The Elephant in The Room; Mixed Methods study of Specialist Inpatient Facilities for People with Learning Disabilities.

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Type of Award: Doctor of Professional Practice: Community Social Care Policy and Practice.

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ABSTRACT

Background

The use of specialist inpatient hospitals (also known as assessment and treatment units) for people with learning disabilities remains a contentious issue as a result of cumulative national scandals and subsequent policies over the decades appearing to have little effect on the associated exposes of abuse and degradation of patients. More recently this has included highly publicised cases at privately-owned hospitals such as Winterbourne View (BBC 2011), and Whorlton Hall (BBC, 2019). For many years, the government response has been to continually drive the closure of such beds, based on a simplistic notion of reducing the law of probability. However, despite this, and the unsavoury reputation that this bestows on specialist inpatient hospitals, they remain in regular use nationally, and the related policies have resulted in some significant implications for people with learning disabilities and their families.

Nature and scope

A three stage mixed method explanatory sequential design was used in this study to sample seven NHS Mental Health Trusts and their associated Clinical Commissioning Groups (eight CCG's) facilitating hospital admissions to people with learning disabilities within a defined region of England. Being employed by an NHS Trust who have retained specialist inpatient beds, and appreciating the sensitivities around this, the overarching aim was to further explore the complexities and challenges within the system of implementing national policy from an operational perspective and to understand why such beds are still in regular use. Additionally, the study sought to ascertain how neighbouring Trusts without local beds were practicing and performing within the framework of national policy to provide further evidence for considering any remodelling of local service delivery.

Originality and value

The originality and contribution to knowledge is captured in the under – researched views, opinions, and experiences of senior NHS commissioners and operational service managers of learning disabilities health services in reflecting the operational challenges of attempting to implement national policy in this area of practice. In doing so, the complexities and unintended consequences that have arisen for people with learning disabilities, their families, clinicians, and commissioners becomes clear, and an argument for pausing to examine legitimate reasons why specialist inpatient services may be required locally is presented. The contribution to practice knowledge naturally follows from the application of the findings to inform discussions regarding the on - going provision of local specialist inpatient beds within my local area. Moreover, although not generalisable in the truest sense, it is anticipated the findings will also be of interest to NHS Trusts and CCGs (Clinical Commissioning Groups) in other regions with whom many of the issues and challenges will resonate.

Authors note:

Please note that throughout the study there may be historical terms and derivatives used to refer to those with learning disabilities and models of service provision that are no longer used or acceptable today. This is done purely for clarity and in order to accurately represent material written and presented during the relevant time period.

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Glossary of terms and abbreviations

ASC	Autistic Spectrum Condition
CCG	Clinical Commissioning Group
CTR	Care & Treatment Review
DH	Department of Health
DHSC	Department of Health & Social Care
LOS	Length of stay
MHA	Mental Health Act
MOJ	Ministry of Justice
NHSE	NHS England
RCN	Royal College of Nursing
TCP	Transforming Care Programme

Chapter 1. INTRODUCTION

> "*When there's an elephant in the room, you can't pretend it isn't there and just discuss the ants*." Ellen Wittlinger (Date unknown).

1.1 Background

The drive for closure and reduction of, what are generally depicted as 'inappropriate' (Devapriam et al. 2015), specialist inpatient beds for people with learning disabilities, is not new and has been intermittently visible on the political and public agenda for a number of decades (Transforming Care and Commissioning Steering Group 2014). It is not hard to see why; perpetually linked to a history of horrific exposures of unforgivable and gratuitous abuse (HMSO 1978, Mersey Regional Health Authority 1977, Berkshire Area Health Authority 1979, Oxfordshire Area Health Authority 1980, Somerset Area Health Authority 1981, Laurance 2006, CSCI 2006, BBC 2007), the visceral outpouring of shock and condemnation that follows naturally brings debate on the use, requirement, and numbers of specialist inpatient beds for people with learning disabilities to the fore (Triggle 2019). This has led to successive governments adopting a policy of mass closure of such beds in an attempt to reduce the likelihood of repeated incidents. With the interminable reputation of being associated with poor care and abuse, and the highly emotive feelings of distain this elicits, the elephant in the room remains the purpose that they serve, and the operational challenges and complexities that maintain their existence, despite sustained national efforts to the contrary.

Although progress has been made from the days of long-stay hospitals when the NHS alone had 33,000 beds between 1997 – 1998 (NHS England 2013, cited in Devapriam et al. 2015), as NHS beds have been reduced, so the private sector has grown to fill the void. From a combined total of 3,901 beds for people with learning disabilities in 2013 (Royal College of Psychiatry 2013), as of March 2019, within a space of six years, this was noted to have increased exponentially to 3,659 in the NHS alone, and a further 3,344 in the private sector (Brown et al. 2019).

Despite consecutive governments having secured these small victories in reducing NHS bed stock, significant concerns prevail, and the issues remain unresolved (Sinclair 2018). Nowhere is this more evident than in the questionable efficacy of the most recent policy iterative, Transforming Care (DH 2012a), implemented as a result of the exposure of systemic abuse at Winterbourne View, a private assessment and treatment hospital for people with learning disabilities (DH 2012). The subsequent uncovering of equally appalling incidences of covert abuse at Whorlton Hall, another privately managed assessment and treatment hospital for people with learning disabilities, a mere two months after the Transforming Care Programme ended, attests there remains more to be understood (CQC 2020).

The continuation of such incidences suggest that what appears to be, on the face of it, relatively straightforward policy directives of reducing inpatient admissions, reducing the distance of admission from home, and minimising any length of stay (NHS England et al. 2015a), have an underlying level of complexity that has yet to be fully appreciated. This has also been borne out by successive governmental and national reviews (Transforming Care and Commissioning Steering Group 2014, DH 2015, NAO 2015, The Strategy Unit et al. 2018). Furthermore, the view that an admission is never a decision taken lightly, and therefore it is not sufficient to demand that such facilities are closed without understanding the reason why people end up in hospital, is also a valid observation (Beebe 2017). This study has been undertaken in the belief that such complex interdependencies require deeper understanding and appreciation of the issues at play if we are to work towards something that clearly requires a more sophisticated solution than those attempted thus far. The value of this study is therefore seen to lie in its' contribution to facilitating this understanding from the unique perspective of those NHS senior commissioners and service managers commissioning and operationalising specialist inpatient services.

1.2 Aims and objectives of the study

The overall aim of this study, undertaken between 2017-2020, was to identify and discuss the complexities and challenges within the current system, thereby providing robust evidence to inform future discussions on what specialist inpatient services in my own region need to take into consideration. A key focus was the exploration of senior NHS operational managers' and commissioners' perspectives on the most recent policy request and issues within the current system. The study aimed to help facilitate debate on the continued use of specialist inpatient beds in our locality, and to contribute more broadly to future policy development discussions.

The study had the following objectives:

1.) Gathering and analysing statistical information about populations of need in each area within the sample group.

2.) Comparing and contrasting the models and use of specialist inpatient facilities in each area within the sample group.

3.) Critically evaluating the efficacy of the differing models against some of the key aims of the Transforming Care initiative.

4.) Collating comprehensive descriptive data from expert participants around service model provision within each area and exploring challenges therein.

To address the aim and objectives of the study, a three-stage explanatory sequential mixed methods approach was utilised with a regionally defined sample group. At stage one this included a preliminary review of populations of need and local Transforming Care implementation plans; stage two involved collection of quantitative performance data against some of the key intentions of the Transforming Care policy; and stage three qualitatively sampled expert participants most familiar with implementing and delivering government policy: senior NHS operational managers and service commissioners working within learning disability services.

1.3 Study rationale

In fulfilling the dual intention of a Professional Doctorate, in that the research makes a demonstrable and original contribution to practice alongside an original and significant contribution to knowledge, I approached my employing NHS Trust with a proposal to undertake a study that would support research-informed practice and service delivery going forward. Currently retaining a local specialist inpatient hospital for adults with learning disabilities, against the backdrop of a national impetus to reduce these services, demand for the beds consistently outstripped supply, resulting in unavoidable out of area placements. As a consequence of the tension between political diktats and operational exigencies, the need, location, and number of beds required is routinely under review. This has led more recently to tentative discussions around regionally centralising and possible expansion of these services within the local Transforming Care Partnership strategy group.

In any consideration of a service provision reconfiguration, it would be essential to understand the challenges and issues faced by those attempting to deliver specialist inpatient services within the area, as well as identifying the elements they feel have worked, so that potentially this can be systemically addressed in any redesign. It was therefore agreed and supported that a regionally defined study would be timely to ascertain how neighbouring areas, both with and without local specialist inpatient beds, were operating, and their efficacy. It was also agreed that a tangible evidence base identifying the complexities and challenges in the current system would be more helpful in assisting with future service planning than the prevailing speculation and conjecture.

1.4 Definition of key terms and context

This study focuses on the population of people with learning disabilities; sometimes internationally referred to as Intellectual Disabilities. In the UK, the term learning disabilities is used widely across the health and social care sector, and on occasion used interchangeably with the term ‘learning difficulties’. In the health sector, these terms are more clearly defined, with learning disability constituting a formal clinical diagnosis and learning difficulty more widely acknowledged as pertaining to conditions such as dyspraxia and dyslexia (Gates & Mafuba 2016).

The current World Health Organisation (WHO) definition of a learning disability is:

> *“… a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development*.”[1]

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[1] http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

The clinical diagnostic criterion for a learning disability is defined by three core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood (NICE 2015). In terms of the population of need, it is estimated that there are approximately 1.13 million, (2.16%), of adults in England with learning disabilities (Public Health England 2016, ONS 2019) within one of the following classifications: mild (IQ 50 – 70), moderate (IQ 35 – 49), severe (IQ 20 – 34), and profound (IQ <20), although not all will have a formal diagnosis (RCN 2017).

A sub – population of this cohort, which will be further discussed within the study, are those people with learning disabilities who may also be defined as having 'challenging behaviours'. Not a formal clinical diagnosis in itself, the term is also commonly used interchangeably with alternatives, such as 'behaviour that challenges' or 'distressed behaviours'. The most widely accepted definition that has endured is one offered by Emerson (1995) of:

> "*Culturally abnormal behaviour(s) of such intensity, frequency, or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities*" (1995:3).

An alternative definition offered by the Royal College of Psychiatrists states:

> "*Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion*." (Royal College of Psychiatrists, 2007).

Recent studies have found that the prevalence of challenging behaviour in people with learning disabilities, known to services, is approximately 1 in every 5-6 adults (Bowring et al. 2019).

This study set out with the intention to focus on people with learning disabilities as a discreet population of need within their own right. Of significant importance in understanding this position within the research approach is that health services for people with learning disabilities and Autistic Spectrum Conditions (ASC), at the time of the study, remained separately commissioned within the NHS, whereby, in all areas included in the study, they were still considered to be two separate patient groups. With regards to specialist inpatient services this becomes a little less clear as a result of the most recent policy iterative, Transforming Care, which enmeshed the learning disability population and those defined as having an ASC, despite these being two distinct and exclusive diagnoses, given to people with very diverse needs. Although it is estimated that 20 – 30% of people with learning disabilities will also have autism (Emerson & Baines 2010) and almost 80% of people with autism are more likely to have mental health conditions[2], autism in itself is not classed as a learning disability (NHSE & NHSI 2019), and therefore the patient population utilising specialist inpatient beds specifically for people with learning disabilities has become somewhat imprecise. Exploration of the rationale behind the joining of the two through policy is not within the scope of this study, but invariably the ability to draw on data solely derived from the population of people with learning disabilities has been limited in some areas due to the systemic association built into national data collection and reporting systems.

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[2] https://www.autistica.org.uk/downloads/files/Mental-health-autism-E-LEAFLET.pdf

1.5 Thesis structure

This thesis is presented over seven chapters. The literature review in chapter two looks to initially provide a brief historical overview and context to these services within the public and political arena. It then discusses the resultant government policy introduced to address the perceived challenges and its' relative impact, showing that the failure by successive governments to offer effective solutions to the concerns, and more pointedly, stop institutional abuse in hospitals, reinforces the notion that the complexity of the situation has been grossly underestimated.

Closer scrutiny is then given to the main aims and objectives of the Transforming Care policy and programme, and the specific key processes and systems it introduced in an attempt to achieve a reduction in the use of specialist inpatient services. The review subsequently considers the current picture, including some of the potentially confounding factors such as the increased prevalence of mental health conditions in people with learning disabilities, patient profiles of those deemed at increased risk of admission and extended lengths of stay, and incongruity within the prevailing legislative framework for detaining people with learning disabilities. The chapter concludes by reflecting on the findings of relevant contemporary studies to contextualise the position of this study.

Chapter three presents the study methodology, describing the philosophy and rationale behind undertaking a regional study whilst choosing a three-staged explanatory sequential mixed methods design. It asserts that preliminary gathering of secondary data in stage one, followed by the collation of quantitative data in stage two were utilised to inform the semi-structured interview questions in stage three. The use of expert participants to further illuminate the findings from stage one and two of the study is then discussed, and the chapter closes with a consideration of the ethical issues, and rigour.

The next three chapters (four – six), present the findings from each distinct stage of the study. In chapter four, populations of need at the time of the study are identified alongside an outline of the service models in each area, as extracted from respective Transforming Care implementation plans. Chapter five depicts the quantitative findings of measuring performance within the sample group against key Transforming Care policy targets using descriptive statistics. The final chapter within this section, chapter six, confers the qualitative findings processed using Framework analysis.

Concluding the thesis, chapter seven discusses the main issues arising as identified in the study and potential implications for policy and practice. A summary then highlights the conclusions drawn and suggests areas for future research, before closing with an examination of the research approach and limitations.

Chapter 2. LITERATURE REVIEW

2.1 Chapter overview

The overarching aim of this chapter is to offer insight into the historical context and current thinking around specialist inpatient services, whilst also highlighting where this study makes an original contribution. In doing so it initially recalls the history of specialist inpatient services and how societal and political perceptions have played a key role in shaping the provision afforded to those with learning disabilities. It proceeds to contemplate the debate around the use of specialist inpatient services for people with learning disabilities, and how, following unrelenting national scandals, legislative and policy reform attempted to address the resultant public discord. The chief aims and objectives relevant to specialist inpatient services in the most recent iteration of discrete national policy, the Transforming Care Programme, are then explored and considered alongside the accompanying processes, procedures, and tools pertinent to managing those at risk of inpatient admission.

The review then moves to consider current thinking around the use of specialist inpatient services and some of the key factors this entails. Discussing those deemed at higher risk of admission, patient complexity, legislative implications, and contentions around ‘treatability’. It contemplates how these features can play a part in delaying subsequent discharges, and thereby inherently extending lengths of stay beyond clinical necessity. The chapter concludes by summarising themes from recent research in the field, and so identifies the gap in knowledge this study is contributing to.

2.2 History of Inpatient Services

Following decades of missed targets and repeated controversies, the issues and challenges surrounding the use of specialist inpatient beds for people with learning disabilities prevail (Taylor 2019). More broadly, questions about the appropriateness, morality, and effectiveness of institutional hospital care persist (Ford 2020) and, disturbingly, national scandals continue to be exposed (Murphy 2019). In order to fully appreciate the nuances of the debate, it is essential to understand the political, social, and policy arena from which it emerged, alongside the needs of the people it supports.

The hospitalisation and social segregation of those with learning disabilities has a significant and pervasively contentious place in English history, with madhouses (*sic*) being traced as far back as the 18th century (McCandless 1978). Into the early 1800's lunatic asylums (*sic*), both private and non – profit, along with workhouses and alms houses, became commonplace accommodation for confining and isolating those with learning disabilities away from local communities (Wright 2000). During the subsequent industrial revolution, segregation and marginalisation continued to be implicitly enforced; the ability to operate complex machinery naturally divided individuals by their capabilities, and as a result, those with learning disabilities were:

> *"… singled out as one of a number of groups who were perceived as having neither the social or the practical competencies to sustain themselves or any dependents in a developing society.*" (Gates 2003:46).

Consequently, societal perception and worth became evermore shaped by the measure of an individual's ability to contribute to the wider economy, inherently disadvantaging those with learning disabilities, who became increasingly viewed as a public financial burden (Gates 2003).

Although now abhorrent to the modern researcher, this was followed in the late nineteenth and early twentieth century by Galton's highly influential theory on eugenics. Based on Darwin's theory of evolution and depicted as the "science of improving inborn human qualities through selective breeding" (Galton 1869), it only served to perpetuate widespread scaremongering about people with learning disabilities (McClimens 2005) and extinguished any remaining empathetic public opinion to one of treatment by custodial segregation (Braddock & Parish 2001). With enforced institutionalisation identified as the way forward in an attempt to contain those who were seen as undermining the genetic base on which Britain's future was to be built, the resultant introduction of the Mental Deficiency Act (1913) formally legalised the assessment, treatment, and detention of those with a learning disability alongside those with mental health conditions, and in doing so, medicalised learning disabilities and its 'treatment' ad infinitum.

Concerns about the appropriateness of hospitalisation of those with learning disabilities, and extended lengths of admission, only started to be mooted in the public arena many years later (Clarke & Clarke 1958, Mittler 1979), with the idea of reducing reliance upon institutional provision becoming increasingly suggested by successive governments since the 1960s (Race 1995, Perini 2000, Richardson 2005). With responsibility for what were formerly called 'sub-normality' (*sic*) hospitals handed over to new hospital authorities under the National Health Service (NHS) Act (1946) from 1948, policy and social attitudes towards people with learning disabilities slowly started to alter.

Repealing of the Mental Deficiency Act (1913) signalled abolition of compulsory certification that had previously detained such individuals in institutions, some for many years. Bolstered by the introduction of the National Assistance Act (1948), and enactment of a new Mental Health Act in 1959, a more compassionate political and societal stance was emerging. Critically the latter Act endorsed the notion of care within the community and confined mandatory and voluntary admission only to those deemed a risk to themselves or others. In conjunction with an increase in the formation of civil and human rights movements, such as the European Convention on Human Rights (Council of Europe 1950), acceptance of people with disabilities became more widespread and a move towards care in the community emerged as the favoured policy direction (Whitehead 1992). With signs of momentum gaining, as early as 1961, then Minster of Health, Enoch Powell, announced in his now renowned Water Tower speech, the decommissioning of 75,000 mental health hospitals, which also housed those with learning disabilities. This consisted of an ambitious halving of patient numbers over the next 15 years with the ultimate aim of having no long-stay patients (Powell 1961).

Despite this outward seemingly progressive transformation of public and political perception, conditions within long-stay mental health hospitals remained largely unchallenged until the publication of ‘Sans Everything: a case to answer’ (Robb 1967). A damming indictment of the quality of care for older people in long-stay institutions, the report encapsulated the general poor state of such establishments and marked the beginning of nearly two decades of high profile allegations in a plethora of state-run hospitals, including those for people with mental health conditions and learning disabilities (NHS 1969, NHS 1971, HMSO 1974). In an attempt to ameliorate the ever-burgeoning concerns and recognising that establishments for this patient population were an “underprivileged area” with a disproportionately low allocation of resources, Richard Crossman, then Secretary of State for Social Services (1968 – 1970), introduced Hospital Advisory Boards. Notwithstanding these efforts to address growing unrest around the conditions inside such institutions, the heightened focus on life for those in large, long-stay hospitals did not abate. The subsequent publication of ‘Put Away’ (Morris 1969), a national survey of such institutions, not only reinforced previous findings but continued to stimulate social and political debate surrounding the question of what future support needed to look like for people with learning disabilities.

On-going pressure on the government for reform resulted in Crossman proceeding to commission the White Paper ‘Better Services for the Mentally Handicapped’ (DHSS 1971), which strongly advocated community-based initiatives such as support within families, local authority hostels, group homes, lodgings, foster homes, and supported independent living. It also set out ambitious figures for significant growth in residential provision by Social Services in England and Wales, whilst looking to reduce hospital beds from 90% to 40% (DHSS 1971). As cited in Stevens (2004) prevailing figures at the time showed a national figure of 4,300 residential service placements, and 52,100 hospital inpatient placements, with the White Paper setting out the aim to increase residential placements to 30,000 whilst concurrently reducing hospital placements for those with learning disabilities to 27,300 over the next twenty years (DHSS 1971). The government stance on future provision was also unambiguous with the very clear view that “…in the long term, hospitals (were) not to be used as homes” (DHSS 1971:37), although as noted by Porter & Lacey (2005:13), there was …” little guidance on how this might be achieved.”

With increasing public focus on the damaging effects of institutionalisation through continued and relentless exposes of further scandals at hospitals such as Normansfield (HMSO 1978), Mary Dendy (Mersey Regional Health Authority 1977), Church Hill

House (Berkshire Area Health Authority 1979), Cotshill (Oxfordshire Area Health Authority 1980), and Sandhill Park (Somerset Area Health Authority 1981), recommendations within the paper could not be instigated soon enough (Martin 1984). Concurrently, the government's shift towards community care, was reinforced by the theory of normalisation gaining momentum (Wolfensberger 1972, 1983, 1999, Nirje 1980,1982). Publication of persuasive and prolific research also provided a compelling rationale for pursuance of alternative non – hospitalised accommodation (Kushlik 1970, Townsend 1973, Oswin 1978, Malin & Race 1979, Tyne & Williams 1979, Felce et al. 1980, Kings Fund 1980, Malin et al. 1980), and there was a growing philosophical debate around the appropriateness of detaining individuals in hospital, who effectively were not ill (Brend 2008). Increasing pressure to act was also gathering from user organisations such as Mencap and the Campaign for the Mentally Handicapped (CMH 1970,1972).

In the ensuing years, the closure of long-stay hospitals for people with mental health conditions and learning disabilities remained on the political agenda and the first signs of empowerment started to emerge through progressive policy and legislation. An influential project set up by the Kings Fund entitled 'Ordinary Lives' looked at how people with disabilities could access ordinary patterns of living alongside others in society and become more integrated within local communities, setting the tone for subsequent years (Kings Fund 1980). Such was its influence that between 1980 – 1992 a further 29,000 patients were discharged from mental health hospitals bringing the total of former inpatients living in the community to more than 40,000 (Porter & Lacey 2005). Equally crucial in facilitating this significant shift in philosophy and service support, was enactment in England of the NHS & Community Care Act (1990) which introduced the concept of an internal market for healthcare, thus converting the State from a position of provider to enabler (Walsh et al. 2006). Integral to the successful repatriation of many people with learning disabilities from long-stay hospitals to their local communities, the 1990 Act, along with central government allocated ring-fenced funding (Hansard 1992), served to maintain the impetus and resource required to support the continuation of closing the large, long-stay institutions.

However, it still took several years and the publishing of the White Paper ‘Valuing People’ (DH 2001), which strongly advocated the use of mainstream health services for people with learning disabilities, including those with challenging behaviour, to see the last designated NHS long-stay hospital for people with learning disabilities, Orchard Hill in Sutton, finally close in 2009 (Tickle 2009). Although the much publicised closure was, in some quarters, perceived as the end of an inappropriate service model (Goldring 2009, Learning Disability Practice 2009), and government endorsement for access to mainstream health services for people with learning disabilities was firmly on the agenda (DH 2001), what was less apparent was that specialist NHS hospitals for those with learning disabilities remained, albeit in a different guise (Gaskell et al.1995).

In the wake of the closure programme for long-stay hospitals and the establishment of an internal market for healthcare under the 1990 Act, health organisations were reconfigured and reformed into NHS Trusts and had been placed in direct competition with one another (Hughes 1991). Aware of the need to maintain levels of public funding, many of the former long – stay hospital sites for people with learning disabilities were retained and repurposed into smaller units (Emerson & Hatton 1994,1998, DH 2001:75). The use of these units fell into two service model types and were renamed, with ‘long – stay’ being changed to either assessment and treatment hospitals, or NHS campuses.

The concept and function of assessment and treatment hospitals had been suggested by leading academics within the field. Founded on the rationale that some individuals with severe challenging behaviour would need brief intensive interventions, the specific purpose was outlined as being able to:

> "…*answer specific questions…. which may be critical in helping local district teams to treat or manage the challenging behaviours or psychiatric disorders which are causing problems for those people and/or their local services*". (Murphy et al. 1991:42).

One such prominent example of the switch was Calderstones hospital in Lancashire, which when it started to accept admissions in 1921, had capacity for 2,100 patients with learning disabilities, and in 2005 announced the closure of all of its long – stay wards (Brindle 2015). Despite what appeared to be a positive move towards the de-institutionalisation of many people with learning disabilities, at the same time Calderstones converted their inpatient services to an assessment and treatment hospital and retained 223 beds (Gammie 2016), making it the largest assessment and treatment hospital for people with learning disabilities still operating in the country today (Grieve 2019). Arguably on a smaller scale at around 10 percent of its original capacity, such decisions also presented the possibility of transposing many of the former institution's staff members, along with potentially outdated attitudes and pervasive work cultures, into this newer reconfiguration, and the associated risks this presented (BBC 2013).

The second model, one of NHS campuses, attempted to emulate smaller community residential homes. However, the construct presented legal issues as although the name had changed, campuses remained hospitals for regulatory purposes, and therefore, people staying there continued to be under the care and treatment of the NHS as a patient. This invariably led to a more constricted existence and support delivered under a medical model, whilst conversely, those living in dispersed community housing schemes who were not subject to the same constraints, were found to have a comparatively increased quality of life and support (Emerson et al. 2000). Consequently, NHS campuses were addressed in a wide-reaching government review of community health care services ‘Our Health, Our Care, Our Say’ (DH 2006) using Emerson et al.’s paper (2000) as an evidence base. Confirming the movement of all people with learning disabilities into community-based settings, once a suitable alternative was secured, it stated that all NHS campuses would be closed by the end of 2010 (DH 2006:102).

Notwithstanding the significant metamorphosis of specialist inpatient services for people with learning disabilities and the reduction to a singular model of assessment and treatment hospitals for those requiring acute admission, the risk of abuse remained ever present. Following further allegations of significant and widespread abuse at Cornwall Partnership NHS Trust (Laurance 2006, CSCI 2006), closely followed by allegations of institutional abuse in Sutton and Merton Primary Care NHS Trust (BBC 2007), all specialist inpatient services for people with learning disabilities provided by the NHS were called into question (Brindle 2007). However, the issue was found not simply to be related to NHS establishments. A joint national audit undertaken by the Commission for Social Care Inspection and Healthcare Commission the previous year had ascertained exponential growth of assessment and treatment hospitals in the independent private sector and noted increasing numbers of patient admissions (CSCI 2006). An unintended consequence of the creation of internal markets for healthcare, the audit reported a continued trajectory of growth in private specialist assessment and treatment hospitals in direct correlation to the closure of NHS services, and concerns around the quality of service delivery in both were equally disquieting. Two further audits followed; one by the Healthcare Commission (CHAI 2007), and a subsequent follow – up undertaken by the Care Quality Commission, which was scathing in its judgement that:

> “*At the time of the inspections, we found that the quality of specialist healthcare services for people with learning disabilities is at best inconsistent and at worst damaging*” (CQC 2009a:3).

Despite the continued consternation, there was little evidence of further improvement, and it took another national exposure of abuse in 2011 for the subject to return to the fore (Mansell 2011). Winterbourne View, a privately managed assessment and treatment hospital based in Bristol, became the subject of undercover filming by the BBC documentary programme Panorama, which publicly exposed the appallingly abusive conditions suffered by those admitted there (Kenyon 2011). Understandably public and political outrage was palpable, and then Minister for Care Services, Paul Burstow, took swift and decisive action directing CQC to undertake an immediate national programme of risk-based and unannounced inspections of all 150 assessment and treatment hospitals providing care for people with learning disabilities (CQC 2011). Concomitantly the government commissioned an expedited public enquiry into the matter, led by Sir Steven Bubb.

With criminal proceedings on-going, in June 2012, an interim report from the enquiry was published by the Department of Health (DH 2012). Critical in its view, the government distanced itself from assessment and treatment hospitals and suggested that the model evolved without their knowledge, boldly stating that:

> “… *with the closure of long-stay hospitals and the campus closure programme, a new form of institutional care developed: what we now know as assessment and treatment units. Not part of current policy, and certainly not recommended practice, these centres have sprung up over the past thirty years*.” (DH 2012:4).

Adding to this damning indictment, it asserted that:

> "*Containment rather than personalised care and support has too easily become the pattern in these institutions*." (DH 2012:4).

Setting out 14 areas for national improvement in services for people with learning disabilities, the paper confirmed those with challenging behaviours were most at risk of inpatient admission (DH 2012:14) and advocated three keys aims: avoiding admission wherever possible, admitting people closer to home if admission was deemed absolutely necessary, and timely discharge, within the context of closing specialist inpatient beds and hospitals at scale (DH 2012:21).

Following conclusion of the criminal case, and publication of the serious case review (Flynn et al. 2012), in December 2012 the full government response 'Transforming care: A National Response to Winterbourne View Hospital' (DH 2012a) was released. Reaffirming the government's aspirations for a "rapid reduction" in the number of people placed in hospitals and facilitated by an accompanying multi-agency concordat (DH 2012b) there was a commitment to review every person occupying a specialist inpatient bed by 1st June 2014. Where appropriate, they were to be discharged to community-based support as soon as possible, and the bed permanently closed behind them, with the associated funding following the patient to provide more comprehensive community services (NAO 2017). The stated expectation of this was one of a "… dramatic and sustained reduction in the number of assessment and treatment units and beds as a result of this shift" (DH 2012a:22).

Despite what had appeared to be a watershed moment and the seemingly very public commitment to resolving the issue, alongside a repeated attempt to embed reasonable adjustments into mainstream mental health services (DH 2013), as the deadline loomed in 2014 it was discovered that only one in ten patients had been rehoused into the community (Donnelly et al. 2014). More concerningly Purandare et al. (2015) found that in the two years post-Winterbourne, whilst the NHS continued its programme of closing specialist inpatient hospitals for those with learning disabilities, referrals and admissions to those remaining open had increased. Furthermore, as availability diminished, the risk of people being admitted further away from home, and potential delays in discharge increased due to close liaison between the hospital and local community services becoming more problematic (Purandare et al. 2015).

Corroboration of increased admissions also came from the national review 'Winterbourne View: Time for change' (Transforming Care and Commissioning Steering Group 2014) which remarked that not only had the target not been reached, but it too had found that more people were being admitted than were being discharged (Transforming Care and Commissioning Steering Group 2014:6). Commissioned by NHS England, and again chaired by Bubb, the review was tasked with devising a new national framework to achieve growth of community-based support for people with learning disabilities with the aim of stimulating movement from inappropriate hospital placements (Transforming Care and Commissioning Steering Group 2014). Within its recommendations it called for a commissioning framework to facilitate step change on two fronts: firstly, putting in place the community-based support to safely discharge people currently in inpatient settings, and secondly proactively supporting people in the community to prevent admissions in the first place. Simultaneously it reinforced earlier commitments that alongside advancement of the national framework, active decommissioning, and closure of "…inappropriate institutional care..." should take place (Transforming Care and Commissioning Steering Group 2014:7).

2.3 National Transforming Care Programme

Having seen an unexpected rise in admissions rather than the anticipated fall, momentum was maintained and in January 2015, as committed to within the first Winterbourne report (DH 2012a), a subsequent formal review ‘Winterbourne View: Transforming Care Two Years On’ was undertaken by Bubb (DH 2015). Citing unforeseen complexity and conveying the subsequent frustration this had caused, the publication set out the notion of an agreed single programme and accompanying plan in pursuit of an increase in the “…pace of change” (DH 2015:7), to take the form of a national Transforming Care Programme. Keen to disseminate some early commitments to “accelerate” the transformation being sought, the government concomitantly published ‘Transforming Care for People with Learning Disabilities – Next Steps’ (ADASS et al. 2015). Creating a new delivery board and identifying senior responsible officers from each organisation involved, the overall pledge was to advance the intentions of the Winterbourne commitment and, in doing so, look to a future of co-design and co-production in taking the programme forward (ADASS et al. 2015:13).

Within the paper, several new processes to support Bubb’s recommendations were clarified. With median stays of four years and three months being identified (NAO 2015), NHS England brought in the immediate right for people with learning disabilities and/or their families to request a Care and Treatment Review (CTR) and challenge their admission and continued placement in inpatient services (ADASS et al. 2015:10). Unlike the discreet CTR programme that had been undertaken previously to speed up discharge of longer-term patients with no discharge plan, a commitment was made to ensure this process would be embedded into “normal business”, the frequency of which would be later determined (ADASS et al. 2015:12). Designed to expedite discharge using a forum where the rationale for detainment could be robustly challenged, and comprised of a clinician, an ‘expert by experience’, and the responsible commissioner, CTR’s were charged with making recommendations to secure a safe and timely discharge.

In addition to tackling the issue of those already in hospital, it was recognised that preventative measures needed to be introduced to avoid inappropriate admissions in the first place. One aspect of this came in the form of confirmation that all CCG’s and local authorities would be supported to compile local registers of those at risk of admission so the situation could be monitored, and preventative work could be undertaken to avoid the need for admission (ADASS et al. 2015:13). Secondly, it was agreed that “robust admission gateway processes” would be introduced, with the aim of not only establishing if there were viable alternatives, but if admission was required, that a discharge plan was in place from the point of admission (ADASS et al. 2015:13). With the preference that any pre-admission meetings would ideally be planned using the CTR format, there was also recognition from NHS England that due to the time-critical nature of escalations in risk, unplanned admissions also needed to be catered for. Subsequent guidance for this scenario, in the form of the Blue Light protocol, was published in September 2015 and aimed to avert admission wherever possible, using a multi-agency approach to pool resources and look at alternative solutions that may sustain an individual in their community (NHSE 2015).

Principal guidance for the execution of the overarching Transforming Care programme followed in October 2015 when three key documents supporting national implementation were published (NHS et al. 2015a, 2015b, 2015c). The evidence base informing the plan was discussed in Building the right support (NHS et al. 2015a). Acknowledging that “change had been slow” (NHS et al. 2015a:4), it set out learning from six ‘fast track’ areas who had already drawn up plans with the aim of reducing inpatient usage by 50% over the three-year programme (NHS et al. 2015a:4). Its ambition was high; in addition to a national service model being in place no later than March 2019, there was an expectation that within the same three year period no area would need capacity for more than 10-15 inpatient beds per million population in assessment and treatment hospitals (NHS et al. 2015a:6).

