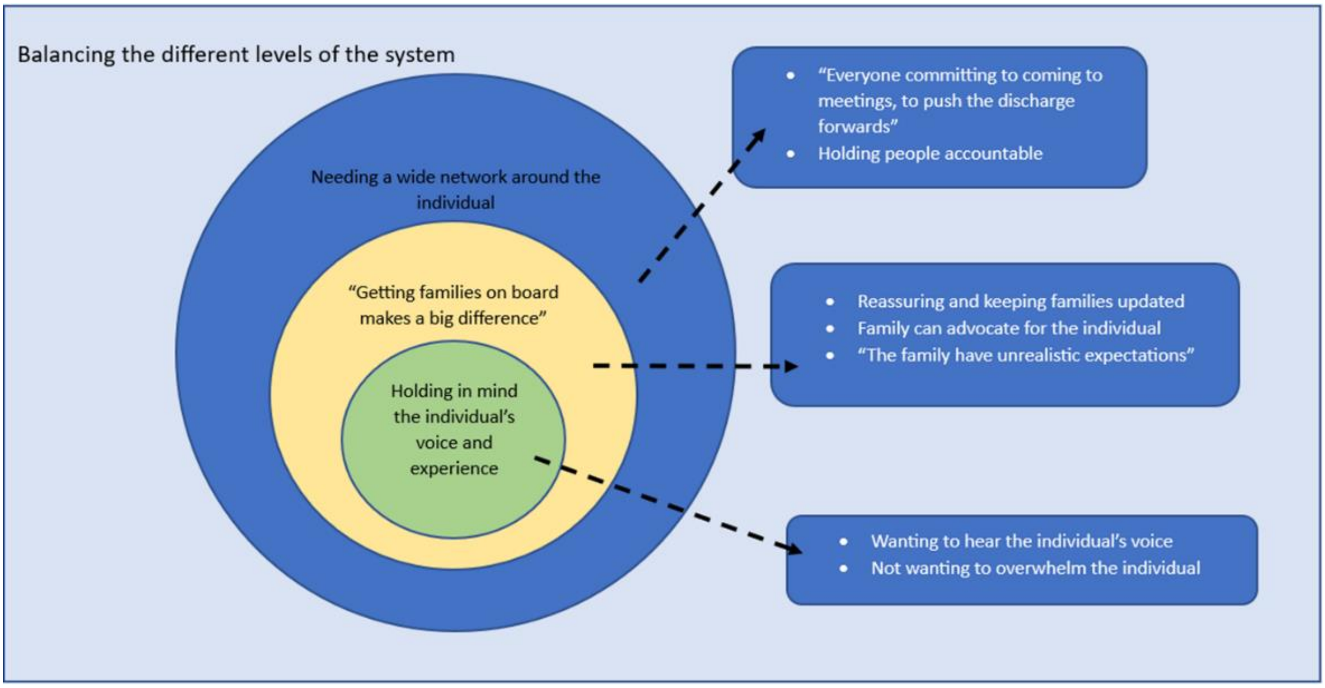
Grounded theory model.



Summary of the concept model: four concepts were constructed: “Balancing the different levels of the system”, “Providing the ‘opportunity to thrive again’”, “Feeling stuck working within the system” and “It’s not easy work”. A diagram of the concept model is presented below with a summary of the categories and subcategories.