Adjunct to this a national service model for commissioners of health and social care services was devised with input from commissioners, clinicians, and people with learning disabilities outlining the service model expectations to be in place by March 2019 (NHS et al. 2015b:6). Recognising the need for highly individualised support, the document focused on the benefits of admission avoidance and highlighted some “common deficiencies and shifts” that all areas would need to make to strengthen practice in this area (NHS et al. 2015b:8). The third and final publication, which provided supplementary information for service commissioners in CCG’s and local authorities, gave further detail on the main tools and systems that were expected to be uniformly developed and embedded in practice to manage those at risk of inpatient admission (NHS et al. 2015c).

Built on nine core principles, this guidance took a holistic approach encompassing all aspects of a person’s life and offered service commissioners tangible outcomes against which progress, and quality were to be monitored (NHS et al. 2015c:12). Critical to supporting admission avoidance, three of the principles outlined preventative services and processes requiring universal implementation in the pursuit of reducing the use of specialist inpatient services. Principle seven imbued the right of all those with learning disabilities to have access to a specialist integrated community-based multidisciplinary health and social care team delivering essential functions. This included supporting access to mainstream health and social care services, upskilling mainstream services to develop their ability to deliver reasonable adjustments, and offering direct assessment and therapeutic support. Furthermore, it directed that anyone requiring additional support to prevent or manage a crisis should be offered support from a hands-on intensive 24/7 multidisciplinary health and social care support, with specialist knowledge in managing behaviours that challenge, within any community setting to prevent placement breakdown and avoid admission. As an overarching principle, all services were expected to work in close collaboration, building support around the individual, and provide a 'seamless' interface between services (NHS et al. 2015c:22).

The issue of those who may be at risk of being diverted into a hospital setting due to contact with the criminal justice system was also addressed, with principle eight enshrining their right to have "…access to the same services aimed at preventing or reducing anti-social or 'offending' behaviour as the rest of the population", in addition to specialist multidisciplinary health and social care support (NHS et al. 2015c:24). To enact this, commissioners were directed to ensure that a community forensic function for this group was offered (NHS et al. 2015c:25). Principle nine, as the last associated directive, reinforced the key aims, processes, and tools outlined prior to the beginning of the programme. These included mandates such as only admitting patients when their care and treatment could not be delivered safely in the community, undertaking either a pre-admission CTR or blue light meeting, and utilising mainstream inpatient services where appropriate (NHS et al. 2015c:31).

Additionally, there was a clear expectation that lengths of stay would be minimised, with the challenge having been set in Building the right support (NHS et al. 2015a) as "… one 'fast track' area aims to reduce length of stay in assessment and treatment services to an average of 85 days." (NHS et al. 2015a:6). This was to be supported by six-monthly CTR’s and discharge planning from the point of admission to expedite discharge (NHS et al. 2015c:26). All efforts to ensure the person would be as close as possible to their ordinary place of residence was also expected after the previous interim report had found:

> *“Some of the people we met, and their families, complained that they were given little say in where they were sent, which fails to meet the requirement safeguarded in the NHS Constitution that patients be allowed to make choices and be involved in decisions about their NHS care.”* (DHSC, 2012:13).

With multiple guidance documents being issued and detailed objectives being outlined, the commitment of the Transforming Care Programme appeared resolute in tackling the perceived issue of overuse and reliance on specialist inpatient services. As a three year programme time was limited, however, with high visibility on the political agenda, underpinned by a simplistic assumption that the risk of abuse in hospitals could be eradicated by reducing both inpatient numbers and beds, the scene was set. What was not so clear, was how much consideration had been given to the inevitable consequences that this would bring.

2.4 Current thinking

The need for additional psychiatric support in a designated environment for some people with learning disabilities, has never been in dispute. Even Mansell (2007) noted in his eponymous report that:

> *“The appropriate role for psychiatric hospital services for people with learning disabilities, where these will have a continuing existence, lies in short-term, highly focused assessment and treatment of mental illness. This implies a small service offering very specifically defined, time-limited services”* (DH 2007:17).

Statistically, any given population has a proportion of people with mental health conditions, and for people with learning disabilities, this is no different (Mental Health Foundation 2016). The most recent national Adult Psychiatric Morbidity Survey (NHS Digital 2014) identified that across the general population, lower intellectual ability was associated with higher symptomatic rates of common mental health conditions (25%) compared to those with average (17.2%) or above-average (13.4%) intellectual functioning (NHS Digital 2014). Research focused specifically on those with learning disabilities has also found that higher prevalence rates are common within this cohort, with some suggesting it could be up to double that of the general population (Cooper et al. 2007, Emerson & Hatton 2007, NICE 2016), despite possible diagnostic overshadowing (Javaid et al. 2019), and variation due to diagnostic criteria (Hatton et al. 2017, McCarron et al. 2017). Social disadvantage has also long been found to be associated with poorer mental health outcomes (Emerson & Hatton 2007), and more recent studies have discovered significantly higher levels of psychiatric conditions in people with learning disabilities who have been exposed to traumatic life events (Bond et al. 2019).

In terms of patient profile, research suggests that the cohort of people with learning disabilities more likely to be at risk of placement breakdown and inpatient admission are those who are deemed to have ‘challenging behaviours’ (Mansell et al. 2001, Taggart et al. 2009, Oxley et al. 2013). The relationship between behaviours that are challenging and psychiatric disorders is much deliberated, and prospective causes include possible latent mental health disorders, which have not yet been recognised or formally diagnosed (Alexander & Singh 1999, Emerson et al. 1999) or a potentially atypical presentation of depression (Meins 1995). The finding that anxiety disorder is one of the most frequent diagnoses made within this cohort (King et al. 1994) is also noteworthy.

Within this sub - group, those most at risk of recurring re-admissions are those classed as having severe challenging behaviour (Seager et al. 2000). For this group, Emerson (1995:3) explains that “…severely challenging behaviour is not a transient phenomenon.". It is this lack of transiency resulting in enduring or reoccurring presentation, and the consequential level of augmented risk, which is identified as the leading cause of hospital re-admission due to safety concerns (Seager et al. 2000). Moss et al. (2000) also found that an increase in the severity of challenging behaviour directly correlated with an increased prevalence in the presence of psychiatric symptoms and highlighted the difficulty demarcating between where the challenging behaviour may serve to exacerbate a coexisting psychiatric condition, and where it is a product of a psychiatric condition. With similar findings, Myrbakk et al. (2008) subsequently questioned if the behaviours were, in fact, atypical symptoms of a psychiatric condition or if living a challenging life was the causative factor of both the condition and the behaviours. Later studies conversely argued that, despite overlap, the presence of challenging behaviours was independent of co-morbid psychopathology in adults with learning disabilities (McCarthy et al. 2010, Thakker et al. 2012).

Intensifying the debate is the acceptance that challenging behaviour in itself is not a diagnosis (NICE 2015:6), but rather a socially determined construct (Royal College of Psychiatrists 2015:4), and as has been highlighted, is not always clear in origin. Given the range of cited causations and conflicting perspectives, it is understandable that medicalisation of a person with learning disabilities, or application of the medical model theory, is a contentious issue (Shearer 1980), with some suggesting that the model is outdated and obsolete (Hallawell 2009). Derived from the biomedical view of disability, the model is based on the supposition that the resultant impairments may impact upon a person’s quality of life, and that with suitably prescribed medical intervention and treatment, this will lessen or be remedied (Fisher et al. 2007).

Proponents of the social model of disability offer further alternative explanations for challenging behaviour such as organisational culture and environment (Olivier-Pijpers et al. 2017), and delays in social interaction and communication skills (Luo et al. 2019). The differing perspectives of causation and association between development, environment, mental health conditions, and challenging behaviour is pertinent to the debate, as it brings into question if the presentation is therefore ‘treatable’ within a medical model. Ultimately it is widely accepted that the origin is not linear, and the exact determinants of challenging behaviour are likely to be multiple and complex, ranging from historically learnt behaviours to a combination of bio-social, psychological, and environmental factors (Moss et al. 2000). However, given the contentious nature of detaining someone in hospital for medical treatment, versus alternatively managing their environment in the community, it is clear to see the potential implications for the person with learning disabilities depends upon the worldview of decision makers.

‘Treating’ a person with learning disabilities with medication has gained increasing focus since the Winterbourne scandal (Sheehan 2017) when a national study found an over-reliance on psychotropic drugs, particularly antipsychotics, administered to those with learning disabilities and challenging behaviour in cases where no mental health condition had been diagnosed (Sheehan et al. 2015). In response, a national programme entitled Stopping Over Medication of People with learning disabilities, autism, or both (STOMP) was launched by NHS England in 2016. Guidance published for clinicians and GP’s (NHS England 2016) called for a planned reduction and stoppage of psychotropic drugs which they identified, in many cases, had been inappropriately prescribed as "…a 'chemical restraint' to control challenging behaviour, or in place of other more appropriate treatment options." (NHS England 2016:2).

Within a landscape of treatment and intervention options being increasingly scrutinised and questioned, the growth in projected population figures and acuity of presentation (Clifford & Kemp 2020), becomes progressively noteworthy. On-going advances in healthcare and standards of living, in line with the general population, have naturally meant that people with learning disabilities are living longer, both with increased rates of survival for premature births and into older age (DH 2001, RCN 2011). Accordingly, projections of future demographics predict that between 2001 – 2021, the number of people with learning disabilities across the UK and internationally will increase by 14% (Emerson & Hatton 2009). As would be expected given these advances, correlating increases are also seen in those defined as having 'multiple and complex needs', such as co-morbid health conditions and behaviours described as challenging (Parrott et al. 2008). In adjunct, it has been found that a third of people classed as having a profound or severe learning disabilities also have an associated ASC (Emerson & Baines 2010). The increase in prevalence of complexity in these two population cohorts are salient given the propensity of those with behaviours that are deemed to be challenging, and those on the autistic spectrum, having been identified as being at higher risk of mental health inpatient admission (Washington et al. 2019). Similar rising trends were also confirmed in a longitudinal study undertaken by Wong et al. (2015) over five decades (1975 – 2013), where between 2011-2013, 86% of those admitted to a specialist inpatient hospital had more than one reason for admission, of which 90% presented with behavioural issues alongside a co-morbid psychiatric condition (Wong et al. 2015:111).

Increasingly complex presentations and an inability to definitively identify a singular causative factor that puts those with learning disabilities at higher risk of displaying challenging behaviour are important considerations within the debate, as it may result in the continued upward trajectory of inpatient numbers in this cohort. This is because although having an learning disabilities in itself is not eligible for detention or treatment under the Mental Health Act (1983 amended 2007), the co-presentation of challenging behaviour is sufficient to enact the process. During revision of the Act in 2007, the definition of what had previously been termed a mental disorder was altered in s1 to one of "any disorder or disability of the mind" (s1 MHA1983). Of significance to people with learning disabilities and challenging behaviour, is that if s1 of the Act is “associated with abnormally aggressive or seriously irresponsible conduct on his part" (s2a MHA 1983), then this is clinically sufficient to detain them under either s2 for assessment or s3 for treatment, without a diagnosed mental health condition. This lack of a diagnosis is controversial as it calls into question the ability to meet the appropriate medical treatment requirement in the MHA (s4 2007), formerly known as ‘treatability’, which some have contended therefore constitutes an illegal act when detaining people with learning disabilities and/or autism (DH 2015a:41). To add to the debate, the depletion in national bed stock has pushed up admission thresholds, and with admission now only considered for patients who have been formally detained, informal patients are now in the minority (Wong et al. 2015).

Another patient group with learning disabilities at higher risk of admission into specialist inpatient services are those diverted from the criminal justice system (Devapriam et al. 2015). Although prevalence is notoriously difficult to secure (Myers 2004, Prison Reform Trust 2007) due to the presence of learning disabilities being extensively overlooked by the criminal justice system (Her Majesty’s Inspectorate of Probation 2015), it has been noted that more than one in five people in learning disability hospital settings have been detained on part III of the Mental Health Act with a Ministry of Justice restriction (NHS et al. 2015a: 23). Additionally, there is a school of thought that despite the broader national drive to reduce the number of people with learning disabilities in hospital it "…may be the right place for some of this group (for clinical reasons often combined with Ministry of Justice restrictions)" (NHS et al. 2015a:22).

For this patient group, it is not the decision to admit that presents the dilemma, as this responsibility sits outside the jurisdiction of clinicians, but more so a timely discharge and repatriation due to any restrictions (MHA s37/41) and enhanced supervision conditions imposed by the Ministry of Justice (MOJ). In these cases, not only does the person have to be deemed medically fit for discharge by the clinician, but also has to secure permission from the MOJ, which can take an extended period of time. A possible rationale for such a delay may be explained by Hayes (2004), who argues that diversion into hospital is not always beneficial for the person with learning disabilities for several reasons and can lead to "indeterminate incarceration" (2004:71) due to the need to prove rehabilitation to gain freedom rather than the defined end of a custodial sentence. Haynes (2004) also observes that for some of those diverted, this can be ordered before a hearing is held, and therefore can place people who have only been accused of a crime, and not proven, into the unconscionable position of having to demonstrate their ability to not 're-offend' prior to release.

The bias in the system for people with learning disabilities can, therefore, lead to extended stays within specialist inpatient services, with Butwell et al. (2000) finding disproportionately increased lengths of stay for those defined as having a 'severe mental impairment' than the general population in secure hospitals. The additional challenges of discharging and resettling such patients back in the community was also acknowledged in 'Building the right support' (NHS et al. 2015a) explaining:

> *"In many cases, it will involve close collaboration not just between the NHS and social care, but also with parts of the criminal justice system, building on recent joint work between NHS England and the Ministry of Justice to facilitate discharges of patients subject to restriction orders* (NHS et al. 2015a:23).

As a result, the complexity in operationalising and achieving the key aims of the Transforming Care policy within this patient group is largely obscured and not immediately obvious when judging overall impact.

Irrespective of one's view on the use of specialist inpatient beds as an alternative to the criminal justice system, using hospitals for those who have or are at risk of offending has long been accepted as an additional arm of the judicial system (MHA 2007). However, as we have seen, the position on using specialist inpatient beds for those with challenging behaviour is not as clear cut due to the opposing medical and social model perspectives and the difficulties in identifying causation of the distress. The commonality for both is the dichotomy for clinicians, operational managers, and commissioners in ensuring that not only is the optimum quality of intervention and support safely delivered to those with the most complex needs, but also public safety is protected, all within the context of sustained political pressure to reduce the use of specialist inpatient services and meet national targets.

The current political view on specialist inpatient hospitals for people with learning disabilities is somewhat confounding. Consigned to the broader NHS Long Term plan, services for people with learning disabilities are no longer afforded a discreet policy, suggesting the level of priority and focus may have lessened (NHS 2019). The concerns, however, have not abated and in November 2018, following national exposure of the stark conditions a young female patient was being kept in at the charity-based St Andrew’s Healthcare hospital (Birrell 2018), Matt Hancock, the incumbent Health Secretary, ordered CQC to review the use of restraint, prolonged seclusion, and segregation for people with learning disabilities and/or an ASC. The interim report released in May 2019 (CQC 2019a) was closely followed by the Joint Committee on Human Rights also publishing their inquiry findings (House of Commons & House of Lords 2019). Contemptuous in its view, the report did not hold back and conveyed the committee’s loss of assurance not only in government policy but also in CQC as the regulating body, stating that:

> *“We have lost confidence that the system is doing what it says it is doing and the regulator’s method of checking is not working. It has been left to the media…to expose abuse. No-one thinks this is acceptable.”* (House of Commons & House of Lords 2019:3).

With a follow up report presented to the House of Commons in October the same year identifying that the “care given to people with a learning disability or autism is not acceptable” (CQC 2019b), the government responded by setting out key actions. This included every person with learning disabilities receiving a review within the next 12 months to identify a discharge date; a regional dashboard of patient data identifying inpatient numbers; £1.4 million government funding to deliver mandatory training to every NHS and social care employee in learning disabilities and ASC; and an independent panel to oversee the reviews of those in long-term segregation (Department of Health & Social Care 2019). However, the plan was perceived as too little too late, and in February 2020, the Equality and Human Rights Commission (EHRC) concurred with the findings of the Joint Committee on Human Rights and launched a legal challenge against the Health Secretary citing that the failure of the government to meet the targets set in the Transforming Care and Building the right support programmes constituted a breach in the European Convention of Human Rights (ECHR). Moreover, it expressed concerns that it was not satisfied the new deadlines set out in the NHS Long Term Plan and planning guidance would be met, suggesting “a systemic failure to protect the right to a private and family life, and right to live free from inhuman or degrading treatment or punishment.” (EHRC 2020).

Although presumed to be on hold due to the international COVID pandemic, it is clear from this recent legal challenge that not only is it felt that the overarching aims and objectives of the Transforming Care Programme were not met, but also the complex systemic issues within specialist inpatient services, and therefore potential solutions, are still not fully understood. In July 2020, most likely as a result of this impending action, the Health Secretary called for a “renewed focus” on ensuring people with learning disabilities were discharged back into the community “promptly”, with an associated £62 million Community Discharge Fund (Department of Health & Social Care 2020). Differing from Transforming Care in shifting the responsibility away from NHS Trusts and commissioners, on to local authorities, the money will be released over the next three years. However, some still feel this may not be enough (Kendall-Raynor 2020), with the Voluntary Organisations Disability Group (VODG) having previously called for a figure of £400 million over four years to improve community services to the required standard to ensure the best chance of success (VODG, 2019).

By issuing the Community Discharge Fund and calling for a “renewed focus” on discharging people with learning disabilities back into the community it appeared that the apparent direction and thinking of the government was one of continuing to support the reduction of use in specialist inpatient services (Department of Health & Social Care 2020). However, in the very same month the announcement was made, £33 million of public money was also authorised to build a new 40 bedded low secure specialist inpatient hospital for people with learning disabilities and ASC by Mersey Care NHS Foundation Trust (BBC 2020). With conflicting messages, ascertaining how the current government sees the future of specialist inpatient services for people with learning disabilities has become ambiguous. Furthermore, with a figure far short of what has been deemed required, it is unclear what the Community Discharge Fund will be able to further achieve in the absence of a "… robust, cross-government strategy to drive forward the transformational change required to truly transform social care" (Harris cited in Clarke 2020).

2.5 Themes from recent research

Contemporary research on the use of specialist inpatient services in recent years is relatively scant, but those undertaken have, unsurprisingly focused on numerous areas of efficacy against the dominant tenets of the Transforming Care Programme. A study by Washington et al. (2019) identified some familiar and recurring themes such as increasing admission rates, extended lengths of stay, and delayed discharges, exceeding professional standards (Nawab et al. 2008, Learning Disability Professional Senate 2016). Reasons for admission also resonated with earlier studies and found that various presentations of challenging behaviour ranked in the top three categories, followed by mental health conditions in fourth position, and diversion from the criminal justice system in seventh (Washington et al. 2019).

For Purandare et al. (2015) within the small hospital unit they studied there had been a reduction in mean length of stay post – Winterbourne, but on review of the referrals it became evident that, as a result of bed closures in other areas, a doubling of the distance patients and their families had to travel had occurred. Arguing that local inpatient services needed to be retained, the paper asserted that services far away from the patient’s ordinary residence lacked oversight of local community services, resulting in prolonged transitions and delayed discharge. More generally Sandhu et al. (2015) agreed that specialist inpatient hospitals as a service model should be retained. Comparing patient demographics and clinical characteristics of those receiving support from a community learning disability team, and those requiring admission to a specialist inpatient hospital, the study found that the demographics significantly differed. Concluding just prior to decommissioning of their local ten bedded unit, it questioned the underlying assumption that expansion of the community team would be sufficient to prevent all future admissions when such distinct and differing needs had been identified.

Conversely, after finding that people with learning disabilities were at risk of higher rates of inpatient admissions than could be explained by prevalence within the general population, James et al. (2017) argued that investing in alternatives to inpatient hospitals would lead to more people with learning disabilities being able to live independent lives. Postulating a possible correlation between higher admission rates in those areas where higher numbers of specialist inpatient hospital beds were available, it suggested that greater focus on understanding the socio-economic and cultural aspects behind inpatient admission rates was required if further bed reductions were to take place, and alternative community support options increased.

Beyond measuring the outcomes of policy objectives quantitatively, qualitative studies have also captured the experiential element of the policy in practice from the perspective of patients and family members using specialist inpatient services. Associated with having “done something bad” (Head et al. 2018) the preference for living in the community over residing for extended periods of time in hospital, and the associated freedom this brings unsurprisingly comes through as a very clear message from former inpatients with learning disabilities (Turner 2019). The impact on human rights and the questionable therapeutic benefit of detention, seclusion, and restraint for people with learning disabilities, have all, justly, been raised as persuasive arguments for closing all specialist inpatient hospitals (Three C’s et al. 2020). However, for carers and family members, with differing considerations, conflicted feelings such as disempowerment, alongside those of relief when their relative was showing extreme signs of distress, were commonplace on admission (James 2015). Irrespective of both positive and negative experiences of specialist inpatient services, families clearly felt that, at times, an alternative was needed when things had broken down in the community and the situation felt unsafe (Williamson et al. 2018). The ideology of living in the community was also not without its problems, and although the ability to be settled and safe was found to have been achievable, an individual's quality of life was not always improved unless support providers were willing to work pro-actively to overcome such barriers (Niven et al. 2020).

As noted by Kerrigan et al. (2017) research into factors specifically influencing the delivery of national policy within learning disability health services is exceptionally limited. Focusing primarily on the commissioning of learning disability services, he found that national policy has had little sustained impact (Kerrigan et al. 2017). This echoed the findings by McGill et al. (2010) pre-dating the Transforming Care programme, who measured service commissioning outcomes for people with challenging behaviours against recommendations made within the Mansell report (DH 2007). The most recent study in this area, commissioned by NHS England, undertook a comprehensive national mixed methods review against the broader objectives of the 'Building the right support' policy and Transforming Care programme as a whole (The Strategy Unit et al. 2018). Awaiting final publication at the time of writing, the review used case studies from 10 Transforming Care Partnerships, a survey of frontline professionals, people and families, and interviews with national and regional stakeholders. Preliminary findings suggested that overall operationalisation of the policy and programme was variable (The Strategy Unit et al. 2018). Furthermore, it also found that Transforming Care Partnerships had been overly focused on closing inpatient beds, to the detriment of strengthening community provision (The Strategy Unit et al. 2018). As a result, it lamented that:

> *“Building the right support stated that no-one should spend time in hospital due to a lack of appropriate community provision…These ambitions remain right; evidence shows progress, yet the vision remains unfulfilled.”* (The Strategy Unit et al. 2018).

A final study of interest, again focusing solely on the efficacy of the Transforming Care Programme, in common with other studies, found that targets to reduce inpatient numbers had not occurred. Also challenging the government suggestion of a 20% reduction in numbers, to one more realistically of 14%, the study identifies that the funding requested by health and local authorities to support the reduction was not forthcoming, and therefore their ability to fully realise the objectives of the policy was impeded. Overall, the study concluded that although some areas of the policy were helpful, the lack of people with learning disabilities and their families leading on the programme was ultimately the reason for its shortcomings (Brown et al. 2019).

2.6 Summary

The aim of this literature review was to set out some of the main areas of influence and interest to the study and give a comprehensive backdrop to both inform and identify where the gap in knowledge lies. It is evident from the review that the hospitalisation of people with learning disabilities has become an increasingly contentious issue as societal and political awareness and attitudes towards people with a disability have evolved. It is also clear that the seeds of public concern and discomfort around the use of such hospitals that first gathered momentum in the late 1950’s remains unresolved, and the continuous exposure of national scandals of abuse in specialist inpatient services, despite numerous policy attempts to curtail such situations, also provides an evidence base that is hard to reconcile.

However, closure of all, or the majority of specialist inpatient hospitals without a robust alternative, has not provided a suitable solution, and indeed, there is evidence to suggest may lead to further unintended consequences. Consideration of the patient profile and increases in acuity and complexity of presentation and life expectancy, alongside the views of families and carers at times of high risk, also highlight the need to carefully consider pressing ahead with any further bed closures in the future. The persistent policy drive to reduce such beds has, naturally, led to a smaller pool of availability, with research indicating that this has resulted in people being admitted to facilities further away from home, making effective monitoring and oversight, in addition to family contact and timely discharge, more difficult to achieve.

For those looking to the government for guidance on how to manage learning disability services to address these issues for people with learning disabilities and their families, their more recent position is somewhat confusing. With millions of pounds of public money concomitantly allocated to both expedite discharge for those in hospital, whilst conversely financing a substantial new secure specialist hospital for people with learning disabilities and ASC, the direction of travel is unclear. Additionally, with the objectives for specialist inpatient care now being subsumed into the NHS 10 year plan, and former research indicating a lack of efficacy in terms of policy sustainability, the impetus and focus appears to have been diluted. Given this position, the impending legal action against the government by the Equality and Human Rights Commission (EHRC 2020), and the affect this is all having on people with learning disabilities and their families, it is asserted that now, more than ever, research that improves clarity and insight around the complexities and challenges that exist within specialist inpatient services would be helpful in informing future policy considerations.

Chapter 3. METHODOLOGY

3.1 Introduction

This chapter initially gives a brief synopsis of supplementary immersive opportunities undertaken whilst researching this field, which provided a richer experience in relation to investigating the subject matter. The theoretical underpinning of the chosen methodological approach, and the rationale for using mixed methods explanatory sequential design as the most appropriate to meet the overall aims and objectives of the research is then discussed. An explanation of the research methods used in each stage of the study is followed by how the sampling strategy was approached, before exploring the data analysis. The chapter then moves to the ethical considerations that were made throughout the study before elucidating the how academic rigour was ensured and concludes with a summary of the research boundaries.

3.2 Additional immersive opportunities

In addition to undertaking the formal methodology of the study, as an NHS employee within learning disability services, numerous opportunities to contextualise the wider forum within which specialist inpatient services operate were available. This included attending the local Transforming Care Partnership strategy meetings monthly as an observer, whereby all those patients currently under commissioning in that area and their movement was discussed. This afforded insight into both local management of the Transforming Care Programme, and also the challenges affecting achievement of the overall aims and objectives. Regular attendance also facilitated networking opportunities and links with other interested parties in the study. One such signposting was to another researcher who at the time of the study was leading on an NHS

England commissioned evaluation of the overall Transforming Care Programme and led to sharing of their preliminary findings. Another contact made was with the NHS England national lead for learning disabilities, and this resulted in a detailed discussion around the issues as perceived by NHS England and the future direction of services, all of which, although it could not be included in the study, added to the researcher's knowledge base and awareness of current issues.

Further opportunities arose in the form of attending Care and Treatment Reviews (CTR's) for inpatients within our service as an observer. Observing these reviews, one within county and one out of county, again allowed for an appreciation of the range of challenges that can prevent timely discharge, and therefore intrinsically, some of the complexities this service model design can present. Outside of the workplace, leading academics in the field of learning disabilities were contacted to share their experience and advice in attempting to secure the most current and relevant datasets identified as useful to the study, which naturally facilitated further discussion around the research.

3.3 Theoretical context

The aim from the outset was to fully exploit any data collected within the study to its maximum benefit in terms of impact upon practice and service provision going forward, so identifying which philosophical approach most closely aligned with producing a rich, all-encompassing perspective was imperative. This led to selecting Pragmatism (Baškarada & Koronios 2017; Žukauskas et al. 2018) as the most apposite approach in meeting the aims of the study, having the distinct benefit of overcoming the limitations of using a single design, assisting in a holistic explanation and interpretation of the phenomena under investigation, and addressing the research questions at different levels (Biddex 2018).

Pragmatism's epistemology conveys that there is no singular approach to acquire learning, but multiple ways of understanding any given scenario, as there are multiple realities (Biesta 2010, Saunders et al. 2012, Collis & Hussey 2014). Originating in the late 19th century in the USA, pragmatism as a theoretical doctrine rejected the notion that social science inquiry could accurately reflect reality by the use of a single scientific method (Maxcy 2003). Noted by Creswell (2009:10) as "… not committed to any one system of philosophy and reality", pragmatism, as the name suggests, very much views the world from a practical lens, with an emphasis on using whatever means necessary to generate new world knowledge (Tashakkori & Teddlie 1998).

Pragmatism is arguably the most common philosophical framework within which to conduct mixed methods studies, which involve "…the collection, analysis, and integration of quantitative and qualitative data in a singular or multiphase study." (Hanson et al. 2005:224). Exponents of pragmatism assert that as an alternative strategy, it facilitates a much broader combination and consideration of both the nature of reality in statistical terms, in tandem with the objective perspectives of those involved in the phenomena (Pope et al. 2006). Critics highlight a perceived inability to address the differing assumptions within quantitative and qualitative paradigms (Sale et al. 2002), with Cameron (2011) also arguing that its use within a mixed methods study risks "Epistemological relativism and short-sighted practicalism" (Cameron 2011: 97). Nevertheless, it is that same ascribed practical flexibility, whereby more emphasis is placed on finding the answer to a question (Onwuegbuzie & Johnston 2006) as opposed to procrastinating over which orthodox singular approach or underlying philosophy is adopted, which Morgan (2007:70) contends provides "… new options for addressing methodological issues in the social sciences”, and Creswell (2009) states has the added advantage that “…the combination of both approaches can offset the weaknesses of either approach used by itself” (Creswell 2009:9).

3.4 Research Design

The rationale for choosing a three-staged mixed methods approach using the explanatory sequential format was due to an awareness that the majority of performance data within the NHS is collated quantitatively. Although this provided a logical place to start, the study’s overriding aim was to understand the complexities and challenges that were present in the current system, and, as noted by Anderson (2010:1) healthcare “involves complex human interactions that can rarely be studied or explained in simple terms”. As a result, it was recognised that one dimensional quantitative performance figures would need further explanation through qualitative data to fully contextualise the prevailing picture. Once the quantitative data had been received, it quickly became evident that, due to the varying state of completeness, full statistical analysis would not be possible, and therefore the collection of high quality qualitative data became a priority. Given this identified need, individual interviews with the expert participants was chosen as the most effective method to illicit data that was reliable and dependable. Undertaking interpersonal interaction with each participant built trust and allowed for spontaneous follow up questions that would not have been possible if an alternative such as a focus group has been used. It also ensured confidentiality for the participant to speak freely and, due to the senior nature of the roles of the participants, facilitated the flexibility to fit in with their busy schedules. Moreover, personal contact pre-interview resulted in a 100% response rate, which, it is asserted, would not have been achieved by an alternative such as a questionnaire.

In brief, the three stages were achieved by initially collecting secondary published data in nine Clinical Commissioning Group (CCG) areas within the sample around population of need and extracting themes from service delivery models within the co-authored Transforming Care Programme plans. This was followed by harvesting quantitative performance data via survey of each CCG for closer analysis, and concluded with qualitative interviews of 16 expert participants, to further explore the findings from the preceding stages (Creswell 2015) by testing for any emergent themes or significant relationships (Bryman, 2004).

To ensure coverage of the topic matter was comprehensive, and the research aims fully addressed, the following areas were examined. In addition, the stages of the study in which these were explored are also highlighted, thereby demonstrating concordance with the explanatory sequential mixed methods design:

- The wider history of the service, including introduction of the Transforming Care Programme, and the current picture. (Literature review, stage two, and stage three).

- The NHS service model for people with learning disabilities in each area of the sample group, the rationale, and how they operated. (Stage one and stage three).

- The performance of NHS Trusts and CCG’s either with or without local specialist inpatient beds in the sample group against the key aims and objectives of the Transforming Care Programme. (Stage two and stage three).

- Implementation of current policy in each area and identification of challenges in the system. (Stage one, stage two, and stage three).

- Any broader complexities and challenges in the use of specialist inpatient beds requiring consideration going forward. (Literature review, stage two, and stage three).

Findings from the research relating to each stage of the study are initially chronologically reported and the broad emerging themes and implications for policy, practice, and research subsequently discussed in the concluding chapter.

3.5 Research methods

As a mixed methods study a range of data collection methods were used at each stage to collate and analyse both primary and secondary data which are now discussed in further detail.

3.5.1 Stage One: Secondary Data and Report Review

Data from each area in the region was gathered from the Institute of Public Care's Projecting Adult Needs and Service Information (PANSI) demographics database to indicate the associated learning disabilities population of need. It also felt pertinent to define further those identified as presenting with challenging behaviour, given the increased risk of that sub - population requiring inpatient admission (Emerson et al. 2001, Glover et al. 2012).

Succeeding this, each area's Transforming Care Plan was obtained and salient areas of their existing, or aspirational service model were extracted. Drawn up in response to the Winterbourne concordat (Department of Health 2012b) by Transforming Care Partnerships[3], and under national guidance (NHS England et al. 2015a), each plan strategically sets out the locale's multi-agency partnership service models and any future intent. With some plans being co-authored by more than one CCG, this resulted in a total of seven plans for review across the nine CCG's sampled. The aims of initial review and examination were two-fold in securing a preliminary outline of the established and aspirational service delivery model and facilitating initial thematic extraction for subsequent investigation. In addition, this information, as is characteristic of the explanatory sequential mixed methods design (Creswell 2015), then influenced and shaped the qualitative semi-structured interviews undertaken in stage three, where questions about the plans and configuration of the service model were used to review progress and further explore service availability in each area (DeCarlo 2018). Participants' perceptions of the challenges and complexities within their service model could then also be viewed within the context of what they had set out to achieve and what they had actually been able to deliver.

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[3] https://www.england.nhs.uk/publication/mapping-of-clinical-commissioning-groups-to-transforming-care-partnerships/

3.5.2 Stage two: Quantitative data collection

Being mindful of the requirement for all CCG's and NHS funded care providers to submit monthly national datasets on patient movement, it was decided that information modelled on these existing data collection requirements would provide a 'snapshot' representative picture of the target population (Lavrakas 2008a), and patterns of use within specialist inpatient services. The benefits of collation and analysis of secondary data in quantitative studies are well documented (Dale et al. 1988, Smith 2008) allowing for consideration and processing of large amounts of data across a wide geographical area and over a significant period within the constraints of limited resources (Johnston 2014).

The timeline identified for data extraction was between February 2015 – September 2018. The rationale for the start date was alignment with the point at which collation and publication of the data were taken over by NHS Digital from NHS England, and the requirement for data broadened in preparation for the Transforming Care programme commencing April 2015. The end date correlated with the period within which stage two of the study was being executed.

Consideration was initially given to accessing the data directly from NHS Digital as the most contemporary public record of patient throughput across secondary specialist services. At the time of the study, this consisted of two datasets; the more established being the Mental health statistics data set (MHSDS)[4] requested from NHS funded service providers, including those in the independent sector. The second more recently

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[4] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set

introduced being the Assuring Transformation collection (AT) [5], submitted by English CCG's for services commissioned and provided by healthcare organisations in England.

While objectively considering the merits of each dataset for use within the study, on initial review, there were two key challenges; primarily, there were noted variances between the two datasets. At the time of the study, the root cause of the incongruity was unverified; however, it was acknowledged that the scope of each data set was slightly different; the MHSDS data being from providers based in England and including care provided in England but may also be commissioned outside England. Whereas the Assuring Transformation data was provided by English commissioners and would typically be submitted in England, but also included data on care commissioned in England and provided elsewhere in the UK [6]. This obscured the decision on which would be the most accurate dataset to use.

The second challenge that presented itself were that the datasets published by NHS Digital were aggregate within defined geographical territories across England, and the configuration and presentation of the data did not geographically align with the region under study. In an attempt to obtain the data in sufficient detail for the area under study, an initial Freedom of Information Act (FOI) (2018) request was made directly to NHS Digital (appendix 1). Upon receipt of their response (appendix 2), it became apparent that any attempt to harvest data from these records for this stage of the study would not be viable. Contact was then made with a leading academic within the field of

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[5] https://www.england.nhs.uk/learning-disabilities/care/atd/

[6] https://digital.nhs.uk/data-andinformation/publications/statistical/learning-disability-services-statistics/at-december-2019-mhsds-october-2019-final

learning disabilities who confirmed they had also been unsuccessfully in attempting to secure similar data historically, and it became evident that individual FOI requests containing a questionnaire would need submitting to each of the nine CCG's within the sample group (appendix 3).

In stage two of the study, in terms of general efficacy of the service model against the broader Transforming Care Programme aims, there were three main areas of interest: inpatient numbers over the study period, number of patients placed > 50km from their usual place of residence, and comparative lengths of stay. A fourth area of interest concerning relative average bed costs of private provision against that of an NHS bed was also posed to ascertain if this appeared to have any influence on the use of specialist inpatient services for people with learning disabilities.

A total of eighteen questions were asked within the FOI requests covering the four areas of interest to the study, which, it was anticipated would present the possibility of undertaking a more sophisticated analysis of patient movement and the prevailing picture. Sixteen of these mirrored the data requested within the AT returns, having been purposively chosen to ease and expedite collation, with the remaining two formulated to ascertain a broad cost comparison between specialist inpatient beds in the NHS and those in the private sector Overall responses to the initial request for information from CCG's were exceptionally variable, with one CCG returning a full AT dataset and another fully answering all eighteen questions. Of the remaining seven, five partially answered the questions, one stated that it did not hold sufficiently detailed datasets to provide any information, and one asserted that as the figures related to less than ten patients, under Section 40(2) of the Freedom of Information Act (2018), releasing it would contravene the GDPR Act (2016) and Data Protection Act (2018). Within two of the partial responses received, the reason given for lack of full disclosure cited the Freedom of Information Act (2018) Section 12 (1) relating to time and cost implications that exceeded the eighteen-hour limit set out in the Act.

As a result of incomplete datasets and the disparity in response levels, a second FOI application was submitted to seven CGG's that had not provided a complete initial response, this time requesting a full copy of the anonymised Assuring Transformation dataset within the specified dates (appendix 4). Again, responses varied, with two further CCG's suppling an AT dataset with redactions to protect patient identity, one of which had essential information missing. After attempting to secure this over an eighteen-month period, it was ultimately unable to be supplied due to a change in data systems, and thereby invalidated all data submitted by that particular CCG. A further five CCG's supplied no AT returns, one supplied no response despite repeated follow-up, and another cited Section 40(2) of the Freedom of Information Act (2018), as above. The remaining three CCG's quoted exemption under Section 21 of The Freedom of Information Act (2018), on the grounds that the information was already publicly available via the NHS Digital website, and therefore accessible by other means, apparently unaware of the aggregate nature of the data published. (See Table 1.)

Table 1: Freedom of Information request for quantitative data - response breakdown by area.

CCG Area code.	No. of FOI applications.	No. of questions answered (/18)	Data submitted 1st application	Data submitted 2nd application
A	2	15	Responses to 15 questions.	Redacted AT return.
B	1	18	Responses to 18 questions.	Not requested.
C	1	0	Full AT return.	Not requested.
D	2	0	Incomplete AT return.	Remaining AT data submitted, but time delay voided data.
E	2	16	Responses to 16 questions.	No data returned. s12 FOI Act: cost of determining data would exceed that set out in the Act.
F	2	13	Responses to 13 questions.	Exemption claimed under s21 FOI Act: reasonably accessible by other means.
G	2	0	No data returned: advised insufficient dataset on record to respond.	Exemption claimed under s40 FOI: risk of identifiable patient data due to small numbers involved.
H	2	17	Responses to 17 questions.	Exemption claimed under s21 FOI: reasonably accessible by other means.
I	2	4	Exemption claimed under s12 FOI Act: cost of determining data would exceed that set out in the Act.	Exemption claimed under s21 FOI: reasonably accessible by other means.

3.5.3 Stage three: Qualitative Interviews

Individual interviews with senior NHS commissioners and operational managers working within learning disability services were undertaken as it was felt important to understand the impact of external and internal influences in each area on the provision of specialist inpatient beds, and the complexities and challenges that exist within the current system. As expert participants it was anticipated that they would be able to convey what had influenced decision making at a local level, and therefore how the current formation of services had been arrived at. Moreover, interviews were an opportunity to shed further light on the quantitative information gathered in stage two, and more closely examine the reasons behind why specialist inpatient beds are still being used, thereby inherently exposing the complex nature of the status quo.

The use of a semi – structured approach permitted identification of key topics and subject matter that had arisen in stages one and two which could then be put consistently to all participants, whilst also allowing for exploration of participants' own topics that naturally flowed from the conversation, thus identifying potential new ways of perceiving, and understanding the topic under examination (Britten 1995). Semi-structured interviews are also best used when there is only one chance to interview the participant as it has a clear and set format which aims to provide reliable, consistent, and comparable data (Bernard 1988). Due to the demanding nature of the roles of the participants, the ending of the Transforming Care Programme in March 2019, and the ever-present retention issues of NHS employees (Buchan et al. 2019), it was anticipated that there would only be one opportunity to secure and undertake interviews with the prevailing post holders.

To aid systematic development and refinement of the interview protocol, strengthen the reliability of interview practice, and therefore improve the quality of data obtained it was designed using the four-stage Interview Protocol Refinement Framework (IPRF) (Castillo-Montoya 2016). Stage one of the process entailed devising a matrix to audit and ensure that the interview questions aligned with the overarching research aims and questions. Subsequently stage two consisted of constructing an inquiry-based conversation, including the addition of an introductory script and prompts for follow up questions. Once completed, feedback on the developed interview protocol was then sought from academic supervisors and then piloted with a professional colleague not associated with the study but with expertise in the field to eschew a "failure to generate the information anticipated from interviewees" (Roulston 2018:12). This offered the opportunity not only to ensure the questions elicited discussion on the topics of interest, but also to test practicalities such as interviewing practice, methods of audio recording, and transcribing. It also gave some indication of what potential themes may emerge. Following reflection upon the experience and resultant transcript with academic supervisors the questions were revised to become marginally more open-ended, with the aim of facilitating a more in-depth discussion and richness of data (appendix 5).

3.6 Sampling strategy

The research used non-probability purposive sampling (Lavrakas 2008) and was based in a region of England. My employing NHS Trust sits within this region, and a study with neighbouring counties which operate within analogous local economies, have comparable populations of need, and face similar geographical challenges in providing a cohesive service to a geographically dispersed population was therefore decided upon. Gathering a regionally focused evidence base was also considered helpful by the Trust in terms of local planning, as one possible long-term solution postulated by the local Transforming Care Partnership board was that of a central regionally-based service to provide specialist inpatient beds for people with learning disabilities. Sampling from one region was also a pragmatic choice adopted within the limitations of undertaking postgraduate study. Using non-probability convenience sampling throughout the study ensured participating organisations and individuals were inherently identified through regional constriction and role, defining the inclusion and exclusion criteria, and therefore self - selecting. As noted by Allen (2017), this can be very helpful where resources, such as the number of researchers assigned to a study, cost implications, and time itself may be limited. A summary of the sampling methods used were as follows (Table 2):

Table 2 - Summary of sampling methods:

Study stage	Data collection type	Sample type	Number
One	Quantitative & qualitative	Population of need – acquired from national database (PANSI).	9 CCG areas
		Local TCP implementation plans – acquired from public publishing on internet.	7 TCP areas
Two	Quantitative	Questionnaire – requested via FOI Act.	9 CCG areas
		Assuring Transformation (AT) returns - requested via follow up FOI Act.	7 CCG areas
Three	Qualitative	Semi – structured interviews of expert sample from NHS learning disability services.	9 Senior NHS Commissioners 8 Senior NHS operational services.

3.6.1 Interview sample and recruitment

In the third qualitative stage of the study, another form of non-probability purposive sampling was used to identify expert participants (Frey 2018). This group consisted of NHS employees that held positions as key decision-makers around the model of specialist inpatient services offered to people with learning disabilities and were chosen to capture a level of experience and subject matter expertise that would be highly useful and insightful (Bala 2017).

Initially Transforming Care Partnership Senior Responsible Officers (SRO's) for each area were identified due to their familiarity and continuing oversight of the Transforming Care Programme plans in their area. However, unfortunately, due to this role ceasing when the Transforming Care Programme ended in March 2019, which coincided with delayed HRA (Health Research Authority) authorisation for the study being granted, this sample group needed to be revised. Further consideration led to a two-pronged approach whereby both senior NHS CCG commissioners and operational service managers assigned to learning disability services were identified as appropriate key informants. The former's participation was believed to be advantageous due to their ability to give a more detailed contemporaneous picture of current service delivery models and emerging developments, with the latter being centrally involved in decision making around contracting of specialist inpatient services for individuals with learning disabilities in their area. In summary, as the study's main focus was on the provision and commissioning of specialist inpatient services, this combined group of expert participants was deemed to have the required level of knowledge and insight to enable exploration of the study's aims.

After expert participants were identified dependent upon job role, the research and development teams in each NHS Trust were approached for agreement to participation in the study through the NHS capacity and capability assessment system. A local feasibility procedure undertaken by an NHS Organisation to assess and confirm whether the organisation has the resources, policies, and patients required to successfully deliver the research study to time and target, capacity and capability confirmation was required as part of HRA approval for the study. Reception of this approach was again mixed; from seven NHS Trusts covering nine CCG areas, three provided written confirmation of capacity and capability, one agreed participation based on additionally receiving an NHS – NHS letter, which confirms the researcher's employment with an NHS Trust, and three agreed to participate following receipt of the HRA and ethics committee approval letters, all of which were subsequently organised directly with the interviewee. CCG's were approached directly as they do not have dedicated research and development teams or a formal application process for research requests. Alternatively, the post holder was contacted to discuss the aims and importance of the study, with the aim of securing their permission and an appointment to interview them, which took an extended period of time.

Once confirmed, all participants were supplied with a copy of the participant information sheet (appendix 6) and a consent form to sign and return (appendix 7). In addition, the interview questions were subsequently supplied, primarily to facilitate participants providing informed consent, but also to help prepare for the interview and state any preferred medium including face to face, via a video calling platform, by phone, or by written submission. Upon receipt of individuals' consent and any stated preferences, appointments were made to interview the participants accordingly.

The interview programme took six months in total, starting in November 2019 through until April 2020 with some appointments requiring multiple re-bookings, reflecting the senior nature of the roles held by the participants. All audio recordings were subsequently transcribed and sent to each participant for factual accuracy checking. Within the overall participant group eight chose to be interviewed over the phone, seven face to face, and two using a video calling platform, with a 100% response rate. For all participants, additional specific verbal permission was sought again prior to commencing the interview to reaffirm consent to audio record the interviews for subsequent transcription and analysis.

3.7 Data Analysis

As the study was mixed methods in nature this required a different approach to data processing, analysis, and comparison for each of the three stages. The approach taken for each will now be discussed further.

3.7.1 Stage one – preliminary information gathering

As a rudimentary starting point, data collection for the first part of stage one, identifying populations of need, consisted primarily of comparison through illustration. As such it did not require further processing or more sophisticated analysis other than consideration of the potential demand on services that may be created as a result. Further data collection in this stage of the study involved reviewing the Transforming Care implementation plan for each area contained within the sample. Participant anonymity was maintained by identifying commonalities and differences in the construct of each service model and producing a thematic description to facilitate a comparison of what each area had available or were aspiring to.

3.7.1 Quantitative data preparation and analysis

As has previously been alluded to, the quality and presentation of the quantitative data received in response to FOI requests varied significantly. Being submitted in various states of completeness and formats and having required two attempts at collation via FOI requests, the data was not sufficiently standardised to be able to undertake statistical analysis. As a result, it was determined that the use of descriptive statistics would be most appropriate in giving a broad summary and overview of the findings.

There were four main areas of interest to the study within this stage, between the sample period of February 2015 – September 2018: 1) monthly inpatient numbers; 2) patients in hospital > 50kms from their usual residence; 3) total lengths of stay; and 4) average bed costs between NHS and private sector.

In preparing the data tables were drawn up, identifying each of the four areas of interest and correlating CGG responses. The data source from each CCG was also identified as either (1) a response to the initial FOI questions, which had been in the form of a questionnaire, or (2) a response to the second FOI request, Assuring Transformation (AT) returns, for clarity. Where data from the initial FOI questions was received these were either directly transposed or calculated, as required, before being recorded in the table (see appendix 10 for an example). For those CCG's that submitted raw data from their AT returns, the most appropriate data contained within the AT reporting template were identified to enable calculation of the figures (see appendix 11 for an example), and naturally these varied dependent upon the area of interest being examined. Therefore, all data received from AT returns was treated as follows for each area of interest:

1. Monthly inpatient numbers by area between the study dates

- Patient ID numbers, appearing in more than one reporting period were recorded to confirm that it was the same patient.

- The earliest date recorded in response to questions Q11a (Start date (hospital provider spell)) or Q11b (Date of first admission to any hospital as part of this continuous period of inpatient care) were then recorded. These were unique, in that there were no two identical repetitions in any dataset meaning it related to the same patient. This identified when the person had been first admitted to hospital.

- The responses to Q38a (Is there an agreed date for the planned transfer?), Q38b (If Q38a is yes, date of planned transfer), and Q40 (actual discharge date) were ascertained. This indicated what month and year they either had, or it was planned that they would be transferred or discharged back into a community setting.

- To then ascertain inpatient numbers per month, the start date (Q11 a/b) and end date (Q 38a / 40), where applicable, were recorded. If no planned transfer date was entered (Q38a), this was deemed to indicate an undetermined end date, and therefore assumed that the person remained an inpatient at the end of the reporting period requested.

- The total number of inpatients per reporting period, per CCG were then established on a month by month basis between February 2015 – September 2018 and recorded.

2. No. of patients > 50kms from usual place of residence

- Patient ID numbers were recorded as a unique identifier as described above.

- Recording the earliest date in response to questions Q11a (Start date (hospital provider spell)) or Q11b (Date of first admission to any hospital as part of this continuous period of inpatient care) as a unique identifier as described above.

- Initially, it had been planned that data recorded for Q8 (Postcode of usual address) would be used as a comparator against Q14c (Postcode of location of care activity) to give a detailed picture of those who had been admitted as an inpatient > 50 km from their usual place of residence. However, due to concerns around potentially identifiable patient data, only one CCG who submitted AT returns had not redacted the information in Q8. It was therefore decided that extracting any meaningful data at this level would not be possible.

- A pragmatic decision was made to use the postcode from the capital city in the county of Q6 (Originating CCG) as a substitute starting place of residence against Q14c (Postcode of location of care activity). This would indicate those placed outside of their usual county of residence, and therefore in all probability, likely to be > 50 km from their usual place of residence.

3. Cumulative total length of stay

- Patients were again coded using the unique identifiers as described above.

- The start date from Q11b (Date of first admission to any hospital as part of this continuous period of inpatient care) was recorded alongside Q38a (Transfer date agreed?) and the date recorded in Q38b (Date of planned transfer).

- Only if a subsequent date was then recorded in Q40 (Actual discharge date) was it interpreted as evidence of that coded patient having left hospital during the period under examination. If no date was entered in this field, then it was assumed that the patient remained as an inpatient for the duration of the study period, and their length of stay was calculated on this basis.

- Similarly, where ‘No’ had been entered into Q38a, this was deemed to indicate an undetermined end date, and therefore a calculation of that person’s total length of stay was recorded based on the end of the study period.

- The total amount of time delineated by the number of years and months spent as an inpatient for the duration of the study period were then rounded up for each month and entered into table.

- Once all patient lengths of stay were tallied up for each CGG a scale of the shortest and longest stays were identified alongside an overall median length of stay in each area during the study period.

4. Average beds costs

This question was asked in the initial FOI requests and could not be repeated in the second request as AT returns do not include this information. Furthermore, as organisations had already responded, it could therefore not be asked again in a second FOI request. In total three CCG’s supplied full responses with an overall monthly average cost for both a private and NHS bed, one submitted a partial response indicating the average weekly cost for a private bed only, and the remaining five responded stating they did not have that information.

Once data had been prepared, each area of interest within the study was examined using univariate analysis across organisations within the sample group, allowing for comparison of distribution and the central tendencies of mean, mode, and median. This form of data analysis was chosen, alongside the medium of descriptive statistics, to present a cross-sectional picture of service provision and patient movement within the sample group at the time of the study, thereby affording a rudimentary comparison of each area to inform the debate at the centre of the research. Initial scrutiny of the quantitative data in this stage allowed for simplistic variations and correlations to be noted and drawn through to influence the questioning and discussions within the semi-structured interviews, as per the mixed methods explanatory sequential design.

3.7.2 Qualitative data analysis

All questions within the semi – structured interview were either directly or indirectly influenced by the findings in the preceding stages of the study and were devised to illuminate these and other issues in more depth. This stage of the research aimed to qualitatively ascertain the prevailing service model on offer in each area; explore how the service model had evolved; evaluate participants' views on the effectiveness of the model and service delivery in their area; and identify any challenges and complexities within the current system using Framework analysis (Ritchie & Spencer 1994). Used widely across different discipline areas within the health sector (McMillen 2008, Smith and Firth 2011, Swallow et al. 2011, Ward et al. 2013), proponents of the approach highlight its ability to offer systematic structure to manage, analyse, and identify common themes within large volumes of text, whilst also being sufficiently flexible to move in multiple directions between and across cases and codes to identify emerging themes as part of an iterative process (Hackett & Strickland 2018). Moreover, it is argued that the lucidity of the process throughout each stage ensures contingent logic and accountability for researcher interpretation, inherently evidencing enhanced rigour (Ezzy, 2002). In terms of epistemological, philosophical, and theoretical approach, Framework Analysis is not exclusively aligned (Gale et al. 2013), and advocates that any resultant analytical ideas, concepts, and themes are "…rooted within the data, rather than superimposed" (Ritchie et al. 2014:280). This method was chosen as it was felt to offer a practical and defined process within which to consider the collective experiences of the sample group. Once collated, the data was taken through the following stages (Table 3.):

Table 3. Stages of data analysis undertaken using Framework method.

Familiarisation	All audio recordings and transcripts were listened to and read though several times. A proportion of the transcripts were also typed up by the researcher, adding to familiarisation and immersion in the data.
Identification of a thematic framework	All transcripts were reviewed and patterns of repetition or similarity within responses noted to produce codes. Using this coding framework all transcripts were then read through again and systematically coded accordingly using NVivo 12.
Indexing	Codes which were deemed helpful in meeting the aims of the research were then considered in terms of broader categories.
Charting	All cases and codes pertinent to the broader categories were assigned to it using a matrix.
Mapping and interpretation	Thematic analysis was undertaken between codes and cases and influenced by the research aims and what had inductively transpired from the data.

By way of immersion and familiarisation with the data, and to elicit a comprehensive overview of the wider content the data presented, particular points of interest were noted during the semi-structured interviews and followed up with probing questions where appropriate. Post-interview a sample of just under half of the audio recordings, seven, were listened to and transcribed, with any recurring topics of interest, or ideas noted as possible codes. All remaining interviews were transcribed by an external professional and checked for accuracy, as some technical terms and acronyms not familiar to the transcriber were used (Corden & Sainsbury 2006), thereby providing an additional opportunity to actively engage with the data.

Next, a preliminary outline of possible codes were identified by sorting and refining the emerging areas of interest and topics noted down in stage one (Furber 2010), to construct an initial framework (appendix 12). This was additionally shaped by other influential factors, such as the initial embryonic foci that had been observed, the research questions that had been asked, and the broader topics under discussion in the semi-structured interviews. The data were then indexed and sorted. Verbatim material from the transcriptions was systematically scrutinised to annotate, label, and assign the relevant narratives and extracts to the most appropriate codes. At this early stage of sorting, it was found that occasionally a response might feel relevant for more than one code, dependent upon what was being stated, and where this occurred, it was multiply assigned accordingly.

Following further refinement and assessment of the coherence between all descriptive extracts, the penultimate stage of data management involved identifying broader categories to which the codes could be assigned and ascertaining if the initial coding labels remained pertinent or needed revising. This resulted in the merging of some codes into broader areas of interest, renaming some, and identifying which category they would most accurately fall under.

The final stage of the process before moving on to the interpretive phase of the analysis, and one unique to Framework analysis, is that of data summary and display. Once catalogued in the matrices, using NVivo 12, descriptive summaries were devised and recorded to provide an overview encapsulating the essence of participants responses to categories, which were then directly linked to relevant transcript text, thus supporting context and translation (Parkinson et al. 2016).

Once the data had been managed through the Framework analysis process, work began on consideration of commonalities and convergences in the responses to the data collected in each stage of the study, which had subsequently informed the questions asked during interview. Final interpretation aimed to offer further enlightenment and context to the findings in the previous stages.

3.8 Ethical Considerations

Ethical considerations were made across each discrete stage of the study, and as the study took place within the NHS, a detailed application was duly submitted to the Health Research Authority (HRA). Following completion of the relevant screening tool, it was determined that a Research Ethics Committee Review by HRA would not be required due to the participants being NHS employees and the study requiring no patient involvement. Once HRA approval had been granted, the study was then subject to the university’s Ethics Committee approval process.

The preliminary gathering of information in stage one used existing material from nationally published statistics and the Transforming Care plans produced by the Transforming Care Partnerships in each area. As such, these plans are widely available within the public domain, and therefore any data used from these did not, in itself, necessitate ethical consideration. However, in order avert any possible recognition between the service models published and the identity of the interviewees describing their local service model in stage three, general themes were extracted from the Transforming Care plans rather than specifics.

In the second stage of the study, data acquired using the FOI process, inherently ensured that any identifiable patient data released had been redacted prior to receipt. For the third stage of the study, all participants had an initial discussion with the researcher about the study, followed by receipt of a detailed participant information sheet outlining the aims, background of the researcher and academic supervisors, contact details of the sponsoring institute, and their right to withdraw at any stage. As a result, participants gave both written and verbal informed consent to participate at several junctures, including initial contact, when signing the consent form, and reaffirmation at the start of the recorded interview.

In stage three thought was given as to how individual data collected via interview from the various expert participants needed to be identifiable for the purposes of processing to the researcher, but then retain anonymity of the individual, and, by association, that of the participating organisation when reporting findings. The result was to code organisational participants alphabetically and individuals by job role and coded organisation as it was felt that having already been defined to one region within the UK, participants needed to feel confident that they could give honest and open responses within their interview without the risk of being identified by organisational proxy.

The other area for reflection and consideration throughout the study, and in particular during the interviewing of participants, was the potential for researcher and respondent bias (Payne et al. 2004) given the duality of my also being an employee of one of the NHS Trusts participating in the study. Moreover, the research project was funded by the employing NHS Trust and aimed to collate an evidence base which they may refer to when considering future service development. With some studies finding an increased risk of inherent bias where the researcher also works for the sponsoring organisation (Lexhin 2012, Mandrioli et al. 2016) it was evident that transparent and decisive steps would need to be taken to mitigate the risks identified as far as possible.

As the first step in managing the potential for bias, Smith et al. (2014) argue that a clearly articulated rationale for the research design alongside additional external scrutiny can provide valuable external evaluation to highlight and subsequently limit bias. Within this study, those external to the research included academic supervisors, ethics committees, and the HRA, who provided robust challenge and enforcement of stringent standards in order to address any potential areas of bias. Additionally, the purposeful selection of both the mixed methods approach and Framework data management process aimed to facilitate the lucidity and triangulation of data (Noble et al. 2019).

As a final safeguard, throughout the study, the researcher’s position and the origins of the study proposal were clearly and transparently disclosed and shared with all participants in both verbal and written communications before seeking informed consent. In terms of any potential respondent bias, the use of a pilot interview, formulating of open-ended questions, and the researcher maintaining a neutral stance by not voicing their personal views or opinions to responses (Lavrakas 2018b) were all used to further assuage bias where possible.

3.9 Rigour

Ensuring rigour within a mixed methods design remains challenging due to the differing ontological and epistemology beliefs and methods that are used in each stage of the study (Eckhardt 2016). As noted by Biddle et al. (2015:811) “Although guidance exists for assessing rigour in quantitative and qualitative methods individually, there is little direction for assessing rigour in mixed methods research.” As mixed methods continues to develop as a progressive entity, numerous frameworks have been proffered (Teddlie et al. 2003, Sale et al. 2004, Onwuegbuzie et al. 2006, Dellinger et al. 2007, O’Cathain et al. 2008, Pluye et al. 2009, O’Cathain 2010) however, as noted by Creswell there remains no universally agreed standard for assessing rigour, and therefore the quality of such studies (Creswell 2015).

Given the lack of a universally agreed standard, and thereby implied researcher discretion, a further review of the options available was undertaken, and the Common Standards of Quality and Appraisal Criteria for Qualitative and Quantitative Studies model suggested by Curry & Nunez – Smith (2015) was decided upon due to its comprehensive and straight forward framework. To follow, the table devised by Curry & Nunez – Smith (2015) is reproduced, identifying how the standards are evidenced followed by a brief summary of how these were addressed within the study. (Table 4)

Table 4. Common Standards of Quality and Appraisal Criteria for Qualitative and Quantitative Studies

STANDARD	QUALITATIVE Appraisal Criteria	QUANTITATIVE Appraisal Criteria
Veracity	**Credibility**–The degree to which the findings plausibly explain the phenomenon of interest or cohere with what is known; attention paid to alternative explanations; correspondence between the researcher's and respondent's portrayal of respondent experience	**Internal validity**–The degree to which the findings represent a "true" refection of a causal relationship between the variables of interest in the population under study
Consistency	**Dependability**–The degree to which the researchers account for and describe the changing contexts and circumstances during the study	**Reliability**–The degree to which observations, measures or results can be replicated (for the same participant or in different studies)
Applicability	**Transferability**–The degree to which findings or research protocols can be transferred to other settings, contexts, or populations as determined by the reader	**Generalizability** (or external validity)–The degree to which the study results hold true for a population beyond the participants in the study or in other settings
Neutrality	**Confirmability**–The degree to which the findings of a study are shaped by respondents and not researcher bias, motivation, or interest	**Objectivity**–The degree to which researchers can remain distanced from what they study so findings reflect the nature of what was studied rather than researcher bias, motivation, or interest

Reproduced from Curry & Nunez – Smith (2015)

Veracity:

Credibility within the qualitative element of the study was achieved in two ways; through corresponding with the interview participants to check their experience through verification of their transcript, and through use of the Framework data management tool, thus transparently explaining plausibility of phenomena.

Due to the need to collate the quantitative data through two different approaches, the true internal validity of any causal relationships between the data was acknowledged as a potential limitation and more in line with providing a general overview of the prevailing picture.

Consistency:

Dependability for the qualitative stage of the study can and will be measured by the level of detailed recording that took place during the research programme and conveyed within this thesis, as it reflects the degree to which the research process is adequately documented (Curry & Nunez – Smith 2015).

In terms of reliability for the quantitative data, it is replicable in so far as the process, and specific fields of data requested are clearly stated, and therefore could be repeated. However, given the inconsistencies experienced in the quality and quantity of responses, it is highly unlikely that these would be duplicated.

Applicability:

The qualitative stage of the study used a pre-determined geographical region, and expert participants based on job role. Nevertheless, the inclusion of procedures for sampling, participants, data collection, and analysis transcription and coding, aims to ensure that other NHS Trusts and CCG's providing inpatient services for people with learning disabilities will be able to evaluate the degree to which their setting is similar to the study context, and therefore the transferability of the study's findings (Curry & Nunez – Smith 2015).

The quantitative data makes some general observations of the overall picture at the time of the study, and similar to the qualitative data, clear procedures on data collection and analysis provide a context within which other NHS Trusts and CCG's providing inpatient services for people with learning disabilities may be able to evaluate the degree to which their setting is similar to the study context. However, as previously noted, due to the different data collections employed, the inconsistencies in responses, and purposeful sampling strategy, generalizability in its purest sense would not be achievable.

Neutrality

Confirmability in qualitative research relates to minimising researcher bias in the devising and reporting of the study (Chenail 2011). An established practice to address this is external audit, and as formerly reported, the study was subject to external scrutiny from numerous parties from conception to conclusion.

In quantitative studies, objectivity is ordinarily perceived as less of a risk than its qualitative counterpart due to utilising random sample selection, explicit protocols, and undertaking statistical computations. However, as this study used purposeful sampling, defined by geographical location, and statistical computations were not possible due to the variation in data collection, this was identified as a potential risk. To counterbalance this, the study undertook to provide maximum transparency through the reporting of key decisions, processes for study implementation, and all stages of the analysis (Curry & Nunez – Smith 2015).

3.10 Research boundaries

The focus and purpose of this preliminary study is such that its target audience are decision makers such as NHS Trusts, CCG's, and policy makers who provide, commission, and administer services, rather than for users of services and their families and carers. On this basis, the study has not been co-produced or had any other forms of consultation or input from those who use services, or their care support systems. However, it is fully acknowledged that user and carer involvement would be intrinsic to any consideration of subsequent service redesign or development as a result of this study.

Although limited in generalisability in its truest sense, due to the use of a non – probability sampling method, it is hoped that the information contained within the study is of interest and will sufficiently resonate with other NHS Trusts and CCG's to continue the debate around the overall use and provision of specialist inpatient services for people with learning disabilities, with the potential to bring about development and change in professional practice and perspective beyond my own workplace (Lester, 2004).

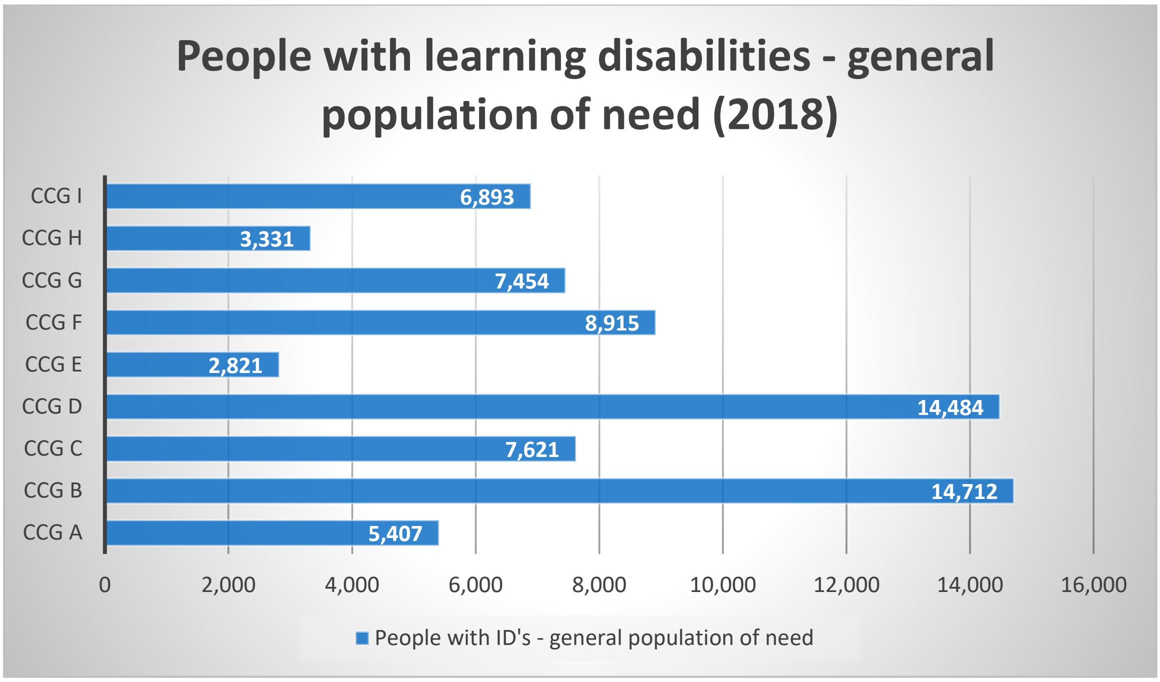
Chapter 4. FINDINGS STAGE ONE: POPULATIONS OF NEED AND TRANSFORMING CARE PLANS

4.1 Introduction

In this chapter, the findings of the first stage of the mixed methods study are reported. The aim of this stage was to undertake a preliminary examination of existing data from each area participating in the study. In brief, this included looking at two main sources; initially the populations of need at the start of the data collection phase (2018) were used to gauge potential demand on services at the time of the study. Following this, the Transforming Care implementation plans, published in April 2016, were reviewed to secure an outline appreciation of local service delivery models. In line with the explanatory sequential mixed methods approach, data gathered at this stage subsequently informed the future areas of data collection and provided baseline data for the study. These areas will now be discussed in more detail.