Figure 2

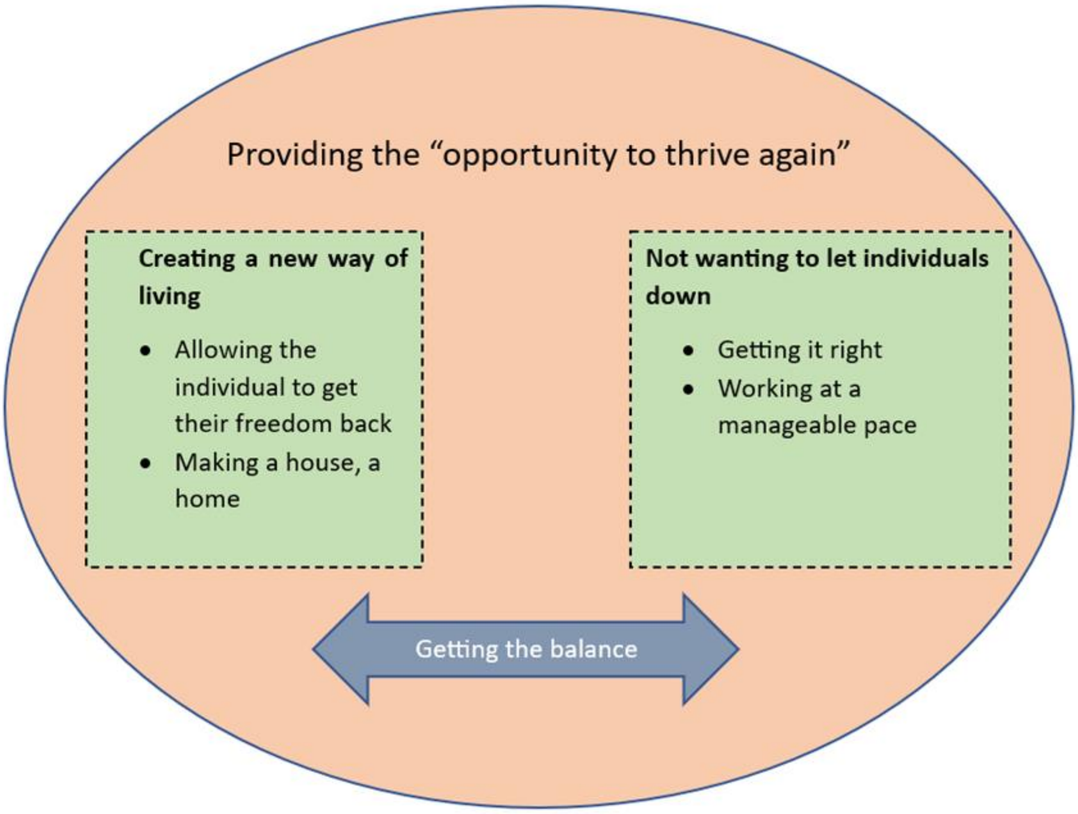
“Balancing the different level of the system” concept.



This concept aimed to capture how community health and social care professionals have to balance different voices in the system, including the individual, their families and the professional network. Participants highlighted the importance of getting the whole system aligned in order to support the individual to move out of hospital.

Figure 3

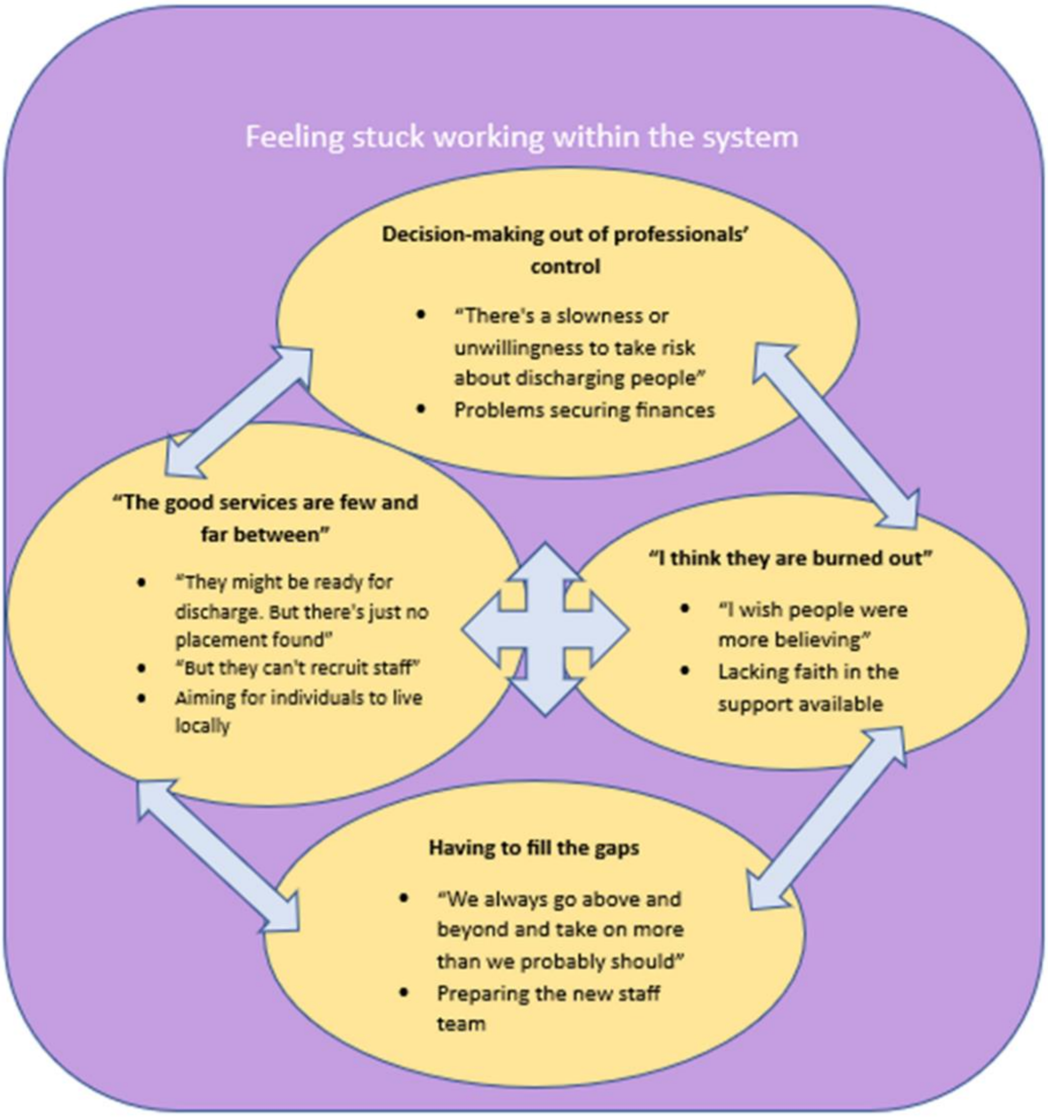
"Providing the "opportunity to thrive again"" concept.