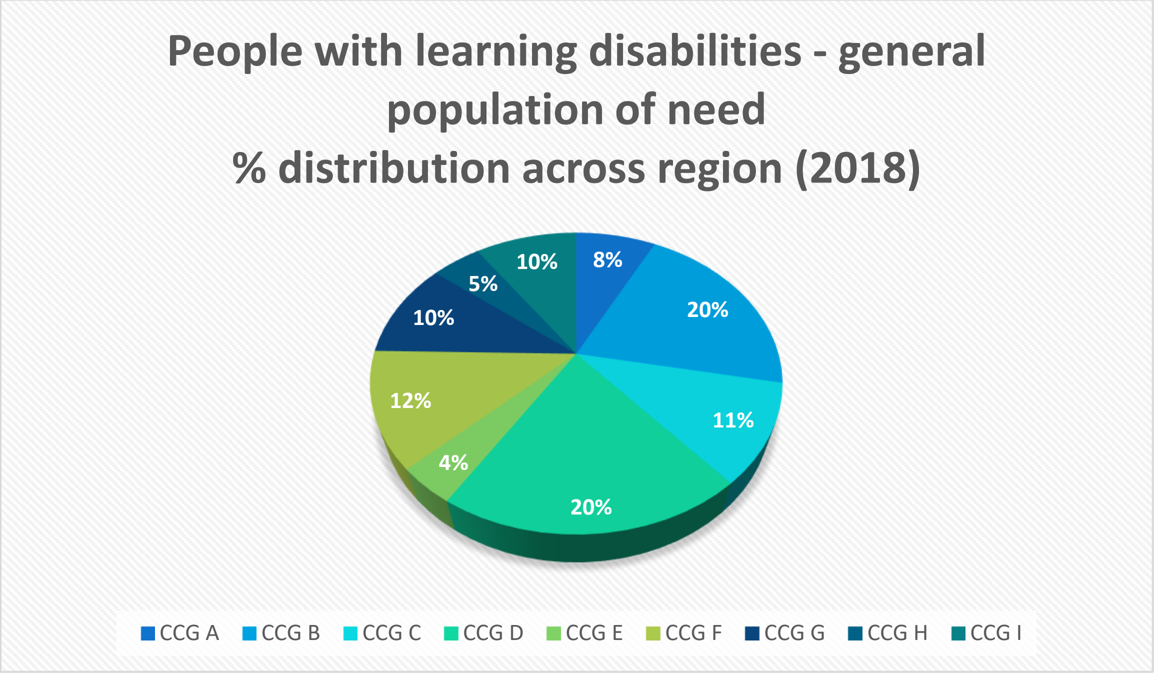
4.2 Populations of need

At the outset, it was decided to gather data about populations of need in each area based on the hypothesis that this would be a key factor for areas in estimating the levels of service demand they might anticipate. Subsequently all adults with learning disabilities aged between 18 – 64 years within the sample CCG footprints were collated from the Projecting Adult Needs and Service Information (PANSI) estimates (Fig. 1):



Data source: PANSI.org.uk Fig. 1

As can been seen, the numbers of people with learning disabilities across the region varied quite significantly, with two areas (B and D) having very similar sized populations, five between the 5,000 – 9,000 range, and the remaining two both having less than 3,500 people with learning disabilities within their areas. Contributing factors to the variation included geographical spread and distribution of habitation across the region, consisting of pockets of high population density in urban areas alongside rurally dispersed communities. The construct of CCG's was also found to be a factor in defining population of need numbers, as this was not uniform, with some amalgamating multiple local authority areas into one CCG, and others being singular but having a much larger geographical footprint. The data was then converted into the percentage of populations of need in each CCG area for further comparison (Fig.2):

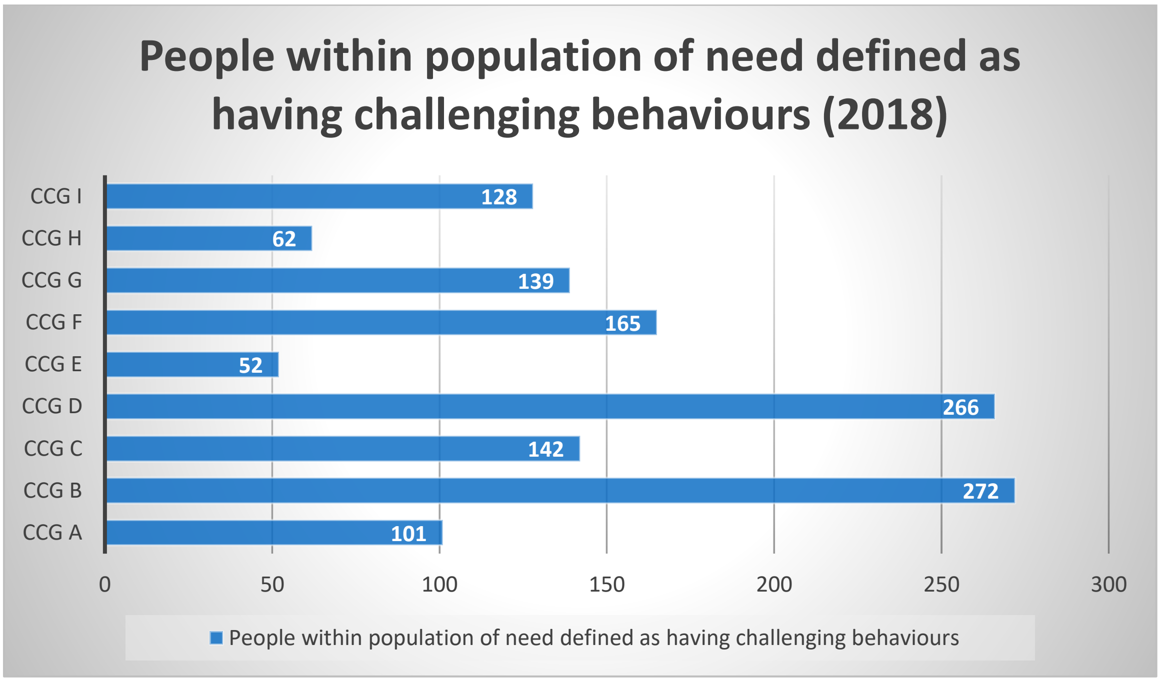


Data source: PANSI.org.uk Fig. 2

Mirroring the previous variation, these percentages further highlighted that the potential ‘burden’ or demand on services in the CCG areas were very different. This was felt important to establish for the second part of this stage of the study as areas with potentially higher demand due to the population of need, such as in CCG areas B and D, may have a direct bearing on the level of service provision found. It was also of interest to the study to note if there were specific implications or additional complexities related to those areas with the lowest levels of population of need, and although this would not be evident in the Transforming Care implementation plans, it was anticipated the qualitative element of the study may further clarify this.

Another area of interest to the study in this initial stage were the numbers of people with learning disabilities within the total populations of need who were also defined as having challenging behaviours. Known as an increased risk factor to inpatient admission (Cowley et al. 2005, Ganguly et al. 2009, Taggart et al. 2009, Oxley et al.

2013) and seen in much higher rates for those with severe disability and in inpatient settings (Emerson & Einfield 2011), the figures within this sub – group were also felt important in ascertaining any relationship with the number of locally provided specialist patient beds. This data was duly sourced for all adults with learning disabilities aged between 18 – 64 years within the sample of CCG areas, predicted to display challenging behaviour, from the Projecting Adult Needs and Service Information (PANSI) estimates (Fig. 3):



Data source: PANSI.org.uk Fig. 3

These figures confirmed that the number of people with learning disabilities and challenging behaviours were proportionate to the overall population of needs figures in each area, with CCG area B having the highest and CCG area E having the lowest amount. Further evaluation to seek refinement of this finding was then undertaken to examine more a precise comparison of the percentage of this sub – group across areas (Fig. 4):

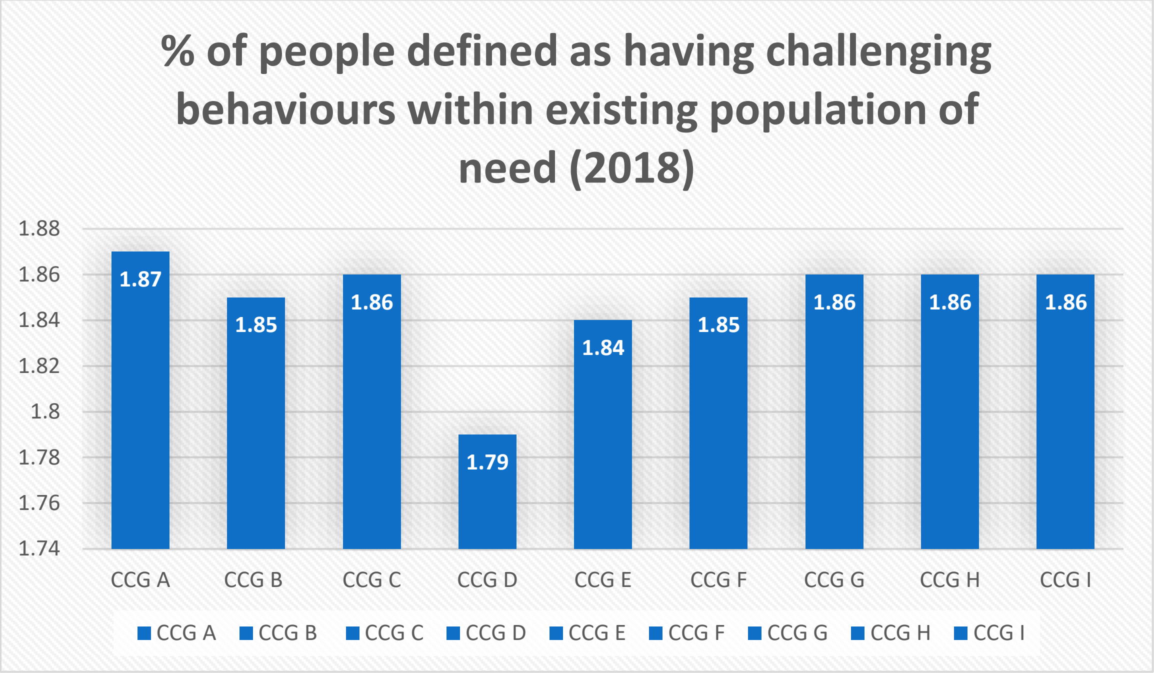


Fig. 4

This analysis showed that despite the overall numbers of people defined as having challenging behaviour initially appearing to be somewhat disparate (Fig. 3), when overlaid onto the total population of need in each area, similar percentages were seen, with a mean average of 1.85%. This average appeared substantially lower than the generally accepted view that 10 – 15% of those known to services with learning disabilities will also have behaviour that challenges (Emerson & Einfield 2011), however this figure is known to vary within studies dependent upon the definition of challenging behaviours used, the characteristics and age range of the sample, the types of services being surveyed, and other methodological variables (Murphy & McGill 2020). Another possible explanation for the discrepancy could be due to the figures from PANSI being estimates and / or projections of populations.

What is striking in these findings is how small the overall percentages are of those who present with challenging behaviours, and therefore more likely to require specialist inpatient services, when considered with the wider context of NHS priorities and resourcing. In 2013 the National Audit Office estimated that the NHS spent £557 million on specialist inpatient services for people with learning disabilities (NAO 2015) suggesting high care and support costs for a comparatively small proportion of the wider populace.

4.3 Transforming Care Plans

Having gained an idea of the populations of need, and therefore the potential demand on services, this stage of the study proceeded to investigate the service models outlined in each Transforming Care Partnership's regional implementation plan. On review, key features of interest to the study identified as being important to understand further and contextualisation in successive stages of the study were captured. These pertained to mechanisms for admission prevention, the provision of local specialist inpatient beds, the inclusion of mainstream acute mental health inpatient beds, and the position on the use of out of area inpatient beds.

4.3.1 Mechanisms for admission prevention

Stated supplementary resources to specialist inpatient bed availability and admission avoidance systems across areas were diverse and included spot purchasing of beds in forensic and acute mental health services, and respite beds managed by the local authority. Additionally, one area was running a community-based pilot scheme to provide short term accommodation for people requiring crisis intervention, including placement breakdown or termination of tenancy. Further discussion in stage three revealed this to comprise of a large private home acquired within the community, purchased using a capital funding bid from NHS England as part of the Transforming Care initiative, and providing accommodation for three people. Transferred to a socially responsible landlord, and ringfenced only for those with learning disabilities, its stated purpose was to act as temporary accommodation for both admission avoidance (‘step up’) and as a ‘step down’ facility for those leaving long – term hospital care and moving back into the community. It was planned that admission avoidance could be facilitated where a person’s normal placement may have broken down, or they required a period of respite to avoid admission to hospital, before returning home or onward to a new community placement. The step down element was envisaged to support those moving back into the community from a potentially highly institutionalised life in hospital, to regain the life skills needed to live independently in the community. Individuals would employ their own support staff whilst residing at the home, and the overall ethos was one of a ‘place of safety’ for those requiring additional support to remain in the community. Its primary aim was to be mid-way option for individuals between the ordinarily stark contrast of living in the community or being in hospital when they did not require treatment for a mental health condition.

In line with one of the fundamental principles set out in accompanying service model guidance for commissioners (NHS England et al. 2015b: 22), all areas confirmed some form of community based health or multi-agency (health and social care) team working to prevent inpatient admission. Hours of operation, and therefore availability, varied from normal office hours to extended hours over seven days a week. None of the plans appraised offered a 24/7 model, as suggested within the service model guidance for commissioners (NHS England et al. 2015b:18), however out of hours services, in the form of mainstream mental health crisis teams operating overnight and at weekends, were included in some of the broader offers.

All of the community team models, by their very nature, offered support within people's homes, to try and support them to remain there following a deterioration in their mental health, and / or an increase in their distressed behaviours. Overall, the stated aim of the teams in each area was two-fold; averting inpatient admission where possible and offering a 'reasonable adjustment' to access mainstream health services given the long-standing health inequalities and poorer outcomes people with learning disabilities generally experience (NIHR 2020). There was found to be a mixture of singular and two-tiered models. The former comprised of one intensive or rapid intervention team for those at risk of placement breakdown. The latter also included an initial broader first point of call, a community learning disability team (CLDT), working less intensively and with less risk, in addition to a smaller additional intensive or rapid intervention team for those more at risk of inpatient admission.

Wider plans for supporting admission prevention across areas included notions such as the delivery of more specialised training and development opportunities for volunteers and private service provider staff, and joint working more closely with mainstream services such as the Community Mental Health Teams (CMHT) and forensic services. Support with implementing positive behaviour support practices[7] were also a common theme offered across many of the areas, which included the development and implementation of behavioural management plans and interventions to ensure safety and maximise independence.

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[7] https://www.bild.org.uk/wp-content/uploads/2020/06/What-does-good-Positive-Behaviour-Support-look-like.pdf

Additional tools and processes to facilitate admission avoidance included regular case discussion meetings, the use of crisis beds in designated units, short respite breaks, and commissioning 'Circles of Support' [8] and befriending services to build upon alternative sources of independent support and advocacy for the individual. Longer term it was hoped that more specialist accommodation and support within the community, such as small-scale core and cluster models of accommodation, and the embedding of individual bespoke service designs would offer more sustainable solutions.

4.3.2 Provision of local specialist inpatient beds

Across all CCG areas sampled only three (B, F, I) retained use of their own specialist inpatient beds for people with learning disabilities, ranging in number between five,13, and seven, respectively. When compared to the populations of need in each area (14,712 / 8,915 / 6,893 respectively, Fig.1), these findings suggested no direct correlation between potential service demand based on population numbers, and the number of beds provided, as had first been hypothesised. Furthermore, with the areas having similar percentages (1.85 – 1.86%) of people deemed more at risk of inpatient admission due to challenging behaviours (Fig. 4), the theory that this characteristic within the local population of need may also have been a deciding factor in the number of locally available specialist inpatient beds was also disproved. The rationale and formulation behind local bed numbers, and any impact this had on the patient journey, was therefore felt important to explore further in stage two and three of the study.

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[8] https://www.mentalhealth.org.uk/learning-disabilities/our-work/family-friends-community/circles-of-support/

For those areas that did retain local NHS specialist beds for people with learning disabilities configurations varied; one area had a unit presented as an admission avoidance community residential facility, another had two units presented as inpatient units, and the remainder had one unit clearly identified as an assessment and treatment hospital. Notwithstanding perception or presentation, all units were registered as assessment and treatment hospitals under the Health and Social Care Act 2008 (CQC 2015). In two of the areas there was a stated commitment within the Transforming Care implementation plan to either fully close or partially reduce bed numbers during the programme. Again, further investigation around the circumstances behind the configuration was felt to be warranted in stage three, alongside establishing if any of the planned bed closures or reductions had been enacted.

Overall, only two areas stated tangible targets for reducing the overall number of admissions into specialist inpatient services. Highlighting that these exceeded nationally set targets of 10 - 15 per million population for CCG specialised treatment facilities, and 20 - 25 per million population for NHS England commissioned beds (NHS et al. 2015a), the ability of all areas in achieving any level of reduction was also an area of interest highlighted as warranting further investigation in stage two of the study.

4.3.3 Inclusion of acute mental health beds

As an alternative, or in addition to the use of specialist inpatient beds, it was found that seven of the sample areas included local acute mental health (mainstream) beds in their stated service delivery model. From these, only one area explicitly stated this would be augmented with in-reach or consultation provided by the assigned specialist learning disabilities community team alongside utilisation of the self-audit Green Light toolkit (DH 2004, revised 2017 National Development Team for Inclusion) to assist in auditing and monitoring the accessibility for people with learning disabilities. Another area within the sample group, which was devoid of any locally retained NHS specialist inpatient beds for people with learning disabilities, ascribed to a preference model of using local mental health acute inpatient mainstream beds, to support admission closer to home. The efficacy and views on using acute mental health beds for people with learning disabilities was identified as important to examine further and so formed part of the qualitative interviews undertaken in stage three of the study, as it was postulated that experiences may have differed.

4.3.4 Position on out of area beds

In relation to out of area beds, without exception, all regional implementation plans reviewed confirmed that their service models incorporated the use of these, including those with locally retained NHS specialist inpatient beds. Many implied the use of such beds would be as a 'last resort' and confirmed that all local provision and options would be thoroughly exhausted first. One area indicated that where an out of area admission was unavoidable local learning disabilities community teams would closely monitor such admissions and prioritise repatriation to the local area at the earliest opportunity. Another indicated that they were awaiting the building of a large private hospital within their area and suggested that their intention was to commission beds there. This allowed them to commit to no further out of area placements being made without a clear, evidence-based rationale.

With none of the areas precluding the possibility of needing to utilise out of area beds, it was felt valuable to further ascertain the levels of use of such beds in stage two of the study for three reasons: i) to determine in those areas with retained local specialist inpatient beds, if all demand could be met locally, ii) to consider if the overall number of specialist inpatient admissions, and particularly out of area admissions, had reduced in line with one of the main objectives in the Transforming Care policy, and iii) the impact on lengths of stay.

4.4 Summary

The main aims of this stage of the study were to provide a baseline picture regarding the populations of need within the sample areas with a view to indicating potential service demand, and to outline the service models in each area as stated in official published plans. There were multiple findings within this stage that were felt to warrant further investigation in the proceeding stages, and this was highlighted throughout.

Key findings in terms of demographics included that the potential demand on services, if determined by population of need, was likely to be variable due to the wide – ranging numbers of people with learning disabilities within each CCG area. Possible explanations for this distribution pattern included the region being made up of high density urban areas and rurally dispersed communities, alongside the differing configuration of CCG areas. In terms of composition, the number of people with learning disabilities and challenging behaviours, who are deemed more at risk of requiring inpatient admission, were found to be proportionate to the overall population of needs figures in each area and averaged at 1.85% of the total population of need across all areas.

Principal findings on review of the Transforming Care implementation plans included an overriding focus on admission prevention. With only some areas able to offer alternative community-based respite beds and houses, the majority relied on the deployment of community-based teams as the mainstay tool to sustain individuals within their own home. Ancillary support included help with implementing positive behaviour approaches and management plans, commissioning ‘circles of support’ and setting up befriending services. Aspirational aims included providing advanced training for paid support staff and working more closely with mainstream mental health services including CMHT and forensic colleagues. Longer term, some areas planned to add community-based specialist small-scale core and cluster models of accommodation to their offer and felt the embedding of individual bespoke service design would be the optimum way forward.

With regards to the provision and use of inpatient beds, only three areas within the sample of nine were found to have retained local beds specifically for people with learning disabilities. In comparing the population of need figures, and those further identified as displaying challenging behaviours against the number of local beds provided, contrary to initial thoughts, no correlation was found. Two of these areas stated an intent to close or reduce their bed stock further during the course of the Transforming Care programme, and this was felt to be one of the areas of interest meriting further exploration with commissioners and senior managers of learning disability services later in the study to ascertain if this had been achieved. A large majority of the areas included local acute mental health beds as an alternative option in their service model. However, with only one indicating that reasonable adjustments might be made through additional support from the local specialist learning disabilities community team and self-auditing, further qualitative investigation into the suitability and effectiveness of such beds for people with learning disabilities was felt to be required in stage three of the study.

The topic touched on in the least detail in all areas was the use of out of area beds, and always in terms of being the last option if all the other preventative measures or local alternatives failed. Conveying a strong sense of reticence to use this bed type, those that did explicitly comment reinforced the need for evidence based decision making, and to make the admission as short as possible, thus implying that such a decision would be the exception rather than the rule. On this basis, a quantitative measure on the use of out of area beds was obtained in stage two to further understand the degree to which they continued to be utilised.

Chapter 5. FINDINGS STAGE TWO: PERFORMANCE AGAINST KEY TRANSFORMING CARE OBJECTIVES

5.1 Introduction

In this chapter, the findings of the second quantitative stage of the study are reported. The main aim of stage two, in line with the explanatory sequential mixed methods design, was to quantitively explore findings from stage one of the study and to build on the wider picture by measuring each areas performance against some of the main objectives of the Transforming Care policy. These included the trends in specialist inpatient bed use, to assess if any reduction in admissions had been achieved, the trends in out of area hospital admissions, to ascertain the levels of use of out of area beds, and the trends in lengths of stay, to observe if these had reduced. Additionally, a fourth area of interest, concerning average bed costs of private verses NHS provision was also explored to later determine if this influenced decision making, thus affecting the patient journey.

As previously explained in Chapter 3 (Methods and Methodology), the data received in response to Freedom of Information requests varied considerably, with an eclectic mix of redacted raw data and pre - compiled responses. As a result, it was not possible to conduct inferential statistical analysis, and so the purpose of this stage of the study was primarily to establish if the datasets displayed any patterns which could be subsequently built upon qualitatively in the third and final stage of the study. Consequently, the findings across each area of interest are presented using descriptive statistics to facilitate cross – area comparison within the region sampled.

5.2 Trends in specialist inpatient bed use

Given that reduction in the use of specialist inpatient beds has been one of the main objectives of national policy for a number of years, it was felt important to further examine this over a ‘snapshot’ period chosen for the purposes of the study (Feb 2015 – Sept 2018). It was also of interest to establish if there were any points of learning between those areas retaining local bed stock compared to those who did not.

Overall, the key findings in this section suggested that the majority of areas saw an increase in inpatient numbers over the course of the study period, and that the demand for beds in areas with a local stock of specialist inpatient beds outstripped supply the majority of the time, thus explaining the on – going need for out of area hospital placements in all areas. An unexpected finding of note was that the largest population of need did not always equate to having the overall highest percentage of inpatients as might logically be expected. Suggesting that populations of need are not reliable determinants for predicting service demand, this reinforced the finding in stage one that none of the areas sampled were using populations of need to calculate the number of specialist inpatient beds required locally. These results will now be discussed in further detail.

5.2.1 Average number of inpatients

This section of the study started by identifying the average number of inpatients in each area throughout the designated data collection period (Table 5):

Table 5: Average Inpatient numbers per annum by area, between February 2015 – September 2018.

CCG	**Year**											
	2015			**2016**			**2017**			**2018**		
	Min	**Max**	**Mean**	**Min**	**Max**	**Mean**	**Min**	**Max**	**Mean**	**Min**	**Max**	**Mean**
A	1	7 (ID)	4.28	7	12	9.58	7	10	10	7	9 (ID)	8
B	28	32	30.42	24	34	28.75	18	24	21.92	19	23	20.12
C	5	6	5.92	4	6	5	5	5	5	5	8	6.37
E	0	0	0	0	0	0	0	1	0.17	0	0	0
F	NDA	NDA	NDA	14	15 (ID)	14.72	14	15	14.67	13	17	16.12
H	1	1	0.33	1	1	0.33	1	1	0.75	1	2	1.5
I	8	8	8	6	8	7.58	8	10	9.17	9	10	9.75

KEY: NDA = Submitted as No Data Available. ID = Incomplete Data submitted.

Before moving on to discuss the trends in data found, for the purposes of interpretation, it is helpful to consider the above data alongside the following caveats: CCG A only provided seven months of data for 2015, so the figure recorded represents the average over seven months instead of 12. Similarly, only six months data was provided for 2018, so the figure was calculated over six months rather than eight. CCG D did not submit viable data to be included in the analysis. CCG E had 0 inpatients except for 2017. CCG F only had data available from 2016 onwards, and 11 months of data was submitted for 2016 so the figure recorded represents an average over 11 months instead of 12. CCG G did not provide a response. The data for 2018 represents Feb – Sept only as dictated by the timeline chosen for the study, therefore the average is calculated over 8 months.

In terms of findings, it can be seen from Table 5. that of the seven CCG's who submitted viable data, five (A, C, F, H, I) saw an increase in their average number of inpatient admissions at the beginning and end point of the data collection period under examination. Only one area (B) saw a decrease in this number, and one (E), stayed the same. Arguably the figures for CCG A are less robust as a baseline due to incomplete data submissions in 2015 and 2018. However, overall, despite national policy, the findings show that most areas had higher average numbers of inpatients towards the end of the Transforming Care programme than they had at the beginning.

5.2.2 Demand on beds

The second key finding when reviewing the data on the use of specialist inpatient beds found that, even in those areas where local beds had been retained (B, F, I), the number of people with learning disabilities requiring admission invariably outstripped supply (Table 6):

Table 6. Demand on local beds

CCG area	**Year**								
		2015		**2016**		**2017**		**2018**	
Range of inpatient No's	**No. of local beds**	**Min**	**Max**	**Min**	**Max**	**Min**	**Max**	**Min**	**Max**
B	5	28	32	24	34	18	24	19	23
F	13	NDA	NDA	14	15 (ID)	14	15	13	17
I	7	8	8	6	8	8	10	9	10

KEY: NDA = Submitted as No Data Available. ID = Incomplete Data submitted.

With the total amount of inpatients in CCG area B at any one time fluctuating between a minimum of 19 in 2018, and a maximum of 34 in 2016, it is evident that the five locally retained specialist inpatient beds were never sufficient in number to meet the demand recorded throughout the period under study. In CCG F there was a similar picture with insufficient local specialist inpatient beds for all dates studied with the exception of a four month period in 2018 when there were an equal number of patients to local bed ratio (13). Lastly, in CCG I the seven locally available beds were only adequate to accommodate the minimum number of six people requiring an inpatient stay for a total of four months in 2016, with demand exceeding this at all other times during the data collection period.

This finding confirmed that overall, having locally available specialist inpatient beds did not mitigate out of area admissions, with all areas observed having required the use of such beds during the period of study to meet demand. It also suggested that further investigation was warranted in looking at how bed numbers in those localities has been arrived at, and possible reasons for why people in those areas were still needing to be admitted to hospital away from their normal domicile. As such, this finding was further explored through qualitative interview in stage three of the study.

5.2.3 Population of need as a predictor

The final finding of interest in this section of the study indicated that over the course of the period observed, those areas with the largest population of need did not always have the highest percentage of inpatients (Table 7):

Table 7. Average number of inpatients as a percentage of the local total population of people with learning disabilities.

CCG	**Total pop. of need**	**No. of inpatients as a % of total population of need**			
Year		**2015**	**2016**	**2017**	**2018**
A	5,407	0.05 (ID)	0.18	0.18	0.14 (ID)
B	14,712	0.21	0.19	0.14	0.13
C	7,621	0.07	0.06	0.06	0.08
E	2,821	0	0	0.17	0
F	8,915	0 (NDA)	0.15 (ID)	0.16	0.18
H	3,331	0.009	0.009	0.02	0.04
I	6,893	0.11	0.11	0.13	0.14
CCG with highest %		**B**	**B**	**A**	**F**

KEY: NDA = Submitted as No Data Available. ID = Incomplete Data submitted.

This finding was noteworthy as it was unexpected; ordinarily one might predict that the larger the population of need, the greater demand is likely to be on inpatient beds. Conversely this finding suggests that may not necessarily be the case, and that populations of need may be a poor predictor of potential demand on specialist inpatient services.

In stage one of the study, it was found that the numbers of locally retained specialist inpatient beds appeared to have no correlation with the local population of need, indicating that it had not been used to calculate the potential demand for beds in the area. This was reinforced in the previous section of this stage of the study (Table 6), which found that local demand for specialist inpatient beds far exceeded the number of beds available, again suggesting that local demand had not been considered when deciding on the number of beds to retain. Given that the study found that populations of need were a poor predictor of potential demand on specialist inpatient services, this reinforced the need to qualitatively explore the influences on bed numbers locally in stage three. Moreover, it indicated that using local populations of need to calculate the number of specialist inpatient beds required to meet projected demand would not be a reliable assumption to make in any future service planning, and that there are other factors influencing decisions about provision.

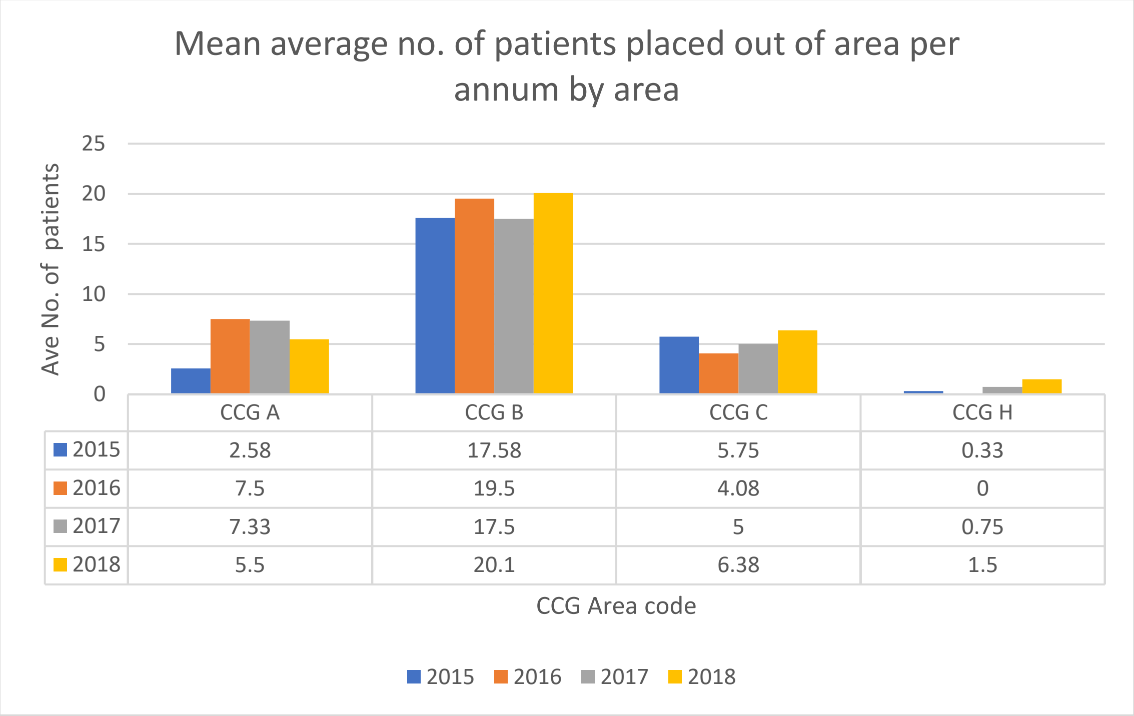
5.3 Trends in out of area hospital admissions

For the purposes of the study, any person admitted to hospital more than 50km from their ordinary residence was classed as being admitted out of area; in real terms, this means they are more likely to be further away from family, friends, and their normal social activities. This was felt important to explore further as one of the main aims of the Transforming Care Programme was to stop this happening. Instead, it advocated that people should be able to access appropriate care and treatment closer to home, without sacrificing the life and support network they had established around them (NHS England et al. 2015a).

Collating this evidence proved challenging (See Chapter 3, Methods and Methodology), due to some CCGs redacting information they perceived as identifiable patient data, including postcodes of where the person was admitted from, which made calculating how far away they were from home more problematic. In these circumstances the data on which CCG area they originated from was used as an alternative to calculate their distance from home. Viable data for comparison was thus available from four CCG's (A, B, C and H) of the nine CCG areas sampled, with CCG B being the only area that retained specialist inpatient beds locally.

An initial finding in this section of the study showed that, of those areas that submitted valid data, all had continued to admit people with learning disabilities to out of area hospitals, for the duration of the study period (Fig. 5):

Figure 5: Mean average number of patients placed > 50kms from their ordinary place of residence per annum by area, between February 2015 – September 2018.



Further to the earlier discovery (see Table 6) that the levels of admissions required in CCG area B had far exceeded the number of locally available specialist inpatient beds, this finding highlighted that consistently this resulted in more patients being admitted over 50kms from home rather than to a local bed. Given that the other areas sampled had not retained any local specialist inpatient beds, and therefore only had the option of out of area beds, the recorded usage of such beds in those areas was not unexpected. However, a key finding of this element of the analysis was that every area that submitted data showed an increase in the mean average number of patients admitted out of area between the start date of the Transforming Care policy in 2015 and towards to the end of the programme in 2018. Due to the end of the data collection period falling in September 2018 it was not possible to ascertain if the trend continued on this trajectory, or what the final position of each area was upon conclusion of the Transforming Care programme in March 2019. Nevertheless, this finding is still pertinent, as it suggests that the use of out of area placements had not desisted or decreased in line with the Transforming Care policy objectives towards the end of the study period. On the contrary, their use had shown an overall increase between the start and end of the programme.