This concept covered the processes participants experienced when supporting an individual to live successfully in their new community placement. Participants described their experiences of wanting individuals to have a meaningful life in the community, by allowing freedom and flexibility. However, it was recognised that this should be balanced with professionals making the right decisions for the individual, such as checking the placement is suitable and ensuring there is a well thought-through transition plan to allow for the individual to move into their placement at a manageable pace.

Figure 4

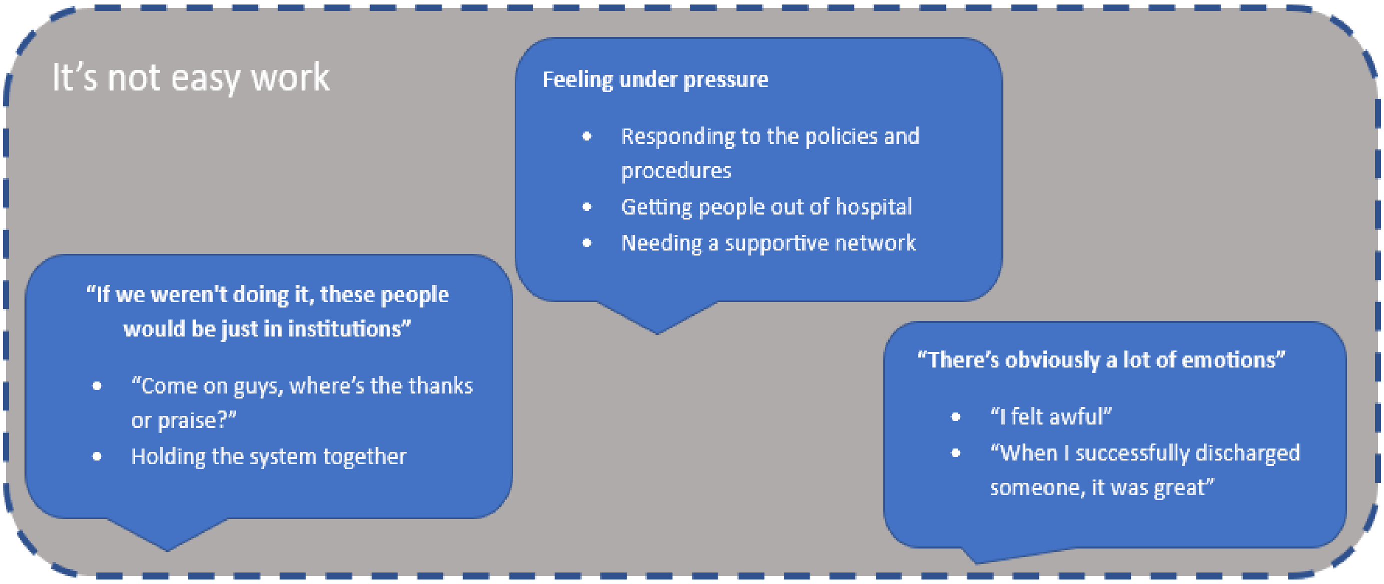
"Feeling stuck working within the system" concept.



This concept captures the difficulties participants experienced within their job roles. Participants acknowledged the barriers they faced when discharging individuals such as lack of placement options and staff, which in turn meant that participants often took on roles outside of their job description and step into roles that were vacant, in order to push forward a discharge for an individual.

Figure 5

"It's not easy work" concept.



The final concept reflects the participants' personal emotions working under *Transforming Care*. Participants reflected that at times their roles were difficult, especially when individuals were 'stuck' in hospital and the difficulty of working within the remits of policies and procedures. However, participants felt proud of themselves when individuals were successfully discharged back to the community but would have liked more praise and recognition for the difficult work they were doing.

A summary of the research project will also be sent to all participants who kindly shared their experiences.

If you have any further questions regarding the project, please do not hesitate to get in contact.

Yours sincerely,

Kayleigh Parker
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Salomons Institute of Applied Psychology