Comparison on the use of out of areas beds for all of the areas that had retained local specialist inpatient beds was not feasible due to the lack of valid and comparable data being submitted from those areas. In the absence of such information the finding from an earlier section of the study (Table 6) was referred to. Having identified that the demand for beds in CCG areas F and I had outstripped local supply for the majority of the data collection period, it was postulated that during those times additional out of area admissions would also have been required to meet need.

Although suggestive that all areas retaining local specialist inpatient beds needed to additionally use out of area beds for the majority of the study period, without the specific data it was not possible to be certain of the numbers of patients this affected, as utilising alternative local services, such as acute mental health beds for people with learning disabilities, remained a possibility. Nevertheless, the important fact remained, that in all the areas that had retained a local stock of specialist inpatient beds, regardless of bed numbers, none had been able to consistently accommodate the level of local demand. With the continued use of out of area beds shown to be equally likely in these areas compared to those without local specialist inpatient beds, the benefits of retaining a local stock of specialist inpatient beds at the established levels were therefore limited.

5.4 Trends in comparative lengths of stay

As well as people receiving care and treatment closer to home, another primary objective of the Transforming Care policy was to reduce the length of stay for anyone admitted to hospital. With national data showing that some people with learning disabilities had remained in hospital in excess of two years[9], data about length of stay in each area was obtained, thereby facilitating further contextual exploration in the subsequent qualitative stage of the study.

Data for this section was calculated to give an average length of stay for any patients discharged within a given year. For those years where no discharges took place 0 was recorded. Once processed, valid data submissions were received from five CCG's (A, B, C, E, H) of the nine areas sampled, and recorded in monthly increments (Fig. 6):

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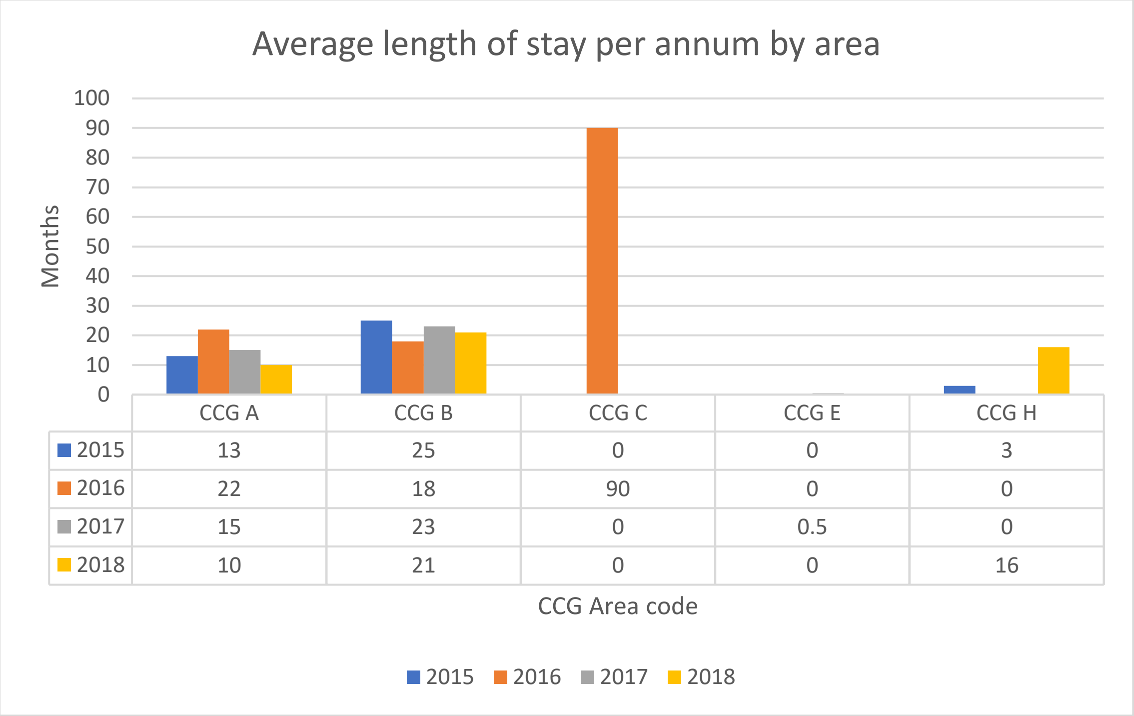
[9] https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/provisional-statistics-at-june-2020-mhsds-april-2020-final

Figure 6: Average length of stay per annum by area, between February 2015 – September 2018.



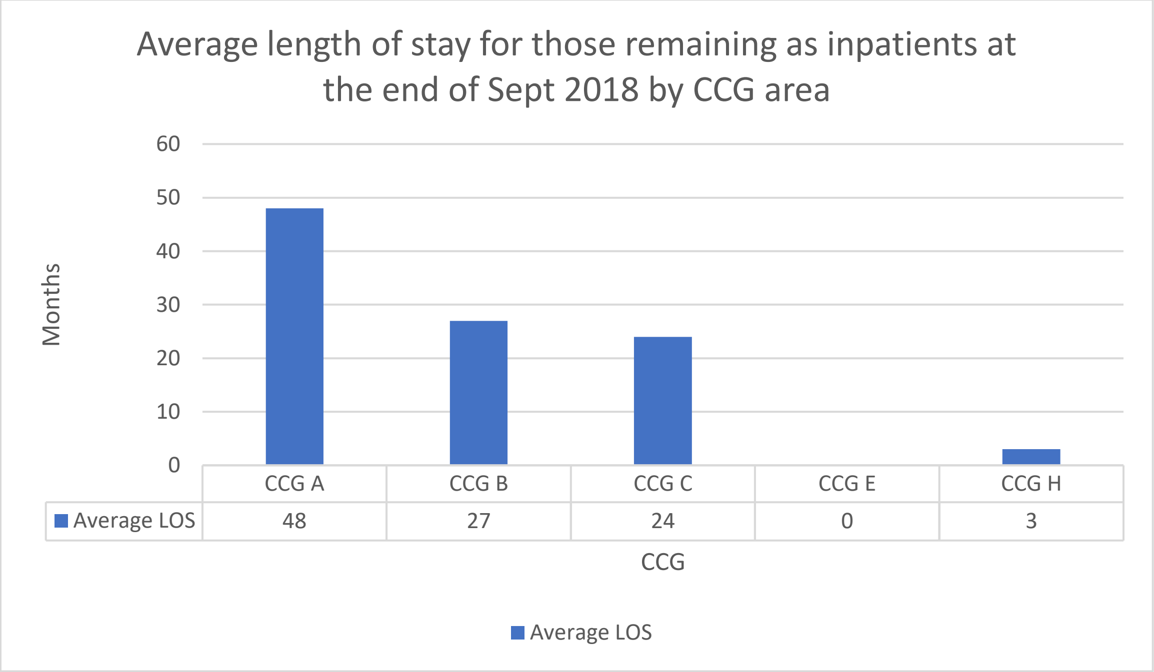
	CCG A	CCG B	CCG C	CCG E	CCG H
2015	13	25	0	0	3
2016	22	18	90	0	0
2017	15	23	0	0.5	0
2018	10	21	0	0	16

The data demonstrates that of those patients discharged, there was a reduction seen in the average length of stay for CCG areas A and B when comparing the figures achieved in 2015 and 2018, suggesting that the aims of the policy may have started to embed more towards the end of the programme. At the same points of comparison, CCG area C remained at zero with discharge of some long-standing patients in 2016, the second year of the Transforming Care initiative. CCG area E also remained at zero activity for the majority of the data collection period with only a very short average six month inpatient stay identified in 2017.

For those with the longest average lengths of stay in CCG areas A, B, and C at 22, 25, and 90 months respectively, discharge occurred within the first two years of the Transforming Care policy being introduced. Reflecting on these statistics, it could be hypothesised that these peaks in discharging those who had been in inpatient settings for much longer periods in the early years may have been a reflection not only of the policy being introduced, but also from a sense of urgency brought about following the Winterbourne View expose. Similarly, for CCG area H, it is possible that the Transforming Care programme coming to an end provided the impetus required to get their number of long – stay inpatients down before its conclusion in March 2019.

Following calculation of the average length of stay for those who had been discharged, the length of stay of those who remained in hospital as of the end of the data collection period was examined to highlight whether there were still patients subject to extended lengths of stay within the sample (Fig. 7):

Figure 7: Average length of stay for remaining inpatients as of end of September 2018.



At an average range of between 24 - 48 months for three of the participating CCG areas (A, B, C), this equated to a minimum of two years length of stay up to a maximum of four years for those remaining in specialist inpatient hospital beds at the end of the data collection period. However, this was only an average, and further processing of the data found that for some individuals their lengths of stay far exceeded this (Table 8.):

Table 8. Range of length of stay for remaining inpatients post September 2018.

CCG	**Range of length of stay - up to and including Sept 2018 (years + months)**	
	Minimum	**Maximum**
A	1yr,11mths	6yrs, 9mths
B	4mths	7yrs, 3mths
C	2mths	9yrs,10mths
H	3mths	3mths

For those areas that submitted valid data it can be seen that, at the end of the data collection period, those remaining in hospital had spent between a minimum of two months up to a maximum of nine years,10 months in hospital. With CCG area H being the exception at 3 months, all other areas had patients that had been in hospital well in excess of five years. Inferring that the Transforming Care policy had not been sufficiently effective for all those requiring specialist inpatient admission, some people had spent many years in hospital despite the implementation of numerous policies and directives to address this issue during that time. The possible factors influencing this particular trend were therefore identified as requiring further qualitative exploration in stage three.

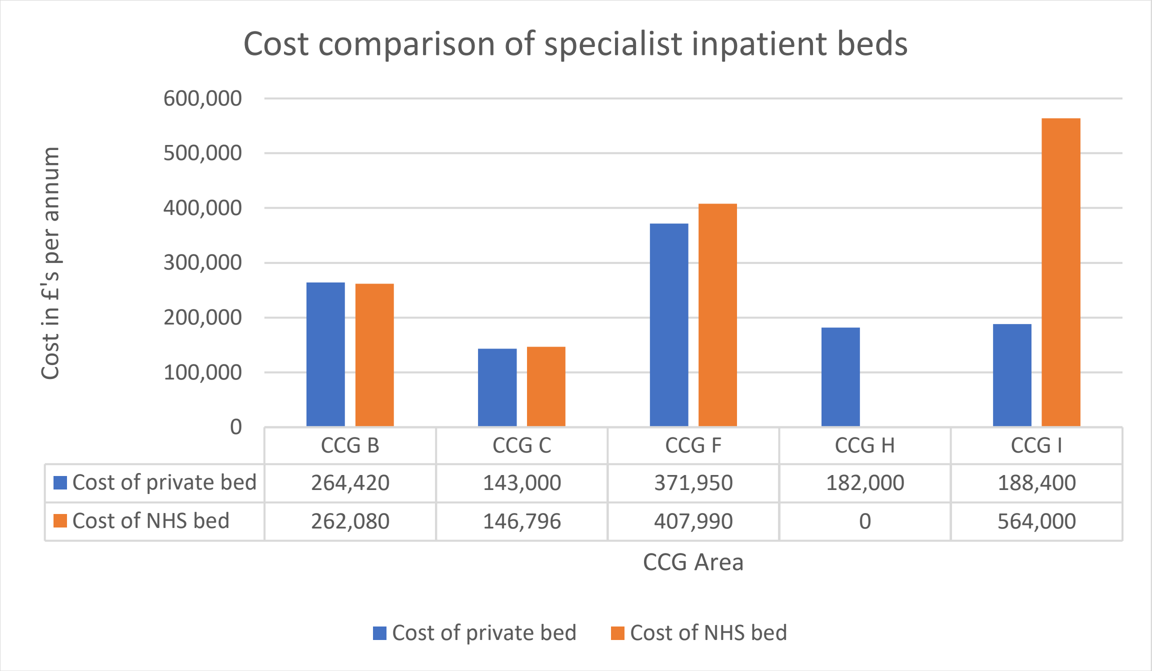
5.5 Bed costs

In the final part of the quantitative stage of the study, as the research was providing an evidence base for future practice and potential service re-modelling within my own NHS Trust, it was felt judicious to ascertain if bed costs played any part in influencing the use of specialist inpatient services for people with learning disabilities.

In the most recent figures available, Hassiotis et al. (2008) found that private hospital beds were the most expensive ranging between £102,000 and £222,000 per person annually, and NHS inpatient beds cost between £96,000 and £197,000 per person annually, depending on the level of care and support needed.

Each CCG area was asked for the average bed costs in both private and NHS provision that they were paying for patients they were responsible for. Five of the nine CCG's sampled (B, C, F, H, and I) submitted viable data to be included for comparison, with CCG area H supplying the cost of a bed in the private sector only (Fig. 8):

Figure 8: Average bed cost in NHS and private sector



The range of bed costs varied considerably across CCG's from £143,000 – £371,950 for private hospital beds and between £146,796 - £564,000 for NHS hospital beds. In three CCG areas (C, F, I), NHS hospital beds were more costly than private hospital beds, and in CCG area A there was a marginal difference between the two. The cost given by CCG I for the NHS bed per annum (£564,000) seemed disproportionate, and therefore was deemed at risk of being an outlier in terms of the overall data (Salkind 2010). Contrary to the findings of Hassiotis et al. (2008), this suggested that the cost of NHS beds had now surpassed the cost of those within the private sector in the majority of areas.

It is posited that the variation in costs may result from wide ranging levels of support required by different individuals whilst they are in hospital provision, and higher levels of complexity will result in higher associated support costs. Of more interest to the study, and an issue that was explored with commissioners and senior managers in stage three, was the degree to which, if any, finances, and cost influenced the decision making when considering admission to specialist inpatient services, particularly given the potential costs involved.

5.6 Summary

Despite the main thrust of the Transforming Care policy being to reduce overall admission rates of people with learning disabilities to specialist inpatient beds, the majority of CCG areas in the sample group showed an increase in the number of patients requiring admission to specialist inpatient hospitals during the period of study. In addition, the demand for specialist inpatient beds in areas where local stock had been retained outstripped supply for the majority of the data collection period.

The disparity found between the number of locally retained specialist inpatient beds and the level of demand appears to reinforce what was found at stage one, in that local bed numbers had not been calculated based on potential demand from the population of need. Linked to this, it was unexpected to find that areas with the largest populations of need did not always have the highest percentage of inpatients. With the findings suggesting that populations of need not being a reliable determinant of potential service demand, the rationale for the locally retained beds numbers found was identified as requiring further exploration in stage three.

In terms of out of area admissions, this continued in all areas who submitted viable data for this element of the study and usage had increased over the course of the Transforming Care programme as opposed to having decreased. Such admissions also continued in those areas who additionally retained local specialist inpatient beds due to demand, and therefore the benefits of retaining such beds at the established levels were likely to be limited.

On scrutinizing average lengths of stay, a reduction was noted for patients in some areas, and the discharge of people who had been in hospital for long periods both at the beginning and end of the Transforming care programme indicated the possibility of an increased focus on timely treatment and discharge. A small sub – group of patients still in hospital at the end of the study period had exceptionally long periods of admission, despite the Transforming Care policy, and its predecessors, thus meriting further investigation in stage three.

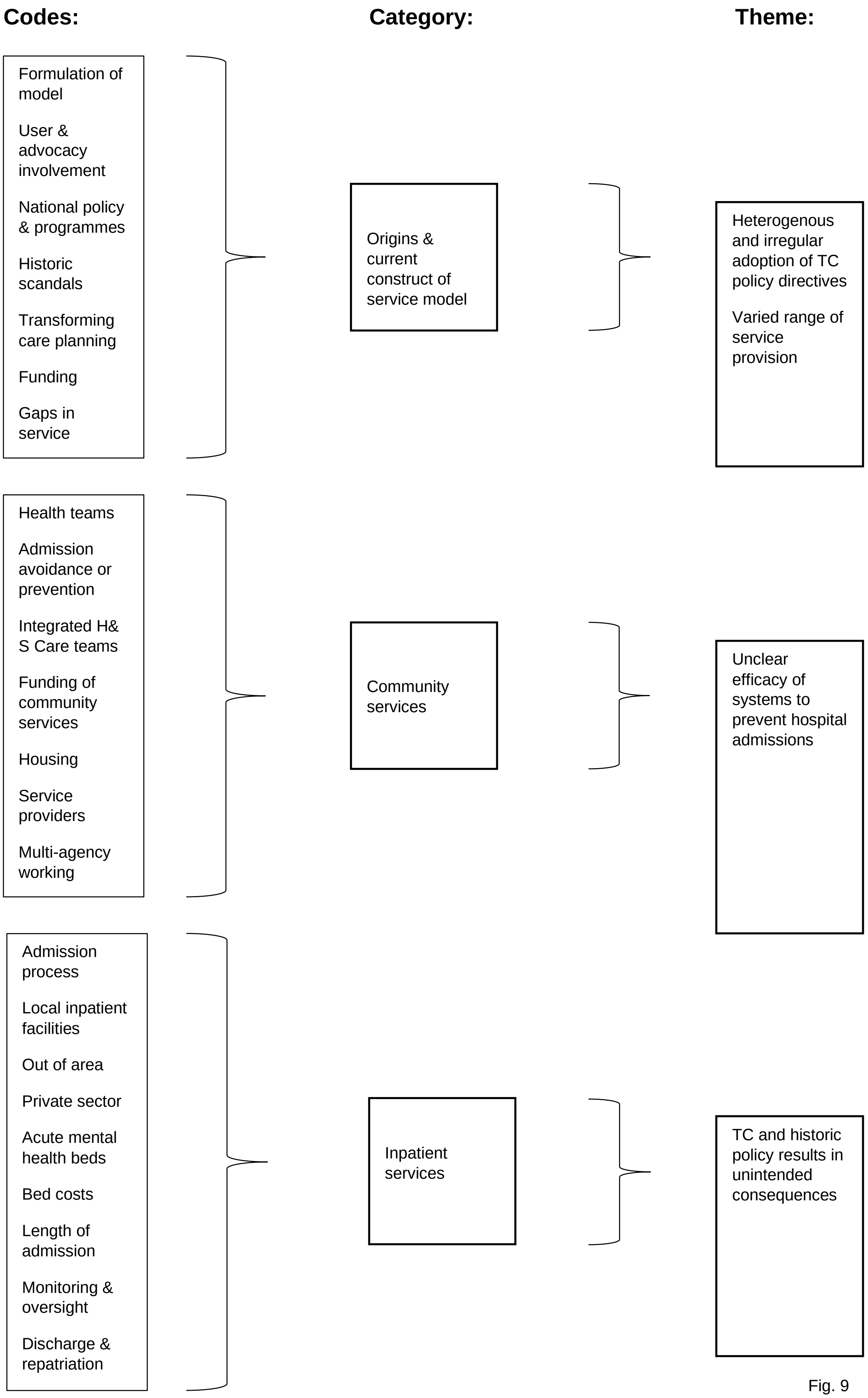
The final area examined in this stage of the study was not within the context of performance against policy but sought to compare costings and later determine if the cost of specialist inpatient beds played any part in the decision making of a patient journey when they required admission. Costs were found to vary dramatically between CCG areas, and surprisingly showed that in the majority of areas, NHS bed costs were higher than those in private hospitals, which was contrary to the most recent national figures available (Hassiotis et al. 2008).

Chapter 6. FINDINGS STAGE THREE: QUALITATIVE INTERVIEWS

6.1 Introduction

This chapter discusses the findings from the third and final qualitative stage of the study, involving in-depth interviews with senior NHS commissioning and operational managers working within learning disability services in the region sampled. This offered the opportunity to expand upon the findings from the earlier stages of the study and to explore the viewpoints and experiences of key NHS stakeholders, adding considered experiential quality to understanding the challenges and complexities for specialist inpatient services.

A total of seven NHS senior operational service managers representing seven NHS Trusts, and nine senior CCG lead commissioning officers representing nine CCG's were interviewed as expert participants. The data was analysed using Framework analysis (Ritchie & Spencer, 1994). For the purposes of this chapter, figure 9 shows the main themes identified and how these were arrived at following initial coding and categorisation of emerging concepts:



Codes:	Category:	Theme:
Formulation of model User & advocacy involvement National policy & programmes Historic scandals Transforming care planning Funding Gaps in service	Origins & current construct of service model	Heterogenous and irregular adoption of TC policy directives Varied range of service provision
Health teams Admission avoidance or prevention Integrated H& S Care teams Funding of community services Housing Service providers Multi-agency working	Community services	Unclear efficacy of systems to prevent hospital admissions
Admission process Local inpatient facilities Out of area Private sector Acute mental health beds Bed costs Length of admission Monitoring & oversight Discharge & repatriation	Inpatient services	TC and historic policy results in unintended consequences

Fig. 9

In this chapter, the qualitative interview findings are considered under three main themes that emerged from the analysis: these were that adoption of the Transforming Care policy and service provision was heterogenous with wide variations; the efficacy of admission prevention systems was unclear; and, that continual policies in the sector had not only affected the success of the Transforming Care policy, but there had also been unintended consequences for people with learning disabilities and their families.

6.2 Heterogenous policy adoption and service provision

When exploring the ability of participating areas to implement the various facets of Transforming Care effectively, respondents suggested that this was influenced by a number of factors. Resources, funding, time pressures, degree of staff and organisational change, consistency in leadership, and how well the policy was understood were all cited as possible agitators to effective implementation. As a result, the level of adoption, planning, and prioritisation afforded to the policy varied. In terms of the associated funding, the majority of participants reported difficulties in both understanding and accessing the offer. Moreover, with the funding model not lending itself to timely investment in service development, participants identified an inability to plug any pre-existing gaps in service, particularly for those with an autistic spectrum condition (ASC), despite their inclusion in the Transforming Care policy.

6.2.1 Mixed adoption of policy in practice

The application of a uniform national policy at local level was more complex than one may have first assumed. Local reception of the Transforming Care policy by stakeholders was mixed, with some areas openly embracing the initiative and working actively across agencies as a cohesive team:

> "…*the transforming care partnership is … made up of the CCG, our two main providers, and three local authorities. It is a cohesive group and we have been together now for quite a few years and I think that the ability of that group to influence and support this agenda has been good*." (Senior commissioner 2)

Reflecting that partnership working and multi – agency involvement within the partnerships had resulted in a feeling of strength, momentum, and the ability to influence, not all participants interviewed reported similar experiences. Some felt that Transforming Care had not been similarly prioritised within their organisation. In particular, those with a smaller number of patients with learning disabilities, commented that they did not believe it was taken "as serious" in their area and that, for some, it had taken NHS England to intervene and criticise implementation as "not good enough" before it started to get some traction.

The origins of the Transforming Care policy also affected the differential implementation evidenced across areas. With a difference of opinion between participants, some perceived the policy as the call to action required, whilst others suggested the lack of autonomy in how to put the policy into practice locally was a result of the inherent autocratic national approach, and that this was overly restrictive:

> *"…it feels very much that we're often told how we should be doing things…we have the understanding and expertise of the local needs of the local population and the blanket approach of Transforming Care hasn't worked.*" (Senior commissioner 7)

Perceiving a lack of power and autonomy over decision making, in conjunction with local knowledge and expertise being disregarded, the ‘top down’ approach of issuing a policy felt disempowering for some. Additionally, there were concerns that a ‘one size fits all’ generic process had not worked due to being insufficiently sophisticated to customise the approach for the nuances in each area:

> “*The problems that some areas faced were very, very different to the ones faced by others. In some places they had 100 people in hospital, in other places they had 12 and there should have been a proportionate approach”* (Senior commissioner 7)

With differing views on the ability of the Transforming Care policy to address the on-going issues within specialist inpatient services, its reception was mixed. In those areas where the policy was talked about in positive terms, the robustness and quantity of human resource allocated was demonstrably higher and more consistent than in those areas where it had been less prioritised. Overall, this suggested that the extent to which the Transforming Care policy was actioned and deemed a success is likely to have been influenced to some degree by the merit or priority afforded it by the senior NHS managers and commissioners tasked with leading and implementing the programme.

As a starting point, completing the Transforming Care implementation plan that was required from each area by NHS England, was beset by numerous challenges and issues that led to its’ value in the round being debatable. One such matter was in relation to time pressures, with participants from three of the areas confirming the use of outside consultants to complete these plans on their behalf, making local ownership and engagement questionable. Gaps in knowledge due to staff turnover and changes to systems and processes as a result of merging CCG's were also highlighted as causing local areas challenges in completing meaningful planning and implementation:

> *"…there was a lot of disruption, a lot of change, people had moved on; so, when I came into post there was no hand over as such, it was basically I had to come and firefight and then react to a whole set of circumstances and at the time we didn't have great visibility on our numbers as well because records had been lost or people had left post and there was a huge knowledge gap*." (Senior commissioner 5)

The combination of such a loss of knowledge and momentum necessitating a reactive response against a background of unreliable or missing data would have undoubtedly made planning and implementing the three-year time limited Transforming Care Programme more challenging. Continuity in resourcing and leadership to drive the programme forward was an evident key indicator of the degree to which it had been successfully implemented in each area. Staff movement within participating organisations also gave insight into the importance of continuity and the differing ways organisations, even within the same region, were implementing the policy:

> *"… I came from X more recently, so I haven't been in Y for a huge amount of time, I came here just over a year ago and it was really interesting seeing the difference in approach, …not everyone understands Transforming Care.*"
> (Senior commissioner 7)

Differences found in terms of levels of organisational ‘buy in’, the resource allocated, workforce stability, and comprehension of the Transforming Care programme compounded in areas where joint working and co-authorship of the implementation plans were required. This led to a lack of engagement, participation, and cohesiveness across some areas, with one participant reporting that while the plan had signatories from the relevant organisations, they were not actively involved or engaged in production of the plan in practice. In areas where the perception of other public agencies, such as local authorities, was that the exercise needed to be completed solely by NHS organisations due to being issued as a directive by NHS England, it was affirmed that a pattern of limited joint or partnership working was further exacerbated.

With regards to co-production, patient and carer involvement in the implementation plans had only occurred in a minority of cases and was largely found in areas where strong representation and engagement pre-dated the policy. Generally, the degree to which agencies or representatives contributed to the plan varied but were predominantly professional-led in the majority of areas sampled in the form of either primarily health personnel or external consultants. Taken alongside the reports of a lack of true engagement by some organisations, this, and the absence of consultation with patients and carers, conveyed a process principally undertaken as a time constrained administrative exercise rather than a valid joint planning opportunity.

Reinforcing this position, none of the participants mentioned supplementary updating or use of the plan as tool for measuring performance or as a live document once submitted to NHS England. On further examination a stronger determinant of the prevailing service models was found to have been historic events and political agendas rather than the introduction of the Transforming Care policy, thereby offering an explanation as to why the implementation plans appeared to hold such little value:

> “*I would say it’s [service model] more likely a reactive one that leaps from crisis to crisis in the system and the solution is that things get bolted on, and oh, here’s a pot of money do something with it; here’s an issue we’ve found, let’s resolve it*.” (Senior commissioner 8)

Within this context, none of the participants offered an explanation of how the volume of services or number of locally retained specialist inpatient beds had been planned to meet need. Moreover, it confirmed that the size of the local population of need had not been a pro – active consideration in the planning process, as previously postulated. Based less on projected or potential demand, and more as a result of a reactive, opportunistic dynamic fuelled by the multi - faceted determinants common to public bodies, this reinforced the question of the value and effectiveness of the implementation plan. Furthermore, it also served to highlight a broader lack of formulaic and strategic planning behind service provision.

The role of the implementation plans as both a starting point and as a future road map for services in all areas was undermined further when additional scrutiny revealed a pattern of moulding and presenting existing services to map against the Transforming Care ethos and format, rather than reflecting a ‘clean slate’ within which to address the perceived issues afresh. Contributing factors included some participants feeling that their model was already sufficiently advanced stating that a “…lot of what we did preceded the national policies” and therefore having a vested interest in maintaining the status quo:

> “*When we came to write the Transforming Care plan three years ago there were some really good examples of care already existing and we didn’t want to jeopardise those models of care just because we were going to write a new model…*” (Senior commissioner 4)

For those areas where staff continuity and consistent leadership or a deficit in allocated human resource had been identified as an issue, replication of the existing service model into the Transforming Care implementation plan and use of external consultants was seen to be the most expedient way of meeting the imposed national deadlines. In all areas a lack of clarity about any ‘new’ funding and resources that would be made available, particularly when actual or projected inpatient numbers were either unclear or unknown, also impeded any aspirations for service expansion. Making the opportunity for service growth and development unviable, this left moulding or reconfiguring existing services to meet the Transforming Care objectives the only option that could be reliably delivered.

This finding is noteworthy, as effectively the Transforming Care programme overtly implied that what had gone before was not acceptable. However, without any immediate new funding streams for development, and a patient group to continue to deliver to without respite, NHS Trusts and CCG’s found themselves in the position of having to re-shape and ‘rebrand’ existing services. Furthermore, these needed to project a commitment and the ability to address a problem the government was asserting had not been satisfactorily resolved, whilst still utilising the very same services previously deemed inadequate to do so.

6.2.2 Funding challenges

Awareness of the funding accompanying the Transforming Care policy, and how to access it, was a key factor in determining an organisation's ability to engage and deliver on the policy aspirations. With the issue of funding to support implementation not being made available 'up front' it was instead targeted primarily at facilitating patient discharge and repatriation following a period of admission as opposed to supporting admission avoidance. Funding came in two forms with both attached to individuals: a dowry for those who had been inpatients for more than five years; and access to capital funding, administered by NHS England to purchase individual housing if required to facilitate discharge.

Making funding available at the end of the patient journey rather than releasing funds to NHS Trusts and CCG's at the start of the programme was perceived to have stymied innovative service development from the beginning. Although the timing was clearly to incentivise areas to discharge those more long – standing or complex patients quickly, many of the Transforming Care implementation plans analysed in stage one focused heavily on preventative services to avoid admissions in the first place. Identifying inpatient admission as a 'last resort', this resulted in the funding streams associated with the Transforming Care programme not mirroring the investment required to support this approach. Consequently, some participants confirmed that any redesign of service models were required to be "cost neutral". It was evident that this was a significant contributory factor to the inability of participant organisations to prioritise funding further service model development under the Transforming Care initiative, and presented a quandary for many who identified its worth in terms of good practice:

> “*I remember when it came out … we thought wow this is gold plated stuff …but are we going to be able to get there?’ … We realised we had some really big gaps … we’ve got hardly any money, how are we going to get from where we are now?*” (Senior commissioner 8)

Despite identifying the Transforming Care policy as having set ‘gold standard’ objectives for practice, all participants were acutely aware that there would be no additional resource or finance to realise this. In short, service availability in every area remained very much the same, with the exception of some reconfiguration within existing resources to work towards the Transforming Care objectives more readily. The resultant effect maintained somewhat of a service ‘postcode lottery’ for people with learning disabilities with some areas retaining comprehensive pre-existing services, such as community-based teams supporting admission prevention and physical health support, and others being more piecemeal:

> “*I don’t think there was any strategic view … generally it came about from other providers not being able to provide a service for various reasons and* [NHS Trust] *feeling able to step in and take over providing that service… We’ve stepped in following a disaster really and picked up little bits of services…”* (Senior operational manager 5)

Describing a model again based on a reactive dynamic, with little planning or strategic direction, this ‘bolt on’ approach led to inconsistent availability of learning disability services in some areas. Without any additional finance, it was evident that the introduction of the Transforming Care policy had failed to provide the resources and opportunity for the levelling up or rectifying of inequities in service provision for people with learning disabilities across the region.

In relation to the limited funding streams that were available, and administered by NHS England, awareness, and accessibility of these was also problematic for some. With similar contributory factors to those affecting overall policy implementation, such as staff turnover and organisational change, there was evidence that the funding opportunities had not been fully understood:

> "*It hadn't really become clear to us about how much money NHSE was making available in terms of capital probably until the last month*"
>
> (Senior commissioner 6)

Reflecting a lack of clarity on the amount of funds available, this had delayed some areas in applying and, as a result, they did not access funding until the last few months of the programme. Some did not apply for any of the funding, and others recalled difficulties in both applying for and receiving the funds, with one suggesting that obtaining capital funding for housing from NHS England, had "been a nightmare". Other participants confirmed that they had "every bid submitted turned down". There were some exceptions to this and a minority of those sampled stated that they had secured "significant money on housing bids", including one participant who confirmed they had successfully obtained funding for two or three community houses from the associated programme funding. Similar to findings earlier in the study, experiences of accessing the available funds appeared to vary greatly even within the same region, and was highly dependent on organisational prioritisation, workforce stability, and the level of staff comprehension of the funding application process.

Without additional ‘up front’ funding, and the multiple challenges encountered in accessing what funding was available, it was evident that prioritising any major policy requiring service development within the NHS was going to have significant limitations by design. Furthermore, the size of the population of need of people with learning disabilities in relation to much larger patient groups requiring universal NHS services presented an issue. With the Transforming Care policy specifically devised to target those with increased risk and support needs, this led to a disproportionate amount of resource being required:

> “*We’re targeting a really small group of people, they’re [The wider CCG’s as service commissioners] targeting the rest of the population and so there is an imbalance but it’s the level of intensity and that dilemma of how do you spend the public purse?*” (Senior operational manager 3)

Acknowledging the quandary of comparatively small patient numbers against high resource cost when being responsible and accountable as a publicly funded body, many areas faced the same challenge. With resources already stretched, competing demands within the broader healthcare offer also had a financial impact on the ability to prioritise and operationalise the Transforming Care policy:

> *“… too often, I think at very senior level, there were bigger fish in the sea to fry. The acute hospital has always been a major pressure in the local system … so they did what was required… without having the full understanding and appreciation of what the impact of that was, so they did enough just to get*

> *underneath the radar, just enough to keep the regulators off their back."* (Senior commissioner 8)

Suggesting a scenario of juggling resource to meet need, other more pressing pressures in the system, and, as a result, doing just enough to appease regulating bodies, many participants felt that learning disability services were a small part of a much bigger system. Therefore, being unable to secure sufficient funding to support implementation of the policy from ringfenced Transforming Care funds became more impactful, as there was an acute awareness that this would not be forthcoming from elsewhere in the system.

6.2.3 Gaps in service provision

As a result of the inability to develop or extend services due to a lack of additional funding, all of the areas sampled identified gaps in service, and in particular, those for people with ASC. Included in the Transforming Care policy as a homogenous group, roll out of the programme had only served to highlight the universally significant gaps in provision for this cohort. Although a minority of areas were found to have very small pre-existing community services for those with ASC, these were primarily diagnostic and provided no further support. Many areas felt that a whole new sizeable patient group had been attached to learning disability services surreptitiously in one policy move, but without any additional injection of resources:

> *"The other thing they've done is they've bolted so many things on to Transforming Care…So you had your LD **and** autism and then it was well now we're going to put in **or** autism. Our numbers have been completely skewed*

> *because we're being told that anybody with high functioning autism who've never come into traditional LD services, … they're being pushed into it."* (Senior commissioner 7).

Reinforcing this view, many participants were also concerned for people with ASC who did not want to be defined as having a learning disability and the risk of marginalising them further. With no designated services available, some participants identified that people with ASC and their carers were being forced to come under learning disability services just to access healthcare support, even where it was not designed to meet their unique needs. Compounding this issue, many areas reported local divisions between acute mental health teams and learning disability teams in terms of responsibility for patient care within this cohort, with both maintaining that neither were commissioned to provide a service to this patient group:

> "*Only there wasn't really a pathway because the mental health pathway say it's autism, that's not us, LD say it's not LD, it's not us…so I think that's a massive gap at the moment…we need to create a specialist autism service*". (Senior commissioner 8)

As a result of this impasse, and an already overstretched resource for people with learning disabilities, many areas reported that people with ASC, but no co-morbidity of a learning disability would be "mostly excluded" from specialist health care services due to being ineligible for services meeting the needs of people with learning disabilities. Participants from all areas sampled expressed that they perceived autism services as a separate area of patient need which would require significant investment in the form of additional funding to set up specific services.

This finding is important, as although the Transforming Care policy dictated the amalgamation of people with learning disabilities and people with ASC into a homogenous patient group, operationally it did not facilitate the ability of organisations to address any pre-existing deficits in services for those with ASC. Despite the Transforming Care programme coming to its conclusion, many of the participants assumed that the legacy of the amalgamation would endure, and therefore discrete autism services were the immediate priority in several organisations. However, they were unable to expand on how this would be funded, with many still being in the very early planning stages, suggesting the service inequity for people with ASC may continue indeterminably.

6.3 Efficacy of admission prevention systems unclear

Upon examining community-based systems and processes to avert inpatient admission some mechanisms, such as community learning disability teams, were found to already have been in existence prior to Transforming Care, whereas others, including specific processes, had been introduced by the policy. Overall, anecdotally, these processes appeared to be helpful, however there was increasing dissonance between local authorities and health organisations. On - going cuts in public expenditure had affected the relationship and presented the risk of both preventable and / or inappropriate specialist inpatient hospital admissions.

6.3.1 Value of community multi-disciplinary teams

The majority of areas included in the study had established community support teams. The configuration of these and the support models offered in some had been reformed either before, or as a result of, the Transforming Care programme. Predominantly these comprised of multi-disciplinary health teams, although in some instances, there were integrated health and social care teams. Models described tended to fall into one of two categories: comprising of either a two-tiered structure with the larger MDT undertaking less urgent, more proactive work and a smaller faction providing intensive support; or a single tiered system of one intensive support team, purposefully designed to be reactive in nature. Although intensive support teams varied by name, all provided a similar function of offering more urgent intervention and support when individuals' community placements were at risk. Usually this was due to an escalation in levels of perceived challenging behaviour and / or a decline in their mental health. As one participant explained:

> *"…it only kicks in … when it really starts to hit the risk register for …transforming care so they're at risk of losing their service, or losing their home, or they're at risk of admission*." (Senior operational manager 8)

Despite the reactive nature of the model, it was found that none of the teams in the sample considered themselves to be providing emergency crisis response services, and, as a result none provided the 24/7 model recommended in national guidance (NHS England et al. 2015a). Some did offer extended hours and days; however, the rationale behind each offer was unclear, including why they deviated from the national plan, again indicating that this had been driven more by the level of resource assigned just prior to the initiative rather than the policy being responsible. In what was perceived as an attempt to rectify this, some areas had stated within their Transforming Care implementation plan that the mainstream out of hours mental health crisis team within their NHS Trust would be available, however the accessibility of that was questionable:

> *"…The belief from within our own organisation was that out of hours somebody with a learning disability would be entitled to and could access the same crisis response ... That hasn't really been our experience in reality. People will wait until the next day… The crisis team don't work with people with learning disabilities … I don't think they feel they have the skill…they feel that the adjustment required for some of the individuals would* [not] *be reasonable looking at the time and resource that they have available*." (Senior operational manager 2).

This finding was interesting, as although none of the areas were following the recommendations within national guidance to provide out of hours cover (NHS England et al. 2015a) within their service model, neither did any report significant challenges by choosing not to do so. What it did appear to confirm was how difficult it was for mainstream services to offer sufficiently reasonable adjustments to enable equity of access, thereby vicariously highlighting the validity of specialist services in supporting people with learning disabilities.

Of those areas that had community teams, all confirmed having thresholds or access criteria in place in order to manage resource against demand, which was found to be a recurring consideration throughout the study. Thresholds were intrinsically linked to risk to self and others, and where one-tiered models of intensive support existed, this inherently meant only higher thresholds of need were eligible. This focus on those with higher risk management needs was felt to have contributed to a significant shift in service objectives, and away from others whose complexities lay elsewhere:

> ” …*Those people with severe, profound learning disabilities who harm themselves or do nothing; that is stuff that doesn’t happen anymore and that breaks my heart because I know that not an awful lot has changed for those people, their lives are as poor and because they don’t make a political noise, they don’t impact on statutory services because they’re passive predominantly, or they’re not impacting on other people or drawing attention to themselves, they’re invisible*.” (Senior operational manager 3)

Many areas concurred and lamented that the pro-active work historically undertaken to support those with multiple and complex needs around quality of life, but not necessitating specialist inpatient admission, had become victim to the relatively narrow focus of the Transforming Care agenda. Notwithstanding this observation, the general finding was that the role of specialist learning disability community teams, and their ability to offer timely intervention in the community, was felt valuable in contributing towards the overriding objective of supporting people to either avoid or delay admission to specialist inpatient services. In terms of efficacy, none of the areas were measuring the number of admissions averted due to the intervention of the community teams, and therefore it was not possible to quantify the true effectiveness of the teams as a mechanism in preventing hospital admission.

6.3.2 New Transforming Care processes

Several participants corroborated the use of two additional processes introduced by the Transforming Care initiative that had helped support planning, and sometimes aided prevention of inpatient admission. Although effectively serving the same purpose, pre - admission care and treatment reviews (CTR's), and blue light meetings were found to differ only due to circumstances, with CTR's being the policy recommended forum in which to discuss individuals at risk of inpatient admissions. Many alternatively stated the use of 'blue light' or urgent MDT meetings, which appeared less formatted and prescriptive in nature, but were designed to pull together all relevant parties for discussion at very short notice in an emergency situation. Used to thoroughly assess both the presenting needs of the individual and explore all possible options for their care and support respectively, both comprised of representatives across health and social care and were noted to be beneficial:

> "… *It does prevent admission to beds; it's difficult to prove because obviously the person never makes it to a bed so you can't prove negative, but certainly there's a feeling that it's a safety net that encourages the multi-disciplinary teams to think in a more urgent and a more empowered way"* (Senior commissioner 4)

Despite the sense of empowerment expressed about these meetings, and the high value they were given by participants for their collaborative and responsive capabilities, this inability to "prove negativity" was an important point as it made it very difficult, if not impossible, to evaluate quantitively the effectiveness of the meetings in preventing admissions. The meeting of agencies provided the feeling of a "safety net" in considering and exploring all other options and shared decision making, reinforcing that decisions to admit people with learning disabilities to specialist inpatient hospital beds were not made lightly, or without first exhausting all alternatives. This was particularly important to participants as overall the meetings were reported to result in delaying admission rather than completely averting it, making the decision to admit inevitable in most cases.

6.3.3 Divergence in joint agency working

Although blue light and urgent MDT meetings were generally hailed a success as a joint working model in some respects, many participants observed a shift in the broader relationship they experienced with their counterpart social care organisation in the local authority. Participants felt this could be traced back to the national austerity drive by the incumbent government and a sustained “disinvestment of monies in local authorities”. Some areas reported significant financial impacts, including one local authority going bankrupt. Most CCG’s did not report significant cuts, but some did have financial difficulties which made advocating for the most appropriate outcome for the patient challenging:

> “…*anything that doesn’t present as a savings opportunity, even if it’s an investor safe opportunity, often doesn’t get traction here”.* (Senior commissioner 5)

Within this context of dwindling public funds, divisions between local authorities and NHS CCG’s, and disputes regarding which agencies were responsible for funding an individual’s care whilst they remained in the community were frequently commented upon and led to some questionable practice. Participants confirmed that once someone was deemed clinically required to receive hospital care and treatment then the cost of an admission did not form part of the decision making, and the CCG would be responsible for funding the bed wherever a vacancy could be found, irrespective of cost. However, whilst someone remained in the community this differed in that it centered around determination of whether a person's needs arose from their social or health care needs, and what was referred to as "cost shunting" was commonplace. In most areas this became more evident at the point of an escalation of risk within the community, when a blue light or urgent MDT meeting would be convened:

> "…*If you're trying to prevent somebody going into hospital and that requires an increase in costs to deliver that preventative approach that's where it falls down because you will have social care colleagues saying it's a health issue, they need to go to an NHS hospital, health pay for that; there's not that joined up approach*" (Senior commissioner 7)

Highlighting the differences in the system as to where financial responsibility lay, either with primarily social care funding in the community, or health funding in hospital, this exposed a perverse incentive for cash strapped local authorities to push for hospital admission when it may not be clinically indicated, thus relinquishing them of the cost pressure. Furthermore, instances of cuts to individuals' care and support packages in the community by local authorities trying to get their overall expenditure down, were also identified as increasing the risk of inpatient admission due to it causing an erosion of adequate risk management in some cases. As examples of self – fulfilling prophecies, the inability of local authorities to increase their funding to prevent community placements breaking down was pinpointed as one of the factors affecting the necessity of specialist inpatient admissions in some areas.

More positively, in a small number of areas, particularly where personal relationships had been built between organisations, encouraging progress had been made. Coming full circle, there was evidence they had managed to move past such barriers to refocus on prioritising the patient's needs, with one participant reflecting the change:

> “…*Let’s just get the best thing in place, and we’ll argue about the money later, but it hasn’t always been like that. At times you had to fight to get the funding sorted, and then you’d look at it, totally the wrong way round. It used to make me so frustrated to think we can all argue about money now, but actually, there’s a person at the end of it*.” (Senior commissioner 8a)

Although only seen in a minority of the sample group, some areas appeared to have made a conscious decision to focus back on the needs of the individual. The fiscal challenges had not gone away, but individual post holders within and across organisations had felt the need to find a way to move forwards in working together rather than being constantly conflicted. Vital to the consideration of any future policy aimed at reducing the use of specialist inpatient services, this highlights an area possibly not previously considered as impacting upon admission rates, and far removed from the presenting need of the individual: the financial position, and thereby incentive, of both the CCG’s and local authorities within each area.

6.4 Unintended consequences of successive policies

The analysis of contemporary specialist inpatient provision within the context of how it had been shaped by a policy drive for reduction formed a key element of the study (see Chapters 4 and 5) and indicated that this had not been without consequence. Whilst recognising that all polices and processes may create unintended consequences, overall, the impact of reducing local specialist beds had a snowball effect in terms of pushing those who required hospital treatment further away from their homes and families, and, generally, for longer periods of time (Shankar et al. 2015). This finding is salient as care closer to home and minimal admission periods were dominant aims of the Transforming Care policy.

As a result, concerns about distance, the correlating increase in private specialist inpatient hospitals, their quality, and apprehension around the efficacy and cost of monitoring visits were expressed by the participants. Impediments effecting discharge at the end of the patient journey were also highlighted and acknowledged as a contributory factor to extended lengths of stay. With these findings having significant implications for policy considerations going forward, these issues are now discussed more fully.

6.4.1 Dilemmas and tensions

Findings reported from stage one (see Chapter 4) in relation to the service models set out in the Transforming Care implementation plans were confirmed in the interviews with participants at stage three. The majority of areas sampled continued to maintain a policy of having no local specialist inpatient beds. For those areas that historically had inpatient beds but decided to close them, it was confirmed that this had been triggered by preceding drivers, such as former scandals and policies, alongside the closure of NHS campuses, rather than the Transforming Care policy. Where beds did exist, no further bed closures were found to have taken place since the Transforming Care implementation plans had been published. In stage two (see Chapter 5) demand for local specialist inpatient beds had been found to predominantly outstrip supply, and consequently, all areas confirmed the need to rely on the additional use of out of area beds where hospital admission was required. Exacerbating this issue, in the areas with specialist inpatient beds, localised bed blocking, with individual lengths of stay sometimes running into several years, was a common occurrence due to placement breakdowns frequently resulting in the individual becoming homeless on admission. Coupled with challenges in identifying appropriate community support to discharge people back to, the combination had caused “silting up” of the system, and effectively turned local hospitals into “long term housing”.

The tension in the system due to the emotive and sensitive origin of the policy was evident; accordingly, strongly held opinions about reinstating or expanding local inpatient beds differed; one area recognised that they needed more beds and were actively working on a proposal, whereas another area reported that the “head of the Transforming Care programme is saying we shouldn’t have any beds at all”. Of those who had proposed increases or suggested re-introduction of specialist inpatient beds, all reported resistance from different parts of the system including clinical leads, consultant psychiatrists, and NHS England. In the latter, the participant noted that the timing of a decision not to reinstate local specialist inpatient beds in their area directly correlated with the Whorlton Hall expose. Clearly a significant influence on the decision making, this demonstrated the considerable degree to which public and political opinion continue to influence policy and practice in this area.

Being mindful of the challenges of securing specialist inpatient beds locally, and previous policy attempts advocating access to mainstream health services for people with learning disabilities, some participants referred to utilising local NHS acute mental health beds as an alternative. This was said to have worked “quite well” in some areas but had primarily been for individuals with mild learning disabilities “usually open to mental health services rather than to our services”. The severity and nature of an individual’s presentation was said to play a key part in determining i) if they were admitted to an acute mental health ward and ii) how successful that admission was, with individuals with challenging behaviour seen as the most difficult to accommodate. As explained by one participant:

> “…W*hen it’s a bona fide mental illness, they have a psychotic episode or a bipolar episode or they are profoundly depressed, they get very well looked after in the mental health hospital. Where they have additional challenges either from autism or from their learning disability per se then it is a significant challenge for the mental health unit to be able to manage and they have a less good experience*. (Senior ops manager 7)

For some individuals with challenging behaviour, the “less good experience” resulted in extended segregation due to the impact they had on other people in the ward. Many areas reported that the use of acute mental health beds for these patients had led to on-going debates within their NHS Trust about what constituted ‘reasonable adjustments’. The general consensus in this respect was that acute mental health inpatient units were not appropriate as the ability to adapt both practice and environment to meet additional needs, and the degree to which this was viable, left some feeling the adjustments were “unreasonable”.

Despite the doubts raised regarding the use of local acute mental health beds, and concerns about them being unable to meet the needs of people with learning disabilities, it was sometimes the only option when there were difficulties in securing “out of county specialist provision in weeks sometimes, certainly not in hours and days". This led to the notion of providing a 'place of safety', as a bed is legally required once detained under the MHA, with the consequence of delaying active assessment and treatment:

> *"People that have quite significant autism and quite significant learning disability have had to access mainstream mental health facilities and have remained there for relatively extended periods of time... it's far from ideal… the individuals aren't really receiving assessment and treatment per se but they're in a safe place."* (Senior operational manager 1)

With potential ramifications for treatment outcomes, and acknowledgement of the less than ideal environment, participants minded not to use local acute mental health beds felt this magnified the lack of specialist inpatient beds nationally. As a result, it was "pot luck" where some people were admitted to, either geographically or at which hospital, and relied solely on where a bed vacancy could be found, and their acceptance of the patient. Several participants identified that this brought with it a heavy sense of responsibility as they knew it would "result in the individual being placed 100-500 miles from the local area", making the situation both pressured and morally testing for decision makers.

To add to this dilemma, as NHS specialist inpatient beds for people with learning disabilities had closed, so private provision had grown exponentially to meet the demand, meaning commissioners had "To go out to the private market when we are looking to place because there is no local NHS provision". Furthermore, there was evidence that the private market was continuing on this trajectory and were:

> “*Actively pursuing linkages with TCP’s* [Transforming Care Partnerships] *and other Senior commissioners to invest locally, so that market is the growing market not the NHS provision*.” (Senior commissioner 2)

With both Winterbourne View and Whorlton Hall having been private hospitals as opposed to NHS facilities there were underlying concerns around the quality of care being offered in the private sector. Moreover, one senior commissioner suggested that private hospitals, unlike NHS counterparts, had an “indisputable conflict of interest” financially to retain patients far beyond their needs, leading to greater lengths of stay than were deemed necessary.

Many participants readily acknowledged the conundrum they faced between agreeing morally with the ethos and philosophy of avoiding unnecessary hospital admissions, against the practicalities of not having local facilities available when required. The result of the impact on people with learning disabilities and their families in being sent far from home was not lost on those making the decision, with one participant reflecting:

> “*The majority of cases are going to have to be put in a hospital out of area, a long way from home, away from their families. Which can be, you know, really really frightening for people, and you know it's bad enough that a member of the family’s had to be admitted to hospital but then to find out that they’re in* [a distant geographical location]*, and the emotional and financial cost of just a visit, is really really enormous*”. (Senior commissioner 2)

Overall, successive policies to drive down the number of specialist inpatient admissions by reducing the number of beds physically available was found to have been implemented in all NHS Trusts sampled. However, as a result, private hospitals identified the gap in the market and had opened up, and were continuing to open up, new beds in response. It is therefore arguable to what degree admissions to inpatient beds reduced as a result of the policies, whilst also creating the need to send people to hospitals very far from home. Many organisations reflected on the dilemma of whether they should meet need through local provision of specialist inpatient beds, thus ensuring people were closer to home and their families, against the backdrop of the national drive and policy to further reduce such beds. Of note, the policy objective of bed reduction appeared seemingly not applicable to the private sector.

6.4.2 Apprehension around monitoring

Compounding concerns around the impact out of area admissions on individuals and their families, participants felt that monitoring, oversight, and quality assurance measures were also more exigent. There was a risk, as one participant noted, that "out of sight is out of mind", and that monitoring needed to be "robust enough to minimise that length of stay as much as possible." In terms of practicalities, distance, cost, human resource, and the inability of local community health teams and service providers to work closely with the hospital to monitor quality and focus on timely discharge planning, were all identified by participants as key challenges to this.

Formal monitoring of people once in hospital took place under the care and treatment review (CTR) system, introduced by the Transforming Care policy, and designed to hold all parties to account and expedite discharge. Many participants raised the logistical and resource implications in undertaking CTR's out of area as an issue, stating that the timeframe of at least one day for the review, plus travel time, alongside the cost of professionals' time made it an expensive process. One participant estimated the cost at around £1,000 per CTR. This cost pressure was a concern for staff in most areas, which had become heightened following a recent increase in the frequency of CTR's from every six months to every three months. Instigated by NHS England in direct response to the abuse exposed at Whorlton Hall, some participants felt it was a "kneejerk" reaction without consideration of the cost implications.

Participants views on the value of CTR's varied significantly and ranged from perceiving this as being "burdensome" to it being a "really robust process". In terms of efficacy, there was little opinion offered on whether or not CTR's expedited a person's discharge. However, evidently some felt it required additional impetus and they used supplementary processes such as regular caseload review meetings, an independent supporter service, and oversight of a complex case manager to maintain momentum. Findings from earlier stages of the study (see Chapter 5) were confirmed during the qualitative interviews in that participants identified that people with learning disabilities admitted during the period when the Transforming Care policy was active generally experienced shorter lengths of stay and were discharged "much, much quicker". It is unclear if this was directly related to the introduction of CTR's and / or the supplementary processes some areas put in place but cannot be ruled out as possible contributory factors.

Concomitantly with the increased frequency of CTR's, NHS England also directed CCG's to increase quality assurance visits to every eight weeks for all adults with learning disabilities in an inpatient setting. Participants seemed generally unsure of the added value that the directive would bring:

> "*I'm not quite sure how going out to do more quality assurance visits will help address some of the poor performance or issues the government are quite concerned that happen in hospitals, because thinking about the Durham case* (Whorlton Hall)*, CQC had been in there recently, so many different professionals had been in and nobody picked up on it".* (Senior commissioner 6)

Within the context of this increased monitoring being a newly introduced directive at the time of the study, participant confidence in the ability of additional, announced, quality assurance visits or CTR's to provide a solution to covert abuse was non - committal. Additionally, concerns regarding the added cost pressures that this would bring, with no further funding attached, were ever present, and led many to question how they would be able to sustain the schedule of monitoring visits demanded going forward.

In order to address some of the concerns and practicalities of the logistics both of monitoring and facilitating a robust and timely discharge, a minority of areas had started to transfer some of their patients to hospitals closer to home. Although still some distance from their usual place of residence, and remaining out of area, participants perceived this as a "sideways move". Ensuring that people were closer to home, the aim was to make it more practicable for families, local teams, and community providers to visit, monitor, and start working with these individuals.

6.4.3 Impediments to timely discharge

Aside from distance, additional causative factors of extended lengths of stay and delayed discharge were suggested to include patient profile, housing availability, funding constrictions, and securing sufficiently skilled support providers within the community. Many areas were said by participants to have a “legacy cohort” of varying numbers of individuals deemed to have more complex needs, and therefore being more problematic to discharge. These were identified as broadly falling into two types; those whose levels of challenging behaviour, which by its very nature, was not going to be “cured” resulting in unmanageable levels of risk in the community, and those who were under Ministry of Justice (MOJ) Orders, with conditional restrictions on their discharge and movement, due to offending behaviour. For both, participants highlighted the importance of sourcing appropriate housing and sufficiently skilled support staff in the community as the two biggest barriers to discharge.

Some of the patients within this particular cohort were found to have been in hospital for extraordinary lengths of time, for example, one participant identified people placed out of the area that had been in hospital for 17 years. As a result of extended periods of institutionalisation, there were instances where this patient group were said to “really struggle to fit into the new model” and adjusting to a more liberal, less boundaried support model in the community had been overwhelming for some and resulted in failed placements. In order to address this several areas were said to providing or planning to offer step-down/step-up beds as a transitional interim measure. However, none of the participants from areas where this had been tried spoke about this model being successfully utilised in this manner, predominantly owing to a lack of suitable onward permanent placements, with reports of bed blocking in all such existing services.

Challenges in securing suitable housing for people with learning disabilities was also a significant factor mentioned in successfully progressing discharge. To varying degrees, the NHS England capital funds available through the Transforming Care policy had supported some individuals in providing bespoke individual housing to meet their needs. As previously discussed, this very much depended on successful application to the fund by an individual's responsible CCG. A lack of suitable housing stock in all areas was highlighted by participants as an issue within the context of national shortages. Adaptations sometimes required to ensure the environment was sufficiently safe to meet a person's behavioural or physical needs, alongside the risk of potential environmental damage in rented property, were all felt to cause significant delays, even if a person was deemed medically fit for discharge.

Funding community support packages on discharge were found to be less contentious than admission avoidance, due to the health funding associated with detainment under the MHA, with the majority of participants not identifying it as a barrier to discharge. Nevertheless, the challenging financial position of one CCG offered insight into the considerable impact a funding deficit within a commissioning organisation can have:

> "*Sometimes I feel like I'm really caught between a rock and a hard place; you've got NHS England saying why are you not discharging and then I've got my very senior management saying you can't because we can't have any additional cost pressure within the CCG. So that's a problem, the money has been a problem; what's been promised has not been delivered so we work on the basis of unless it's in our pocket, there is no money.* "(Senior commissioner 7)

Linked to the difficulties previously discussed in accessing the monies associated with the Transforming Care policy, this reflects the serious implication of needing to purposefully delay discharges when policy funding is inaccessible or insufficient. Although an isolated observation in one organisation, this finding was an unexpected cause of discharge delay and is of great consequence due to its immediate and enduring impact on discharges, and the human cost therein.

The final area of challenge participants felt delayed discharge, particularly for those with multiple and complex needs, was a view that the skills and expertise of local community-based service providers were insufficient to support such individuals:

> "*A lot of our longer admission times are due to us not being able to meet the need locally with the right home and the right support… there are a number of people stuck in hospital because we are struggling to get the right providers that we feel can do it.* "(Senior commissioner 4)

To address this, participants highlighted how some areas were offering an individual service design model where housing, location, support, and individual aspirations were all incorporated into the discharge planning, although this approach was not universal or necessarily considered always attainable. More widely evident was a consensus that individuals needed some element of a customised approach, but the difficulty in securing that in time for discharge still presented an issue:

> "*There isn't the service to cover the need so it's going to be a bespoke service so that can take some considerable time. So, they're looking at other options*

> *because the hospital where she's staying gave notice some time ago*." (Senior operational manager 8)

While participants noted that numerous community service providers marketed themselves as 'specialists', this had not proven to be the case, and placements had broken down quite rapidly as a result. Many confirmed that not having providers able to take on "really complex people" was a major problem. Also identified as problematic by participants, the pace at which providers could respond presented an issue. Unable to free up capacity quickly enough when someone required re-housing due to a placement breakdown, this was felt to lead to unnecessary inpatient admissions on the basis of alternative accommodation not being available at short notice.

Acknowledging problems with availability of the right kind of community-based services, some participants recognised that developing the market was "the key to success" if placement breakdowns were to be minimised and discharges expedited. Some areas had already started to consider initiatives to engage community service providers in upskilling their workforce but were conscious of progression stalling without sourcing the additional funding or resources to support the project.

6.5 Summary

The findings from the qualitative interviews, whilst further illuminating previous findings from earlier stages, also draw attention to the multifarious issues and complexities within specialist inpatient services that may not be immediately apparent. It is evident that numerous barriers existed in planning and delivering the Transforming Care policy, and that historic policies and events had already had a significant influence on the shape of services. This, accompanied by the lack of funding available, resulted in the organisations being unable to utilise it to maximum effect and, therefore, its ability to support a further reduction in specialist inpatient admissions, was found to be limited.

Perception and reception of the policy by local decision makers was a key influence on the value and status placed upon it, and although the ethos and philosophy were widely welcomed, this directly affected the prioritisation and resource it was afforded. This was mirrored in the drawing up of the implementation plans, where the use of consultants, and non - participation by some areas hampered the level of organisational buy-in. A lack of patient and carer involvement in many areas indicated that the planning process itself had not been consultative and added to the perception of a time constrained administrative exercise, reinforced with the finding that it did not remain a live document post submission.

Many of the prevailing service models, in terms of a reduction in locally retained specialist inpatient beds, were ahead of the Transforming Care initiative as, again, historic triggers were found to be the overriding determinant of service models in place at the time as opposed to introduction of the policy. Participants confirmed that services were, generally, borne out of wider political, financial, and systemic pressures as opposed to policy, and described a ‘bolt on’ model of progression rather than a planned, pro-active sense of direction. In this context, confirmation that the size of the local populations of need did not determine the size of health service provision was explained and reinforced a reactive approach rather than one of broader strategic or formulaic thinking.

A lack of clarity around the funding associated with the Transforming Care programme was also found to have a substantial impact on the ability of organisations to fully implement the policy and their plans. Uncertainty of patient numbers, awareness of how to access the funding, the amount available, and preparing a strong case all contributed to varying degrees of success in securing funding that accompanied the policy. Some areas seemed to fare much better than others, leading to a potential inequity in service contingent upon how au fait the responsible CCG was with the process. More generally, the lack of funding maintained existing service inequity, and did not allow for any service gaps to be addressed. This was particularly pertinent for those with ASC, who had been grouped together with people with learning disabilities in the Transforming Care policy, but without any additional funding allocated to set up discrete ASC services.

All areas focused heavily on admission prevention both within their implementation plans and service models. Indicating that a potential solution in keeping admission rates and lengths of stay down may be to avoid admission in the first instance, community teams and processes, such as pre-admission CTR's and blue light meetings, were key tenets in all service models. Despite being identified as effective in either preventing or delaying inpatient admission, the accompanying funding structure did not support future or innovative investment in preventative measures, and therefore, areas were unable to further build on averting admission at this stage of the patient journey.

Broader funding issues had also caused a more marked divide in organisations, and the success of joint working between CCG's, NHS Trusts, and local authorities seemed wholly reliant on the relationships built between individuals across agencies. Putting pressure on decision making, reduced budgets had led to the potential of patients being admitted to hospital due to a lack of social care funding rather than requiring treatment for a mental health condition.

The specialist inpatient service for people with learning disabilities was found to have many systemic issues that contribute to the on-going issues and complexities for those that needed to be admitted. Paramount was that the persistent pursuit of bed reduction for people with learning disabilities over the decades had diminished NHS bed stock nationally and resulted in people often being admitted many miles away from their home, family, and friends into private hospitals. Not accountable to political oversight, hospitals in the private sector expanded to meet demand as the NHS closed its beds; led by wherever a viable market had been established, they continued to facilitate the admission of people with learning disabilities, seemingly able to bypass the aims of the Transforming Care policy. With no obligation to admit people close to home, and extended stays common, decision makers felt a huge sense of responsibility knowing the implications.

Furthermore, this put them in a very difficult position when it came to choosing between advocating for provision of beds and care locally, which would go against the grain of national policy, or knowingly having to send individuals much further away from home, at the risk of a much longer admission period, and the significant impact for individuals and their families. Despite this moral confliction, a reticence in forming opinion against a policy and public belief derived from the position of protecting people against abuse was seen, and so opinion differed quite considerably on reinstating or expanding local bed stock.

Of those areas that did have beds, this did not come without issue, and alongside supplementary supportive models such as step up / step down beds, 'silting up' was found to be a common problem. Pertaining to those patients with more complex needs or requiring higher levels of risk management, many areas found that any local specialist inpatient beds they had retained were susceptible to becoming blocked. Whether in a local bed, or many miles away from home, instigating an effective discharge for any long – stay patient who fell within this high a risk category was a widespread challenge, and many areas had a 'legacy cohort' of such individuals. Comprising of those with significant levels of offending or challenging behaviour, sourcing the most appropriate and safe, housing, environment, and support for these individuals was cited as an on – going barrier to discharge.

The many challenges and complexities found in the prevailing inpatient system and wider health services for people with learning disabilities goes some way to explaining why the implementation and effectiveness of the Transforming Care policy was so varied across areas. It also identifies some common problems experienced across all areas sampled, and the implications for future policy, practice, and research, which are now discussed in the concluding chapter.

Chapter 7. DISCUSSION

7.1 Introduction

This thesis began with the metaphor of an elephant in the room to highlight the sensitive nature of the topic of specialist inpatient beds for people with learning disabilities. With the literature review outlining how, principally as a result of enduring national scandals of abuse, policy makers sought to drastically reduce the use of such beds, it has, understandably, created a situation where the ability to openly advocate for their retention is incomprehensible for most. Proffering a position that many do not wish to publicly align themselves with has subsequently stifled constructive discussion and consideration of both the purpose they continue to serve, and the operational challenges and complexities that have maintained their existence. However, this study has shown that those discussions are required and important if we are to find a more sophisticated solution. The need to understand more fully what the issues are could not be better highlighted than in the latest government figures where, despite successive policy drives, as of March 2021, depending upon which dataset is used, between 2,035 – 3,205 people with learning disabilities still remain in specialist inpatient beds in England[10].

The primary aim of this study was to conduct mixed methods research to examine in more detail the systemic complexities and challenges that have resulted in the continued use of specialist inpatient services, despite policies to the contrary, and why further reduction may indeed be problematic. A secondary aim was to ascertain how

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[10] https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-march-2021-mhsds-january-2021-fina

neighbouring NHS Trusts to my own, that were operating without local beds, were practicing, and performing within the framework of national policy to facilitate future considerations of service configuration within my own NHS Trust.

A unique contribution of this study to practice knowledge lies particularly in the study capturing the experience and perspectives of those responsible for commissioning and operationalising said policies and services, which adds a fresh perspective to the debate about the future of specialist inpatient services for people with learning disabilities. In addition, the use of a mixed methods approach to yield both quantitative and qualitative data has provided a greater depth and breadth of information about this area of health provision (Amalki 2016), and by doing so has sought to illuminate previously under-researched and less well understood aspects of the tension between policy and the use of specialist inpatient services in the NHS. Moreover, the evidence base collated has the potential to inform service planning and practice within my own region.

This study has covered many areas of interest relevant to the use of specialist inpatient services and how they operate within a defined region of England. Numerous issues emerged from the research in relation to the ‘hidden’ systemic complexities and challenges faced by those attempting to operationalise it, which are now discussed further.

7.2 The problem with macro level policy

As a tool, national policy is a blunt one and many participants in this study felt the ability to apply local customisation dependent upon the situation, would have been more effective. Tensions arising from national policy issued by government and delivered by NHS agencies are well documented (Klein 2019). Elements such as local priorities and nuances, ability to finance, and competency of the human resource allocated to implementation, all had a profound impact on levels of engagement and, ultimately, effectiveness at local level. A mixed picture emerged both in terms of approach and service availability across areas. Although the intent behind the policy was not contended, the ability and willingness of each area to fully implement it varied quite markedly. In common with the findings of McMurray (2007), as a public body subject to constant change, elements of ‘change exhaustion’ were also evident with some areas expressing aspects of apathy, and loss of shared communication, decision making processes, and comprehension, which compounded matters further.

Besides the lack of flexibility to customise the Transforming Care policy, another key barrier to successful implementation was the incongruence between national and local perspectives, with policymakers at national level targeting additional funding at the end of the patient journey while Transforming Care partnerships sought to concentrate resource on admission avoidance. With operational and practice opinion differing to that of policymakers, and a system relying on bed closures to release any funds, (NHS England et al. 2016), additional investment in areas of community prevention systems was near impossible. Moreover, reflecting the findings of a National Audit Office review undertaken at the midpoint of the Transforming Care Programme, none of the areas sampled reported receipt of any further funding due to bed closures (National Audit Office, 2017). With the expected reinvestment savings of between £50,000 - £125,000 per person per annum made by discharging an inpatient to community support and closing the bed behind them (Transforming Care and Commissioning Steering Group, 2014) against an estimated £135m - £195m annually required to support programme targets, the challenge of implementing a time limited policy, with such a significant financial shortfall, becomes apparent (National Audit Office, 2017).

As a result of this lack of injection of additional finances, areas had to work with what they already had and, in common with the findings of Roy et al. (2020), an inequity in the range of service provision and delivery, or the creation of a ‘postcode lottery’ was clear. Consequently, any aspirational services contained within the plans to close service gaps, such as those for people with an ASC, were not possible to pursue. There is scant evidence available about the planning assumptions for the model including the rationale for the timescale beyond what fast track areas “believed possible” (NHS England et al 2015a:27). This calls into question whether important matters, such as existing service continuity, equity of access to services, and ability to reform within timescales, were sufficiently considered at the policy planning stage.

Due to successive government’s attempts, many areas in the sample group already had few or no local beds even before Transforming Care was introduced. The majority of participants cited the Community Care Act (1990) and White Papers such as Valuing People (DH 2001), Valuing People Now (DH 2009), and The Mansell report (DH 2007) as already having been instrumental in facilitating bed closures prior to Transforming Care. Therefore, it was questionable from the start of how effective the Transforming Care policy would have been in achieving further bed closures. Aside from the financial impact this had due to the positioning of the associated funding, it would appear that a plateaux has been reached. Thus, there is a question about just how useful further national policy to reduce specialist in-patient provision would be, and, consequently, to what degree it would be meaningfully implemented.

Overall, it is speculated that the emotive driver for this policy, and the subsequent inertia displayed in enacting the Winterbourne Review recommendations (DH 2012a, 2012b) created the perfect storm in which decisive and immediate action then needed to be taken. However, in doing so the timescales were tight, and the degree of research into the policy, and its unintended consequences, was limited. As a result, any overriding achievements secured by the policy have still not been publicly released (The Strategy Unit et al. 2018). This indicates that any further policy issued in this area requires thorough research and planning prior to implementation, and not to just be reactively issued in response to the next public expose of hospital abuse.

7.3 More complex than simply closing beds

It is hard to ascertain when the reduction and closure of specialist inpatient beds will have been deemed a success. Within the government report ‘Building the right support’ a figure of no more than 10-15 inpatients per million population was outlined as a suitable target (NHS England et al. 2015a). More recently, this has been revised to 50% by 2023 - 2024 compared to March 2015 (NHS 2019). However, for others, the aspirations of Transforming Care will not have been reached until all such beds have been closed and exposes of abuse cease[11]. The difficulty with this latter view, however, is that in spite of repeated political and policy initiatives and assertions that inpatient beds are overused, they remain a well-used part of our health system. Suggesting they continue to serve a purpose, and that suitable alternatives remain elusive, some of the reasons for this, as highlighted by the study, are now further discussed.

7.3.1 An issue of risk and clinical need

One of the primary reasons for the continued use of specialist inpatient beds was the need to safely manage risk when this could no longer be guaranteed in supporting people’s needs in the community. Many of the sample group had grappled with ‘legacy’ cohorts of long-stay patients, with the most prolonged on-going stay recorded at 17 years and seven months. With periods of between six to nine years being relatively commonplace, it was clear that there were a small specific group of patients for whom the most recent policy initiative, and all those that had predated it, had not been sufficiently effective to address all barriers to discharge back into the community. Defined generally as people with more complex needs, the patient profile fell broadly into two sub-types and were undoubtedly related to levels of perceived risk to

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[11] https://theatuscandal.wordpress.com/

themselves and in particular to others; those who had offending behaviour and were under section from the Ministry of Justice (MOJ) as forensic patients, and those who displayed significant levels of severely challenging behaviour.

In some circumstances forensic patients who have learning disabilities remain assessed as presenting an enduring risk to either themselves or others through further offending behaviours (Sinclair 2018), and it would be difficult to argue that the presence of a learning disability somehow lessens that risk or automatically warrants community placement when this would not be the case for forensic patients without learning disabilities. Taylor et al. (2017) encapsulated this dilemma by arguing that the pressure to close hospital beds, against a lack of investment in community services, resulted in providers being inadequately resourced to manage levels of risk that forensic patients presented, and also risked people being discharged before they were fully rehabilitated. Given this scenario, it is reasonable to suggest that a small number of people with learning disabilities who present levels of offending risk that are not safe to manage in the community need a highly managed and protective environment in which to reside. As an alternative to the criminal justice system, specialist inpatient hospitals avert the risk of victimisation for people with learning disabilities and ensure they receive the specialist support they require (Bradley 2009). Therefore, removing or reducing this option for this particular patient subgroup is likely to result in either unacceptable levels of risk in the community, or increased diversion to a prison environment.

The other, possibly more obvious reason, for continuing to provide specialist inpatient beds is to meet the needs of those people with learning disabilities who have mental health conditions and a clinical need for assessment and treatment or intervention. With research suggesting that admission can help to reduce the frequency of challenging behaviours and improve people's mental health (Slevin et al. 2008), denying this right to people with learning disabilities may well increase the health inequalities they are currently subject to (Scheepers et al. 2005, Cooper et al. 2011, Mencap 2012, Heslop et al. 2013). This risk to health cannot be underestimated, with recent studies finding that men with learning disabilities die an average of 23 years earlier and women 27 years earlier than that the general population, as a result of their disability (University of Bristol, Norah Fry Centre for Disability Studies, 2019). In the face of such bleak statistics, it could be contended that continuing to reduce access to a specialist tertiary health service for those with a diagnosed mental health condition compounds the marginalisation and restricted access to services already suffered by this patient group. This concurs with the findings of Alexander et al. (2015) who asserted that if bed closures continue to be implemented without full consideration of the clinical rationale, this will further disadvantage an already disadvantaged population.

In terms of other options for this patient group, alternatives have proved unsuccessful. Mirroring the findings of Standen et al. 2017, and Durrant (2020), most participants interviewed in this study considered admission to mainstream acute mental health beds had not worked well or that they are inappropriate for the majority of patients with learning disabilities due to the degree of reasonable adjustments required. Indicating that admission to such a ward is unlikely to provide an efficacious substitution, it is not clear where people with learning disabilities would be able to access appropriate medical support if treatment cannot be safely delivered in the community, and specialist inpatient beds are not available. Arguably, in the same way that a small proportion of the general population with a mental health condition require hospital admission to recover safely, having a learning disability does not make it easier, or any less risky to treat some mental health conditions in the community, particularly at times of significant mental distress. More importantly, people with learning disabilities are entitled to the same medical support and intervention as the general population, and it could be argued that in not providing this, and merely attributing their distress to their learning disability, would not just be inequitable, but bordering on inhumane.

7.3.2 Proficiency of community services to meet needs

Another area requiring further examination and assessment prior to continuing down the path of bed reduction is that of the efficacy of current systems and services set up within the community to avert the need for hospital admission. With a heavily weighted focus in the Transforming Care implementation plans on achieving an overall reduction in admissions, the use of rapid intervention health, or health and social care learning disability teams - appeared to be the favoured strategy. Although a perfectly logical assumption to make, it was less clear if this was because areas believed this truly was the answer, or it was a matter of necessity based on prevailing resource allocation and no additional funding injection to develop alternative service models.

Disappointingly, in common with Barnoux (2019), evidence on the efficacy of preventative intensive input from community-based health teams was stated by participants as non - existent. Organisations within the sample group did not monitor the number of admissions that had been prevented, and so it is not possible to conclude to what degree such teams are able to measurably contribute to reducing admissions. Although reported anecdotally as useful in this respect, assumptions made in each area that sustained admission prevention was achievable through ‘rapid’ community intervention, were thus uncorroborated by any quantifiable evidence. Further research in this area has already started and with a small – scale local study by Fuchs & Ravoux (2019) reporting improvements in behaviour, wellbeing, and quality of life, in addition to cost savings, alongside recent preliminary studies on a national scale indicating statistical validity and clinical utility, it is clear that the work of these preventative teams may be having some effect (Hassiotis et al. 2020). Nevertheless, with clinical effectiveness still to be ascertained, and community support providers reporting that specialist health team input was withdrawn too early (Clifford et al. 2018), it remains to be seen if this is an effective tool in bringing down the number of admissions long – term. This will be important to determine as with the step up / step down model having been reported as failing, these community teams are the main current pro – active tool within the health system to prevent admissions, and so would need to be proven effective before specialist inpatient services are further reduced.

The other key stakeholders who have an impact on admission rates are community providers who support people with learning disabilities to live in either group or individual placements within the community. Many of the participants in the study reported placement breakdown was due to either skill deficits in support staff or the living environment. These were identified as key causes of 'unnecessary' hospital admissions and it was felt that training to upskill community support staff would avert this. This position is an interesting one, as it is postulated that although increased investment in training and upskilling the support staff may have some impact on reducing the need for hospital admission, it could also be argued that many domestic set ups would not be sufficiently environmentally robust for someone in significant distress who communicates that through their behaviour. Therefore, further investigation into the effectiveness and role of support providers in averting hospital admissions would need to be two-fold; looking at the impact of up-skilling the staff, and also considering what types of environment are required when risk to self or others exceeds that of an individual's usual place of residence and an alternative place of safety is required. It is strongly contended that until an alternative solution is created for this scenario, then admissions to specialist inpatient beds are unlikely to reduce or cease for individuals with learning disabilities in those circumstances.

7.3.3 Impact of public funding cuts on implementation

One of the more concerning findings from this study was the implications for admission rates arising from the chasm opening up between health and social services in the wake of nationally reduced funding to public services. Possibly obscured to the untrained eye due to the indirect correlation, continual government cuts to spending in local authorities is one of the contributing factors in maintaining the need for specialist inpatient hospital admissions. Identified by participants as a ‘cost shunting’ exercise, the inability of local authorities to allocate additional funding for increased support in the community at times of distress, was identified as a causative factor in a proportion of admissions. Similarly, cuts in community support packages designed to mitigate risks were also identified as a trigger factor in some individuals’ deterioration prior to admission. This scenario was concerning on two fronts. Firstly, it was leading to people being admitted to hospital when it was not clinically indicated but the risk had become so great that the placement had broken down. Secondly, and of more concern, it suggested that those people with learning disabilities in distress were not receiving the increased support they needed at the right time, and thus their mental health deteriorated to the point of requiring hospital admission.

With the public consultation on the MHA reforms having recently closed[12], the issue of reduced public spending in local authorities is likely to become more problematic when

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[12] https://www.gov.uk/government/consultations/reforming-the-mental-health-act/reforming-the-mental-health-act-summary

these are introduced. Recognising that both learning disabilities and ASC are ‘lifelong conditions which cannot be removed through treatment’, once implemented, people with learning disabilities will only be detainable, and therefore admitted to hospital, if they have a diagnosed or suspected co-occurring mental health condition. Moreover, if following a period of assessment, it is determined that the driver for their admission is not a mental health condition, for example, an unmet need (support, social, emotional, physical health) then grounds for detention will be no longer be met and detention will cease (DHSC 2021). Effecting discharge back into the community, the potential impact on cash strapped local authorities, and therefore vicariously for people with learning disabilities, is not hard to predict. It is difficult to see how local authorities who are currently unable to provide additional community support to prevent admission are going to be in any stronger position to support those with learning disabilities that do not have a diagnosed mental health condition but may be in high states of distress and presenting a risk to themselves or others due to an alternative ‘unmet need’. Multi – agency work and co-operation is complex (Read 2020), and therefore it is asserted that this is yet another reason to pause the reduction in specialist inpatient beds, whilst the systemic impact of the reforms are assessed and sufficiently robust community alternatives are put in place to support this shift in legislative approach.

For the Government’s part, it has again decided to focus its most recent initiative, the Community Discharge Fund (Department of Health & Social Care 2020), comprising of £62 million of public funds on getting people out of hospital, rather than concentrating on admission avoidance. Given this study’s findings on the complexities of discharging the ‘legacy cohort’, and that more recent lengths of stay are starting to reduce, it is not implausible to suggest that the government are seeking a ‘quick win’ where one is not available, particularly in the shadow of threatened legal action by EHRC. In going forward the rationale and evidence base for the allocating of funds in this policy area requires further examination to ensure it focuses on the optimum areas for gain. The interrelationship between a lack of social care funding as a causative factor in sustaining the need for specialist inpatient admissions, also has to be addressed if the expectation remains that such beds and admissions need to be further reduced.

7.3.4 Getting the balance of Human Rights for all

In concluding this section of the discussion, it is argued that one of the main reasons why it is not only a matter of closing local beds, is the impact that the policy has had on people with learning disabilities and their families. The need for people to be admitted to specialist inpatient services located far from their home, the lack of choice of where they were admitted, extensive lengths of stay, and apprehensions about quality and oversight, were all key concerns raised by this study’s participants. As a direct consequence of the sustained closure programme, for all of the gains policy directives may have made, there seems little attention being given to the effect it has had on those who have needed hospital admission during this time.

Generating an internal paradox, the Transforming Care policy advocated continued bed closures and at the same time demanded that people be cared for closer to home. Effectively, one aim precluded the other. This scenario was the result of NHS hospitals being mandated to follow the national policy directive and duly closing either all, or a large majority of their beds. However, private hospitals that are seemingly exempted from national policy directives, stepped up to fill the void, which has resulted in no central control over where beds are provided. Subsequently, establishments are built on a business model, driven by financial considerations first and foremost, as opposed to prioritising the strategic dispersal of beds geographically, to provide the widest patient coverage.

It is also of concern that if the government continue to push for reduced usage of such beds, in conjunction with the new MHA proposals, the provision of beds in the private sector may become financially unviable, and they are closed. Although superficially an argument for success, in that this may present as less people with learning disabilities in hospital, it does not mean, as the study has shown, that the current admission avoidance systems and teams are yet proven to be sufficiently effective in completely mitigating the increased levels of risk this may transpose into the community. In this scenario, unless the myriad of findings within this study that drive continued use of specialist inpatient beds are considered and addressed, and the NHS are given permission to be able to scope providing local beds again where indicated, the shortage may worsen.

It is not immediately apparent if there is an appetite for recognition of the protection of human rights of those with learning disabilities that require hospital admission for assessment and treatment, beyond that of expediting it at all costs. With the focus persistently diverted to a questioning of why anyone with an learning disabilities would or should need to be in hospital, there does not appear to have been clear and formal acknowledgement of the part policy has played in creating some of the conditions for patients with learning disabilities that are considered unacceptable. In short, it is more complex than just closing beds, because it is that very exercise that has given rise to some of the injustices and inequalities people with learning disabilities and their families have to face when they require specialist healthcare and treatment.

Collectively, society has to decide if it is acceptable to continue down this path, irrespective of impact or infringements on human rights for those requiring admission. It is asserted unequivocally that at some stage a ‘cost benefit’ analysis has to be undertaken in relation to how many people with learning disabilities and their families are being negatively affected by the continued drive to reduce these beds, and if it is counterproductive to their wellbeing. As has been previously discussed, restricting the access to such services, and potentially withholding treatment may also be deemed discriminatory, and compound the health inequalities already suffered by people with learning disabilities (Ali et al. 2013), with further research in this area being urgently required.

7.4 Is there a case for having local beds?

The secondary aim of this study was to secure an understanding of how those neighbouring Trusts without local beds had been managing to support any patients requiring hospital admission, in order to review our own retention of local specialist inpatient beds. This was felt important given the national directive, having a practice model that advocates the least restrictive care, and in light of sensitivities around retaining beds.

The key benefit of having local beds, as identified by the participants, was the ability to meet the policy directive of providing care and treatment closer to home, and to not feel morally torn by putting people with learning disabilities and their families through the trauma and stress of being admitted to a hospital geographically distanced from their home. In terms of patient numbers, it is arguable that any area with its own beds, naturally, will need to admit less people out of area. For two of the sample areas this resulted in only periodic out of area admissions, suggesting that, although not based on any agreed formula or predictor, they had the bed numbers at around the right levels to accommodate need. However, it was evident in the third sample area that demand consistently outstripped supply at inordinately high levels, and the lack of a formulation underpinning bed numbers was more problematic. So, for two areas, overall, having local beds did make a difference, with the majority of people requiring it being able to be admitted locally, but further national data to include more areas retaining local beds would be needed to draw any meaningful conclusions from this.

For those unable to access a local bed, due to the current geographical location of private hospital beds in relation to the region under study, this meant being a substantial distance from home. In this respect there is a strong case for providing more local beds within the sample region if the objective of providing care closer to home is to be met. In terms of lengths of stay, although some reduction was seen in more recent admissions, the paucity of valid data submitted was felt to affect any inferences that could be made. As a result, it was not possible to conclude with any confidence that having local beds makes a key difference based on evidence gathered by this study, and further research in this area would need to be undertaken. However, it is argued that the humanity of keeping families together in distressing times alone, offers a sufficiently valid reason to reconsider the need for more local beds.

7.5 Policy position post study

Now incorporated into the NHS 10 year plan (NHS 2019), the aims for specialist inpatient services are that by March 2023/24, for every one million adults, there will be no more than 30 people with a learning disability and autism cared for in an inpatient unit. However, some feel this target is under ambitious and will be missed again, highlighting that the 35-50% reduction by March 2019 and a revised 35% reduction by March 2020 were not achieved (Mitchell 2021). With recent actions by the government communicating conflicting messages (Department of Health & Social Care 2020, BBC 2020), their current position on specialist inpatients beds is unclear. In terms of any new discreet policies or programmes in this area, it would be imperative to ensure that their affiliation and intent are transparently set out. Similarly, as previously discussed, their position on the private sector market would also need to be ascertained. Simplistically, it could be argued that if the government were absolutely committed to reducing or closing such inpatient beds it is within their power to direct CQC to de-register existing or stop registering new hospitals. In omitting to do so, it indicates that there is a view held somewhere in central government that understands that there remains a function for these types of beds, or, more cynically, that privatisation is being covertly advocated.

In removing a discreet policy and embedding the aims for learning disability services within an organisation wide plan, the impetus for continuing to reduce specialist inpatient beds appears somewhat diluted, and it is as of yet to be seen if this naturally brings about a pause in the programme for continued reduction of beds. However, whilst this issue remains unaddressed, and discussion is deemed distasteful, people with learning disabilities and their families are still having to cope with the aftermath of the unrelentless historical drive to close local beds, and those operationalising the system remain in an intolerable position.

Chapter 8. RESEARCH APPROACH, LIMITATIONS, AND FUTURE IMPLICATIONS FOR POLICY, PRACTICE, AND RESEARCH

8.1 Research approach and limitations

An initial challenge in adopting a mixed methods study was identifying relevant and reliable data sources to investigate in a sequential manner that could be built and expanded upon at each subsequent stage. The approach taken in stages one and two looked to establish the context, including the contemporaneous population needs, service models, and performance indicators against key policy objectives. The preparation of this data subsequently allowed for identification of potential areas of operational complexity and challenge, influencing question formation, and facilitating deeper mining of these issues using qualitative methods in stage three.

Although the Transforming Care policy and programme were in operation at the time of the study, the aim was to focus on the current state of specialist inpatient services, its' genesis, and any residual operational issues that may challenge further progress more broadly. From this perspective, the study as a whole served a multitude of purposes in looking at the past, present, and future of specialist inpatient services for people with learning disabilities and thus highlights wider issues for consideration by both policymakers and practitioners.

A key strength of the study lies in capturing the experiences and perspectives of senior NHS commissioners and operational managers in their attempts to administer ‘top down’ policy directives. With limited research from this perspective, insights are offered on the operational realities for such stakeholders which convey their unique ‘lived’ experience of service delivery and its' constraints. Kimmons (2022) identifies that the relative importance ascribed to each data collection stage within a mixed methods design can vary, and with barriers to full policy implementation being a dominant area of interest to this study, coupled with a paucity of research with the participant group, this qualitative aspect became critical.

Given my own role as a practitioner – researcher, with a need to generate knowledge in context as opposed to establishing generalised truths (McLeod 2019), the focus on operational complexities also fit well with the Professional Doctorate objectives. Each stage of the study has helped to build a broader picture of the system as a whole, and to move from anecdotal assumptions and suspicions to an evidence base, thus making a practical contribution to towards future organisational policy, planning, and practice.

With regards to sampling, conscious choices about the purposive sampling of experts was made in stage three. As explained by Etikan et al. (2015) this entails a deliberate choice of participants due to the qualities they possess and facilitates selection of those who are ‘information rich’, thus optimising relevant experiences and viewpoints. As a sole researcher without additional resources, this was an important factor in terms of viability and manageability of the study. As the method is self – selecting, based on the generic employed position of the participants, sampling bias is also minimised.

Whilst acknowledging the strengths in sampling these professional perspectives, it is also recognised that the absence of patient and carers’ perspectives in the study limits the ability to understand the human impact upon individuals and their families when using specialist inpatient services or give a voice to what they would like to see happen. With many studies finding personal, organisational, and operational barriers to true co-production of care and treatment decisions (Henry & Gudjonsson1999, Alexander & Hegarty 2001, Chaplin et al. 2009, Ball & Shanks 2012), this study also found that, at a strategic level, the involvement of patients and their representatives in the Transforming Care implementation plans was limited to the point of being arguably tokenistic. Several papers have previously attempted to capture the experience of patients and their families in using specialist inpatient services (Scior & Longo 2005, Gibbs et al. 2008, Head et al. 2018, Turner 2019) and it is important that this continues if the system as a whole is going to be effective in meeting the needs of all stakeholders.

Whilst recognising that the patient voice is imperative to the debate, this study aimed to complement existing evidence by reflecting the complexities and challenges in operationalising national policies dictated by government, and thereby offering insight and a potential rationale of the end user experience. As key decision makers in the hospitalisation of people with learning disabilities, the absence of Psychiatrists and Approved Clinicians in the sample, and local authorities as stakeholders in community care, will have also limited exploration of their perceptions and experiences and this is a recommended area for future research.

Stage two of the study was limited by challenges arising from gathering quality data, which was not unexpected with previous studies having found working with available data to be difficult (James et al. 2017). Requiring individual FOI requests, completeness of original records, alongside constraints with patient confidentiality and that of the FOI Act (2000) resulted in gaps or partially processed data to varying degrees. The inconsistency of this data meant that undertaking inferential statistical analysis was not possible, and only indicative patterns could be drawn out. It is also acknowledged that the use of purposeful regionally defined sampling may be somewhat nuanced to local issues, and therefore the findings may not be directly translatable to other geographical locations.

A final observation is that due to the pragmatic approach taken within the study, and it being rooted in practice, the aim was to focus very much on applied research rather than attempting to advance theory. As a result, the lack of theoretic engagement could be perceived as a limitation of the study, and contextualisation of the findings within a theoretical framework, such as institutional theory and construct (Scott 1995, 2008a, 2008b), or health policy implementation (Gunn (1978) in Hunter 2003, Buse et al. 2005, Powell et al. 2009, Jenkin et al. 2013,), could have added further value to the research and a deeper consideration of the issues at play.

8.2 Personal and practical considerations

My professional experience, and employment could be perceived as both a strength and a weakness of the study. While there was potential for bias, the expertise and insight brought to bear on the study from my experience added a breadth and depth of experience and understanding to interpretation that would be lacking if undertaken by a non-practitioner. An inherent facet of the Professional Doctorate design, for a practitioner/researcher, in contrast to those undertaking a traditional PhD route, the primary intention of the study is to inform decision makers on areas of future development. In this respect, the overriding aims are relevance, practicality, and meeting the specific needs of said decision makers (Patton 1986).

Focusing on solving real world problems in real time, factors such as ‘situatedness’, usefulness, and purpose have all affected and influenced the chosen methodology, and therefore, must be considered when evaluating the study as a whole (Costley & Armsby 2007). Of additional relevance in terms of my ‘situatedness’ is that during the time of the study, my professional role has changed from one of NHS operational manager to a senior Trainee Approved Clinician responsible for patients with learning disabilities detained under the MHA (2007), therefore altering my professional considerations, and potentially my perspective on the issues.

8.3 Implications for future policy, practice, and research

More broadly, this study suggests that of overriding importance to any future policy decisions in this area would be a national, in – depth demand / provision analysis of the current purpose and function of specialist inpatient hospitals. Based on the primitive scientific principle of cause and effect, it is patent that alternative and creative approaches and solutions cannot be generated until it is determined why, after all these decades of pressure to close, specialist inpatient beds still exist and are in regular use. Moreover, contrary to our growing knowledge and collective discomfort about the potential risk of abuse and restriction these services may present (Joyce 2020), intelligent, highly trained, and experienced caring professionals are still consciously making clinical judgements to admit people with learning disabilities to these hospitals, and so the reasons behind that cannot be merely derided without further and detailed investigation.

With regards to practice, this study has offered new and valuable insight into the layers of operational complexities that impact upon the system as a whole, such as a lack of uniform formulation for bed numbers across the sample area, the mixed efficacy, and views on utilising mainstream mental health beds for people with learning disabilities, and the inconsistent availability of services across areas. It is felt that these particular findings would be important for CCG's, as commissioners of local services, to be aware of in order to plan for and meet local health needs. For policy makers, the study found that the most recent policy iteration, Transforming Care, was ineffective in reducing beds any further, and concomitantly, the numbers of people being admitted to such beds showed minimal reduction over the total study period, at times increasing beyond pre-policy levels. Such findings are pertinent to policy planning, as they suggest an element of saturation in terms of effectiveness in achieving additional bed closures and are indicative that future policies in this area may be equally ineffective.

For practitioners, the ability to operationalise the policy found a plethora of issues affecting delivery, not least of which was no additional funding to realise the aims. Resulting in differing levels of 'sign up' and prioritisation, and no other choice but to 're-invent' existing services to meet policy objectives, practitioners were left with managing the tensions of effectively operating the same services, which the policy implied had previously been inadequate. Additionally, the interminable issue of resource and funding were found to play a significant part in sustaining the need for hospital beds, and a lack of both funding and sufficiently skilled providers within the community were contributory factors causing delay and unnecessary hospitalisation at the point of both admission and discharge. The resulting divergence in working between health and social care practitioners has significant and on-going implications for practice, indicating that further discussion, understanding, and appreciation of the constraints on either side need to be acknowledged in order to find a conducive way forward.

Overall, the study found many variants that affected implementation of the policy, its levels of success, the continued use of the beds, and the unintended consequences for people with learning disabilities and their families. History, politics, public opinion, public funding, the medicalisation of learning disabilities, policy, and the impact of institutionalisation were all found to play a part in the current state of the system, and, as a result, it is important that this new information is brought to bear on current discussions. Dissemination to other NHS Trusts, CCG's, Local authorities, and NHS England teams designated to support people with learning disabilities and their families is seen as imperative if this debate is to move forward, and the needs of those who require inpatient support for a mental health condition is to be more equitably met. The metaphoric elephant needs to be addressed, and asked, politely, to leave the room, as it is postulated that until this is possible, the prevailing situation for those with a learning disability who require inpatient support with their mental health, and their families, remains bleak.

In terms of further research there is much that needs to be established before more decisions regarding this provision are directed within a national policy or programme. The following are suggested areas and topics that future research should focus on which emerged from this study:

- Engage local stakeholders to gain a better understanding of local nuances or barriers to implementation or practice of any proposed policy.

- Examine the views of clinicians responsible for admission and overseeing an individual's hospitalisation as they hold the legal power and ultimate clinical decision making responsibility.

- Capture the views of patients, their families, and carers, on the role they see specialist inpatient services providing as part of the wider health system.

- To secure a better understanding of the efficacy and role that CTR’s, Intensive support teams, and community service providers play in preventing admissions.

Chapter 9. CONCLUSION

Derived from emotive and inexcusable incidences of abuse, it is manifest that the sensitivities around the reduction of specialist inpatient services make it a taboo subject around which to advocate the reinstatement of local beds, or a pause in government thinking. However, this study has shown that someone needs to raise their head above the parapet, address the elephant in the room, and outline the complex decisions and challenges that the drive to close beds has created, and the untenable position it has left key decision makers in when trying to support people with learning disabilities that require hospital admission. Clearly no one wants to place vulnerable adults in a situation where they might be traumatised and abused, and it is unfathomable that a place such as hospital, usually revered as a place of safety where people are cared for and nurtured to recover their health, has become insidiously associated with abuse, hurt, and detriment to a person's wellbeing. But simplifying such a complex web of interdependences down to a singular solution of, as far as possible, closing all beds, on the assumption that all such hospitals must be equally abusive, is to disregard the rights and needs of those individuals the policies have been set up to protect.

In order to address the elephant in the room, the emotive history of the policy must be neutralised, political point scoring needs to be put aside, and practitioners and strategic leads alike must feel able to discuss the purpose and need that such services currently meet openly and honestly. Senior Commissioners, Operational Managers, and clinicians need to be in a position to speak out for those individuals and families who are affected by requiring hospitalisation many miles away from home and be supported at all levels to discuss the opening of more local beds if they feel that is what would help those families. Contentious as the matter is, health services are, ordinarily, based and commissioned on the clinical needs of the local population, and yet the history of specialist hospitals for people with learning disabilities has significantly skewed this most basic of principles. Returning to this may offer one possible solution, but unless the stigma of discussing such possibilities is removed, then the status quo, and inequity in services for people with learning disabilities, is likely to remain.

One of the key challenges within the current system is that of its binary nature, for all people with learning disabilities there are only two options: community living placement or hospital, with no in-between. Attempts to remedy this, by way of step down / step up models, as found in this study, have been unsuccessful, and, in many cases, have inadvertently become long – stay placements for those with more complex needs. This inability to conceive a suitable ‘third option’ undoubtedly currently results in hospital admissions being used as a place of safety rather than for assessment and treatment. With the new amendments to the MHA precluding this option for people with learning disabilities who do not have a diagnosed mental health condition, it is apparent that a timely re-focus on alternatives would be judicious.

When hospital admission is required, needing to place people out of area and frequently in private hospitals, removes the safeguards of being able to admit them locally, such as more frequent visits from family, friends, carers, and other professionals. Their ability to sustain regular contact with the people that know them best and would be more readily able to spot signs of distress or a change in behaviour is made more difficult, and the frequency of external stimulus to expedite discharge is reduced. The intrinsic conflict of financial interest for private hospitals in retaining patients is passively accepted, and their continued omission from national policy directives renders any attempts by the government to reduce such beds impotent.

To temper the argument that specialist inpatient hospitals equal abuse, in stimulating debate to move matters forward; how do we know that abuse against this vulnerable group is more prevalent, or more likely to happen in a hospital setting than that of a community setting? Controversial as this may be, it serves a purpose; if we can think about why we feel being supported in the community reduces the exposure of risk to abuse for people with learning disabilities, then perhaps we can start to think about what the hospital model would need to do to replicate that, or even if it is possible? Thoughts such as the ability of people to live locally to their families and friends, to stay in frequent contact, have open visiting access, and to have days meaningfully occupied all appear to reinforce the argument for local beds to be made available.

Overall, this study provides evidence to suggest that if the debate on re-opening local beds is not started soon, then the status quo will be at best maintained, or at worse, deteriorate further for people with learning disabilities and their families. With the suggested changes to the MHA being underway, and the impact on specialist inpatient services and community support for people with learning disabilities not yet known, this has increased the urgency with which solutions must be found. Courageous conversations must take place, and more respect must be given to the complexities of the system if we are to uphold the human rights and show humanity and compassion towards people with learning disabilities and their families.

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APPENDICES

Appendix 1. FOI request to NHS Digital

From: LEdwards10@uclan.ac.uk;
Received: 2018-09-24T12:19:13Z
To: enquiries@nhsdigital.nhs.uk
Subject: Ref no: NIC-234230-W6Q0T RE: Research study for <redacted> NHS Trust / FOI request

Dear Sir / Madam,

I have contacted your organisation today to find out the best way to obtain some data for a Doctorate study I am currently undertaking with the support of my employer <redacted>, where I work as a Clinical Team Manager for the Intensive Assessment & Treatment Team (IATT), supporting people with learning disabilities. I'm doing a mixed methods study looking at the use of specialist in - patient services for people with learning disabilities in <redacted> England in order to provide an evidence base for <redacted> to decide if it’s remaining dedicated LD hospital beds continue to be the most appropriate support model for our area.

In the quantitative stage of the study, I am collating and analysing secondary data around patient movement through the specialist inpatient services in each identified Trust / County within the sample group; this consists of the following areas and their associated NHS Trust / equivalent:

<redacted>

I have started to review and analyse the AT and MHSDS monthly stats that you publish on your website from Feb 2015, however it has become evident very quickly, that apart from the comparator data you started publishing in Feb 2018 to identify the disparity in figures between the two datasets, all other data is reported on an England wide basis. For the purposes of my study, I would like to request, on a freedom of information basis if required, for the following data from both the AT and MHSDS on a Trust by Trust / County by County (however you collated it is fine) from Feb 2015 onwards, based on monthly reporting please:

1. No. of patients at beginning of month
2. No. of patients admitted during month
3. No. of patients discharged during month
4. Length of stay for each patient per monthly reporting period
5. No. of patients in hospital at end of monthly reporting period
6. Total length of stay per patient (cumulative)
7. No of first admissions / readmissions / transfers to other hospitals per monthly reporting period
8. Distance from home per patient per monthly reporting period
9. No of patients per ward type (LD or MH) per monthly reporting period

I am hoping that this will be relatively straightforward to generate as the above stats are the ones you currently collect, and the information will be key in assisting the completion of a regional analysis that the study requires. I fully appreciate that the breadth of data collection has expanded and evolved over the course of reporting since the stats collection started, and would be very grateful if you could just indicate on the response the start date of any 'new' areas of data fields as and when they were added, for example, I think the ward type (no.9 on my list) was only a relatively recent addition, and hasn't been collected since Feb 2015? I would be very grateful for any assistance or further support and advice you would be able to give me to support this study, and please do not hesitate to get back to me should you require any further information. I look forward to hearing from you in due course. Many thanks.

Yours sincerely,

Lisa Edwards

Doctoral student
Doctor of Professional Practice - Community Social Care Policy & Practice

Appendix 2. FOI response NHS Digital

11 October 2018

Our ref: NIC-234578-R5L0X

Dear Lisa Edwards

Re: Information Request – Freedom of Information Act (FOIA) 2000

Thank you for your email dated 24 September 2018 requesting the following information:

“For the purposes of my study I would like to request, on a freedom of information basis if required, for the following data from both the AT and MHSDS on a Trust by Trust / County by County (however you collated it is fine) from Feb 2015 onwards, based on monthly reporting please:

1. No. of patients at beginning of month

2. No. of patients admitted during month

3. No. of patients discharged during month

4. Length of stay for each patient per monthly reporting period

5. No. of patients in hospital at end of monthly reporting period

6. Total length of stay per patient (cumulative)

7. No of first admissions / readmissions / transfers to other hospitals per monthly reporting period

8. Distance from home per patient per monthly reporting period

9. No of patients per ward type (LD or MH) per monthly reporting period

I am hoping that this will be relatively straightforward to generate as the above stats are the ones you currently collect, and the information will be key in assisting the completion of a regional analysis that the study requires. I fully appreciate that the breadth of data collection has expanded and evolved over the course of reporting since the stats collection started, and would be very grateful if you could just indicate on the response the start date of any 'new' areas of data fields as and when they were added, for example, I think the ward type (no.9 on my list) was only a relatively recent addition, and hasn't been collected since Feb 2015?”

We have considered your request and in accordance with S.1 (1) of the Freedom of Information Act 2000 (FOIA) I can confirm that we do hold the information that you have requested.

NHS digital have been publishing Learning Disability and Autism (LDA) data on both the Assuring Transformation (AT) data set and also the Mental Health Services Data Set (MHSDS) since March 2015 and July 2016 respectively. (Prior to MHSDS we reported on this data via the Mental Health and Learning Disabilities Data Set (MHLDDS) data set).

We believe that the data you are asking for is already available within our publications on our website. Please see below for the links to this information. The metadata files for both publications can also be found in the below links along with the publication files. The meta data file contains a change log within them, where you can find the dates when new fields were added to each dataset.

MHSDS publications including LDA patient publications files from July 2016 – May 2018:

https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthlystatistics

Learning Disability Services Monthly Statistics publications (AT publications since March 2015

including the LDA MHSDS publications from May 2018):

https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics

MHLDDS Reports from September 2014 to November 2015:

https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-and-learningdisabilities-

statistics

LD Census publications (Prior to the AT collection from 2013 - 2015):

https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-census-report

In line with the Information Commissioner’s directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS Digital website. I trust you are satisfied with our response to your request for information. However, if you are not satisfied, you may request a review from a suitably qualified member of staff not involved in the initial query, via the enquiries@nhsdigital.nhs.uk email address or by post at the above postal address.

Your request to NHS Digital will now be closed on our internal CRM (customer relationship

management) system.

Yours sincerely,

Graeme Holmes

Information Assurance Advisor

Further information about your right to complain under the Freedom of Information Act is available from the Information Commissioner’s Office, Wilmslow, Cheshire, and on The Information Commissioner’s website www.ico.org.uk.

www.digital.nhs.uk

enquiries@nhsdigital.nhs.uk

Appendix 3. First FOI request to CCG's

Ms Lisa Edwards
University of Central Lancashire
School of Social Work, Care and Community
Preston,
Lancashire,
PR1 2HE

30/10/18

Dear Sir / Madam,

RE: Freedom of Information request

I would like to make a freedom of information request for the following data within your CCG area, for the purposes of a Doctorate research study, which will be treated in the strictest confidence and anonymised regionally in the final thesis. As the NHS learning disability services / Transforming Care Partnership (TCP) within your area will be aware, this data is already collected in two current datasets – the Assuring Transformation (AT) returns and the Mental Health Statistics Data Sets – LD (MHSDS) for NHS Digital, so hopefully will be very straightforward to supply. The cumulative information is currently published by NHS Digital on an England wide scale but is required regionally for the purposes of this study, hence the need for a freedom of information request.

Please note that the information required is specifically for those patients with learning disabilities requiring admission on the basis of an increase in their distressed behaviours and / or a decline in their mental health who require initial assessment and treatment; please do not include those admitted to acute medical wards for the purposes of treating a physical illness or condition.

Can you please provide, from February 2015 – your most recent month end data collection, on a month by month basis:

1. No. of patients with learning disabilities at beginning of month in a private provider hospital bed.
2. No. of patients with learning disabilities at beginning of month in an NHS hospital bed.
3. No. of patients with learning disabilities admitted during month to a private provider hospital bed.

4. No. of patients with learning disabilities admitted during month to an NHS hospital bed.

5. No. of patients with learning disabilities discharged during month from a private provider bed.

6. No. of patients with learning disabilities discharged during month from an NHS hospital bed.

7. Length of stay for each patient with learning disabilities per monthly reporting period in a private provider hospital bed.

8. Length of stay for each patient with learning disabilities per monthly reporting period in an NHS hospital bed.

9. No. of patients with learning disabilities in a private provider hospital bed at end of monthly reporting period.

10. No. of patients with learning disabilities in an NHS hospital bed at end of monthly reporting period.

11. Total length of stay per patient with learning disabilities (cumulative).

12. No. of first admissions / readmissions / transfers to other hospitals of people with learning disabilities per monthly reporting period.

13. Distance from home per patient with learning disabilities per monthly reporting period.

14. No. of patients with learning disabilities accommodated out of county per monthly reporting period. i) in private provider hospital beds & ii) in NHS beds.

15. No. of patients with learning disabilities accommodated in county per monthly reporting period. i) in private provider hospital beds & ii) in NHS beds.

16. No. of patients with learning disabilities per ward type (Learning Disability specific or mainstream Mental Health ward) per monthly reporting period.

17. Average cost of bed per month per patient with a learning disability in private hospital bed.

18. Average cost of bed per month per patient with a learning disability in an NHS hospital bed.

I would be very grateful for any assistance you would be able to give me to support this study, and please do not hesitate to get back to me should you require any further information. I look forward to hearing from you in due course. Many thanks.

Yours sincerely,

Lisa Edwards.

Lisa Edwards

Doctoral student

Doctor of Professional Practice - Community Social Care Policy & Practice

uclan UNIVERSITY OF CENTRAL LANCASHIRE

Appendix 4. Second FOI request

Ms Lisa Edwards
University of Central Lancashire
School of Social Work, Care and Community
Preston,
Lancashire,
PR1 2HE

25/03/19

Dear Sir / Madam,

RE: Freedom of Information request

I would like to make a freedom of information request for the anonymised Assuring Transformation data within your CCG area between the dates of February 2015 – March 2019, for the purposes of a Doctorate research study, which will be treated in the strictest confidence and anonymised regionally in the final thesis. The cumulative information is currently published by NHS Digital on an England wide scale but is not available regionally for the purposes of this study, hence the need for a freedom of information request.

I would be very grateful for any assistance you would be able to give me to support this important study, and please do not hesitate to get back to me should you require any further information. I look forward to hearing from you in due course. Many thanks.

Yours sincerely,

Lisa. Edwards.

Lisa Edwards

Doctoral student

Doctor of Professional Practice - Community Social Care Policy & Practice

uclan UNIVERSITY OF CENTRAL LANCASHIRE

Appendix 5. Interview questions

Interview questions

IRAS Project ID No: 245729

Thank – you very much for agreeing to be interviewed for the research I am undertaking looking at the use of specialist inpatient services for people with learning disabilities across <redacted> England.

The study is one of mixed methods, and this interview will provide some rich qualitative data to provide some context to the quantitative data I collected in the first stage from all CCG's in the area.

I'd just like to remind you that any reference to you in the study will be anonymised using your general job title i.e., General LD manager (A) / CCG Commissioner (B). The study will also anonymise the geographical area you work in i.e., Area (A). I will be recording the interview using a digital recorder, and once transcribed (verbatim), will send you a copy for checking. If either during the interview or following receipt of the transcription there are any direct statements that you'd prefer not to be included in the final study, then please just let me know. As you'll recall from the consent form, you can withdraw your consent to remain in the study at any time.

The interview should last between 1 – 1.5hrs maximum, and can I just check that you are still happy for me to record it? The questions were supplied to you before you agreed to this interview, and the main topics are around the rationale of the service model in each area, how it operates, challenges and complexities you feel the system currently has, and any future plans you may have going forward.

1. Can you please describe your current service model provision for specialist inpatient services for people with learning disabilities?

(My prompts)

* In – house *Private (In – county / out of county)

* Additional community services (preventative) *Use of mainstream MH inpatient beds

\- Can you tell me more about that please?

2. Do you know how this model came about, and which organisations were / are involved in deciding how to meet needs locally?

(My prompts) * CCG's *NHS Trusts *LA's *Service user groups / advocates *NHSE

* Any Others?

3. As you'll be aware, national policy drivers under TCP have aimed for reduced admissions, people being closer to home, and shorter length of stays. In the first part of this study the data collected suggested that these objectives may still not be being met. Can you discuss why you think this may be the case in your area?

(My prompts)

- So, if we start with reduction in admissions
- people being closer to home
- shorter length of stays

4. Overall, which part(s) of your current model/approach to service provision do you feel works well for ensuring an effective response to presenting need?

5. And which part(s) of your current model/approach to service provision do you feel works well for the patients that use the services?

6. Is there anything that you feel presents challenges / difficulties for ensuring an effective response to presenting need?

7. And anything that you feel presents challenges / difficulties for patients who use the service?

8. As you will be aware, the national TCP programme officially ended in March 2019, and the NHS have more recently published their 10-year plan. Can you please explain how you are intending your service model for this patient group to look going forward please, and any key changes you are looking to implement?

9. Is there anything else you would like to add which you feel is relevant to the study that we haven't covered elsewhere?

Thank – you for your time. Once the recording is transcribed, I will send it to you as a document for checking before using in my analysis. Once received, if there are any direct quotes that you prefer me not to use in the study, then please just let me know. The final data will be anonymised as previously discussed prior to being included in the study.

Appendix 6. Participant information sheet

IRAS ID: 245729

Dear <NAME>,

I am currently undertaking the above research project as part of a Professional Doctorate qualification and would be very grateful if you would consider giving consent to contribute as a participant within the context of your employed role. Please find attached a consent form, and do not hesitate to contact me should you wish to discuss any aspect of the form or this study further. The consent form will also be discussed prior to any interview, which will give another opportunity for any questions you may have about it. Your consent to participate will also be checked again at this point.

A mixed methods approach has been chosen in order to add rich qualitative data to enhance quantitative data collected in the initial stages of the study. To this end I would like to interview you face to face to capture your understanding of the decision making in your County, specifically in relation to specialist inpatient services, within the context of the Transforming Care Programme (TCP). It is anticipated that this will involve meeting with you, at your convenience, for a one-time interview of approximately 1 – 1.5 hours maximum. The interview would be audio recorded for ease of data collection, and all responses will be anonymised in the final thesis. Although not anticipated at the current time, follow up contact may need to be made for clarification, but this would be kept to a minimum. An alternative to this would be for the questions to be provided in writing, and you could then provide a written response if preferred. There will be a total of seventeen participants invited from across the area, consisting of eight Senior NHS Managers of LD services and nine CCG Commissioning leads.

The overarching purpose of the research is to ascertain if there are any established or emerging sufficiently robust alternative service models of community support being commissioned to negate the need for specialist inpatient services, which could be adopted elsewhere. It is also to look at the decision making, including external and internal influences and the complexities and challenges behind each area's current specialist inpatient provision, within the context of the Transforming Care agenda.

As a participant of this study a summary of the main findings will be made available to you on request, which may be beneficial to future decision making around the use of specialist inpatient services in your area.

If there were to be an issue with the study and it was aborted, then all data collated to that point would be deleted / destroyed in line with GDPR guidelines.

If you initially agree to the study, but subsequently decide to withdraw, or lose capacity to consent, then you would be withdrawn from the study. Your participation is voluntary and that you are free to withdraw at any time without giving any reason, or legal rights being affected.

Other than the signed consent form, no personal information outside of your work role will be collated, and participants will be coded and referred to in gender neutral terms to avoid possible identification. Confidentiality about your geographical location and employer will be retained. All data collected will be kept securely on password encrypted IT equipment, or in locked office equipment whilst needed for analysis. The Chief Investigator will destroy the identifiable information in the consent forms as soon as practicable once the study has been marked and validated by the University. All other data will be coded and therefore will be destroyed five years post completion of the study, in line with the data storage policy of The University of Central Lancashire.

The University of Central Lancashire is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Central Lancashire will not keep any identifiable information about you, as it will be coded on first recording.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible. You can find out more about how we use your information by contacting the Chief Investigator, Lisa Edwards (ledwards10@uclan.ac.uk).

The Chief Investigator will collect information from you in the capacity of your employed role for this research study in accordance with our instructions.

The Chief Investigator will keep your name, organisation, and contact details confidential by using a coding system, and will not pass this information to the University of Central Lancashire. The Chief Investigator will use this information as needed, to contact you about the research study, and to oversee the quality of the study. The Chief Investigators supervisors from the University of Central Lancashire and regulatory organisations may look at the research records to check the accuracy of the research study. The University of Central Lancashire will only receive information without any identifying information.

The study is financially sponsored by an NHS Trust with whom the researcher is an employee, and this will be clearly stated in a prominent place on the final paper. The results of the study may be of interest to the participating organisations in relation to future decision making around the use and provision of specialist inpatient services within learning disability services in the region.

On completion the study will be submitted to the awarding university and may be put forward for publication to sector specific journals in whole or extract. It may also form the basis of presentations at sector specific or educational conferences. The study will be archived at the University of Central Lancashire.

It has been reviewed and approved by educational supervisors, UCLan board of ethical approval, and the Health Research Authority (HRA). The study is being supervised and overseen by Dr Julie Ridley as Director of Studies, Professor Lois Thomas, and Dr Stephen Gethin – Jones; please find their contact details below should you wish to contact them about any aspect of the study.

If you require further information about this study, then please get in touch with the Chief Investigator:

Lisa Edwards

Email: ledwards10@uclan.ac.uk

Many thanks in anticipation.

Lisa. Edwards.

Additional contact details:

Director of Studies:

Dr Julie Ridley,
University of Central Lancashire,
Preston
PR1 2HE

jridley1@uclan.ac.uk

Tel: 01772 893402

Academic Supervisor:

Professor Lois Thomas
University of Central Lancashire,
Preston
PR1 2HE

lhthomas@uclan.ac.uk

Tel: 01772 893643

Academic Supervisor:

Dr Stephen Gethin – Jones
University of Central Lancashire,
Preston
PR1 2HE

sgethin-jones@uclan.ac.uk

Tel: 01772 895464

If you are unhappy or have concerns about any aspect of the project, and do not wish to contact the research team, you can contact the University Officer for Ethics (officerforethics@uclan.ac.uk) who is entirely independent of the research and will respond to your concerns.

Appendix 7. Consent form

IRAS ID: 245729

CONSENT FORM

Name of Researcher: Lisa Edwards

Please initial box

1. I confirm that I have read the information sheet dated 08/07/19 (version 3) and a copy of the interview questions for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time
without giving any reason, or legal rights being affected. ☐

3. I understand that the information collected from me may be used to support other research in the future and may be shared anonymously with other researchers. ☐ ☐

4. I understand that the assessment will be audio recorded and transcribed, and I will have the opportunity to read through the transcription and request that any specific direct quotes be omitted from the final thesis. ☐
5. I consent to taking part in this study.

Name of Participant Date Signature

Appendix 8. Quantitative data for question 1.
Q1. Patient count per month: **YEAR ONE 2015 - 2016**

(**KEY**: NDA = Submitted as No Data Available. NDP = No Data Provided. ID = Incomplete Data submitted.)

CCG Code	Data source – FOI 1/2	Feb 15	Mar 15	Apr 15	May 15	Jun 15	Jul 15	Aug 15	Sept 15	Oct 15	Nov 15	Dec 15
A	2	12	12	12	13	13	13	13	15	16	17	18
B	1	30	29	31	32	31	32	31	32	31	29	28
C	2	6	6	5	6	6	6	6	6	6	6	6
D	2	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0	0	0	0
F	1	NDA	NDA	NDA	NDA	NDA	NDA	NDA	NDA	NDA	NDA	NDA
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	0	0	0	0	0	0	0	1	1	1	1
I	1	8	8	8	8	8	8	8	8	8	8	8

CCG Code	Data source – FOI 1/2	Jan 16
A	2	16
B	1	29
C	2	6
D	2	ID
E	1	0
F	1	NDA
G	N/A	NDP
H	1	0
I	1	8

Q1. Patient count per month: **YEAR TWO 2016 – 2017**

(**KEY**: NDA = Submitted as No Data Available. NDP = No Data Provided ID = Incomplete Data submitted.)

CCG Code	Data source – FOI 1/2	Feb 16	Mar 16	Apr 16	May 16	Jun 16	Jul 16	Aug 16	Sept 16	Oct 16	Nov 16	Dec 16
A	2	15	14	16	17	17	18	19	18	19	21	19
B	1	26	26	26	30	30	32	34	32	31	28	26
C	2	6	5	4	4	4	4	5	5	5	4	4
D	2	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0	0	0	0
F	1	NDA	14	14	14	15	15	15	15	15	15	15
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	0	0	0	0	0	0	0	0	0	0	0
I	1	8	8	8	8	8	7	7	8	8	7	6

CCG Code	Data source – FOI 1/2	Jan 17
A	2	20
B	1	24
C	2	4
D	2	ID
E	1	0
F	1	15
G	N/A	NDP
H	1	0
I	1	8

Q1. Patient count per month: **YEAR THREE 2017 – 2018**

(**KEY**: NDA = Submitted as No Data Available. NDP = No Data Provided. ID= Incomplete Data submitted.)

CCG Code	Data source – FOI 1/2	Feb 17	Mar 17	Apr 17	May 17	Jun 17	Jul 17	Aug 17	Sept 17	Oct 17	Nov 17	Dec 17
A	2	24	23	25	24	24	25	25	25	22	20	19
B	1	24	22	21	18	22	23	23	24	22	21	22
C	2	5	5	5	5	5	5	5	5	5	5	5
D	2	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	1	1	0	0	0	0	0	0	0	0	0
F	1	15	15	15	15	15	15	15	15	14	14	14
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	0	0	0	1	1	1	1	1	1	1	1
I	1	8	8	8	9	9	9	9	10	10	10	10

CCG Code	Data source – FOI 1/2	Jan 18
A	2	20
B	1	23
C	2	5
D	2	ID
E	1	0
F	1	14
G	N/A	NDP
H	1	1
I	1	10

Q1. Patient count per month: **YEAR FOUR 2018**

(**KEY**: NDA = Submitted as No Data Available. NDP = No Data Provided. ID = Incomplete Data submitted.)

CCG Code	Data source – FOI 1/2	Feb 18	Mar 18	Apr 18	May 18	Jun 18	Jul 18	Aug 18	Sept 18
A	2	20	20	21	20	19	22	23	24
B	1	23	22	20	19	19	19	19	20
C	2	5	5	5	6	6	8	8	8
D	2	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0
F	1	15	17	17	17	17	17	16	13
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	1	1	1	1	2	2	2	2
I	1	9	9	10	10	10	10	10	10

Appendix 9. Quantitative data for question 2.

Q2. No. of patients > 50kms from normal residence - YEAR ONE 2015 - 2016

(**KEY**: NDP = No Data Provided. ID = Incomplete Data submitted).

CCG Code	Data source – FOI 1/2	Feb 15	Mar 15	Apr 15	May 15	Jun 15	Jul 15	Aug 15	Sept 15	Oct 15	Nov 15	Dec 15
A	2	10	10	10	11	12	11	11	13	13	14	14
B	1	18	19	19	19	19	18	18	17	17	16	16
C	2	5	5	5	6	6	6	6	6	6	6	6
D	N/A	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0	0	0	0
F	1	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	0	0	0	0	0	0	0	1	1	1	1
I	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP

CCG Code	Data source – FOI 1/2	Jan 16	Average over 12mths
A	2	13	11.83
B	1	15	17.58
C	2	6	5.75
D	N/A	ID	ID
E	1	0	0
F	1	ID	ID
G	N/A	NDP	NDP
H	1	0	0.33
I	N/A	NDP	NDP

Q2. No. of patients > 50kms from normal residence - YEAR TWO 2016 – 2017

(**KEY**: NDP = No Data Provided. ID = Incomplete Data submitted.)

CCG Code	Data source – FOI 1/2	Feb 16	Mar 16	Apr 16	May 16	Jun 16	Jul 16	Aug 16	Sept 16	Oct 16	Nov 16	Dec 16
A	2	12	12	12	11	11	11	12	12	12	13	15
B	1	16	17	20	20	21	23	21	21	19	19	18
C	2	5	5	4	4	4	4	4	4	4	3	4
D	N/A	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0	0	0	0
F	1	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	0	0	0	0	0	0	0	0	0	0	0
I	N/A	NDP	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID

CCG Code	Data source – FOI 1/2	Jan 17	Average over 12mths
A	2	13	12.16
B	1	19	19.5
C	2	4	4.08
D	N/A	ID	ID
E	1	0	0
F	1	ID	ID
G	N/A	NDP	NDP
H	1	0	0
I	N/A	ID	ID

Q2. No. of patients > 50kms from normal residence - YEAR THREE 2017 – 2018

(**KEY**: NDP = No Data Provided. ID = Incomplete Data submitted.)

CCG code	Data source – FOI 1/2	Feb 17	Mar 17	Apr 17	May 17	Jun 17	Jul 17	Aug 17	Sept 17	Oct 17	Nov 17	Dec 17
A	2	12	12	14	14	14	15	16	17	16	16	16
B	1	18	16	15	17	17	17	19	18	18	17	19
C	2	5	5	5	5	5	5	5	5	5	5	5
D	N/A	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0	0	0	0
F	1	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	0	0	0	1	1	1	1	1	1	1	1
I	N/A	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID	ID

CCG Code	Data source – FOI 1/2	Jan 18	Average over 12mths
A	2	15	14.75
B	1	19	17.5
C	2	5	5
D	N/A	ID	ID
E	1	0	0
F	1	ID	ID
G	N/A	NDP	NDP
H	1	1	0.75
I	N/A	ID	ID

Q2. No. of patients > 50kms from normal residence - YEAR FOUR 2018

(**KEY**: NDP = No Data Provided. ID = Incomplete Data submitted.)

CCG Code	Data source – FOI 1/2	Feb 18	Mar 18	Apr 18	May 18	Jun 18	Jul 18	Aug 18	Sept 18	Ave over 8 mths
A	2	16	16	16	16	16	16	15	15	15.75
B	1	17	16	16	15	14	14	15	15	15.25
C	2	5	5	5	6	6	8	8	8	4.25
D	N/A	ID	ID	ID	ID	ID	ID	ID	ID	ID
E	1	0	0	0	0	0	0	0	0	0
F	1	ID	ID	ID	ID	ID	ID	ID	ID	ID
G	N/A	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP
H	1	1	1	1	1	2	2	2	2	1.5
I	N/A	ID	NDP	NDP	NDP	NDP	NDP	NDP	NDP	NDP

Appendix 10. Example of quantitative data for question 3 using response from FOI request No.1 (Questionnaire)

3.) Total and Average length of stay of patients.

CCG B – DATA SOURCE 1

Patient	Admission	Month discharged	Total length of stay (Years & / mths) at point of sampling.	Notes
G1	11/10	28/02/17	6yrs 4mths (76mths)	
L3	06/14	31/08/16	2yrs 2mths (26mths)	
T2	12/13		4yrs 9mths (57mths)	Still inpatient as of Sept 2018
M2	03/14	30/09/16	2yrs 6mths (30mths)	
G4	07/11	29/02/16	4yrs 7mths (55mths)	
S4	06/16	06/15	12mths	
F4	06/10	31/12/15	5yrs 6mths (66mths)	
T3	04/10	31/08/15	5yrs 4mths (64mths)	
T1	09/13		5yrs (60mths)	Still inpatient as of Sept 2018
O3	09/12	31/08/17	4yrs 11mths (59 mths)	
I1	02/15	02/15	12mths	
H4	05/13	31/03/16	2yrs 10mths (34mths)	
F3	03/15		2yrs 6mths (18mths)	Still inpatient as of Sept 2018
L2	02/11	02/15	4yrs (48mths)	
R4	08/11	08/15	4yrs (48mths)	
J2	09/07	07/16	8yrs 10mths (106mths)	
A1	10/14	10/15	12mths	
A2	06/11		7yrs 3mths (87mths)	Still inpatient as of Sept 2018
A3	09/14	10/15	1yr 1mth (13mths)	
A4	08/11	12/15	4yrs 4mths (52mths)	

B2	12/14	06/15	7mths	
D2	08/11		7yrs 1mth (85 mths)	Still inpatient as of Sept 2018
C4	02/15		3yrs 7mths (43mths)	Still inpatient as of Sept 2018
C3	04/15	12/15	8mths	
E2	08/15	01/18	2yrs 5mths (29mths)	
R2	05/17		1yr 4mths (16mths)	Still inpatient as of Sept 2018
R3	08/17		1yr 1mth (13mths)	Still inpatient as of Sept 2018
P4	08/17	02/18	6mths	
O4	09/17		12mths	Still inpatient as of Sept 2018
Q1	08/16	06/17	10mths	
J1	12/15	01/17	1yr 1mth (13mths)	
F3	03/16		2yrs 6mths (30mths)	Still inpatient as of Sept 2018
R1	03/16	06/18	2yrs 3mths (27mths)	
I2	03/16	04/16	1mth	
Q3	04/16	04/18	2yrs (24mths)	
N2	04/16	03/17	11mths	
N1	04/16	02/17	10mths	
I4	04/16	05/16	1 mth	
P1	05/16	01/17	8mths	
J4	06/16	07/16	2 mth	
P3	07/16	07/16	1mth	
B4	07/16	10/16	3mth	
M4	08/16		1yr 11mths (23mths)	Still inpatient as of Sept 2018
D3	09/16	10/17	1yr 1mth (13mths)	
Q4	09/17		12mths	Still inpatient as of Sept 2018
R4	05/17		1yr 4mths (16mths)	Still inpatient as of Sept 2018
S1	11/17		10mths	Still inpatient as of Sept 2018
P2	08/18		1mth	Still inpatient as of Sept 2018
T4	07/18		2mths	Still inpatient as of Sept 2018
O2	06/10	08/17	7yrs 2mths (86mths)	
N4	02/13	02/15	2yrs (24mths)	
L4	10/12	09/16	3yrs 11mths (47mths)	
N3	03/09	03/15	6yrs (72mths)	
B1	08/13	11/15	2yrs 3mths (27mths)	

I1	03/15	03/16	12mths	
S3	03/15	04/15	1mth	
G2	04/15	12/15	8mths	
E3	5/15	09/15	4mths	
I3	7/15	05/16	10mths	
M3	11/15	10/16	9mths	
J1	11/15	11/15	1mth	
B3	09/15	09/15	1mth	
H1	01/16	01/16	1mth	
R1	02/16	02/16	1mth	
H3	02/16	02/16	1mth	
M1	05/16	09/16	3mths	
Q1	06/16	03/18	1yr 9mths (21mths)	
L1	06/16	08/16	2mths	
D1	09/16	01/17	4mths	
B4	11/16	06/17	7mths	
S2	03/17		1yr 6mths (18mths)	Still inpatient as of Sept 2018
E1	05/17	07/17	2mths	
D4	06/17	06/17	1 mth	
F1	06/17		1yr 3mths (15mths)	Still inpatient as of Sept 2018
F2	04/18		5mths	Still inpatient as of Sept 2018
E4	05/18		4mths	Still inpatient as of Sept 2018

YEAR DISCHARGED	**PATIENT**	**DATE DISCHARGED**	**LOS**
2015	F4	31/12/15	5yrs 6mths (66mths)
	T3	31/08/15	5yrs 4mths (64mths)
	R4	08/15	4yrs (48mths)
	A1	10/15	12mths
	A3	10/15	1yr 1mth (13mths)
	A4	12/15	4yrs 4mths (52mths)
	B2	06/15	7mths

	C3	12/15	8mths
	N4	02/15	2yrs (24mths)
	N3	03/15	6yrs (72mths)
	B1	11/15	2yrs 3mths (27mths)
	S3	04/15	1mth
	G2	12/15	8mths
	E3	09/15	4mths
	J1	11/15	1mth
	B3	09/15	1mth
	S4	06/15	12mths
	I1	02/15	12mths
	L2	02/15	4yrs (48mths)
Ave LOS of those d/charged in 2015		**480/19**	**25mths**
2016	L3	31/08/16	2yrs 2mths (26mths)
	M2	30/09/16	2yrs 6mths (30mths)
	G4	29/02/16	4yrs 7mths (55mths)
	H4	31/03/16	2yrs 10mths (34mths)
	J2	07/16	8yrs 10mths (106mths)
	I2	04/16	1 mth
	I4	05/16	1 mth
	J4	07/16	2 mth
	P3	07/16	1mth
	B4	10/16	3mth
	L4	09/16	3yrs 11mths (47mths)
	I1	03/16	12mths
	I3	05/16	10mths
	M3	10/16	9mths
	H1	01/16	1mth
	R1	02/16	1mth
	H3	02/16	1mth
	M1	09/16	3mths
	L1	08/16	2mths

Ave LOS of those d/charged in 2016		**345/19**	**18mths**
2017	G1	28/02/17	6yrs 4mths (76mths)
	O3	31/08/17	4yrs 11mths (59 mths)
	Q1	06/17	10mths
	J1	01/17	1yr 1mth (13mths)
	N2	03/17	11mths
	N1	02/17	10mths
	P1	01/17	8mths
	D3	10/17	1yr 1mth (13mths)
	02	08/17	7yrs 2mths (86mths)
	D1	01/17	4mths
	B4	06/17	7mths
	E1	07/17	2mths
	D4	06/17	1 mth
Ave LOS of those d/charged in 2017		**300/13**	**23mths**
2018	E2	01/18	2yrs 5mths (29mths)
	P4	02/18	6mths
	R1	06/18	2yrs 3mths (27mths)
	Q3	04/18	2yrs (24mths)
	Q1	03/18	1yr 9mths (21mths)
Ave LOS of those d/charged in 2018		**107/5**	**21mths**
Those remaining in hospital post Sept 2018	T2		4yrs 9mths (57mths)
	T1		5yrs (60mths)
	A2		7yrs 3mths (87mths)
	D2		7yrs 1mth (85 mths)
	C4		3yrs 7mths (43mths)
	R2		1yr 4mths (16mths)
	R3		1yr 1mth (13mths)
	O4		12mths
	F3		2yrs 6mths (30mths)
	M4		1yr 11mths (23mths)

	Q4		12mths
	R4		1yr 4mths (16mths)
	S1		10mths
	S2		1yr 6mths (18mths)
	F3		2yrs 6mths (30mths)
	P2		1mth
	T4		2mths
	F1		1yr 3mths (15mths)
	F2		5mths
	E4		4mths
Ave LOS of those remaining in hospital post Sept 2018		**539/20**	**27mths**

Appendix 11. Example of quantitative data for question 3 using response from FOI request No.2 (AT return)

3). Total and average length of stay of patients.

CCG A – DATA SOURCE 2

Patient	Q11b (Date of first admission to any hospital as part of this continuous period of inpatient care)	Q38a (Transfer date agreed)	Q38b (Date of planned transfer)	Q40 (Actual discharge date)	Total length of stay (Years & / mths) at point of sampling	Notes
A	27/06/2008	Y	23/10/2014	23/10/2014	6yrs / 10mths	
A	23/07/2012	Y	25/04/2016	25/04/2016	3yrs / 9mths	
B	10/06/2013	Y	31/03/2015	-	5yrs / 3mths	Assumed still inpatient end Sept 2018.
C	01/01/2008	Y	08/11/2016	08/11/2016	8yrs / 10mths	
D	03/12/2013	Y	29/08/2017	01/09/2017	3yrs / 9mths	
E	31/12/2012	N	-	-	6yrs / 9mths	Assumed still inpatient end Sept 2018.
G	30/10/2013	Y	30/10/2014	30/10/2014	1yr	
F	22/08/2014	Y	30/06/2015	08/07/2015	11mths	
G	24/10/2014	Y	30/06/2015	-	4yrs / 1mth	Assumed still inpatient end Sept 2018.
H	07/01/2015	Y	09/03/2016	09/03/2016	1yr / 2mths	
I	31/01/2015	Y	18/01/2016	18/01/2016	1yr	
J	15/10/2014	N	-	-	4yrs / 1mth	Assumed still inpatient end Sept 2018.
K	02/05/2015	Y	01/12/2015	01/12/2015	7mths	
L	09/06/2014	Y	31/05/2016	02/06/2016	2yrs	
M	28/08/2015	Y	17/08/2016	17/08/2016	1 yr	

N	09/10/2007	Y	14/12/2016	14/12/2016	9yrs / 2mths	
O	15/05/2013	Y	16/01/2017	16/01/2017	3yrs / 8mths	
P	22/10/2015	Y	01/02/2016	01/02/2016	4mths	
Q	24/09/2014	Y	10/10/2016	11/10/2016	2yrs / 1mth	
R	17/12/2015	Y	04/12/2016	04/12/2016	1 yr	
S	05/04/2013	Y	24/11/2017	27/11/2017	3yrs / 5 mths	
T	22/04/2016	Y	10/05/2016	10/05/2016	1 mth	
U	26/04/2016	Y	29/06/2016	29/06/2016	2mths	
V	25/05/2016	Y	22/11/2016	22/11/2016	6 mths	
W	15/06/2016	N	-	05/07/2016	1 mth	
X	01/07/2016	N	-	14/04/2018	1yr / 9mths	
Y	05/07/2016	Y	04/12/2017	-	2yrs / 2mths	Assumed still inpatient end Sept 2018.
Z	13/07/2016	Y	06/04/2017	06/04/2017	9mths	
A1	25/07/2016	Y	16/02/2017	16/02/2017	7mths	
B1	16/08/2016	N	-	-	1yr / 11mths	Assumed still inpatient end Sept 2018.
C1	12/08/2016	Y	29/12/2016	29/12/2016	4mths	
D1	15/10/2016	Y	15/11/2016	14/11/2016	1 mth	
E1	04/11/2016	N	-	06/12/2016	1mth	
F1	01/02/2017	Y	03/03/2017	03/03/2017	1mth	
G1	02/02/2017	Y	14/03/2017	14/03/2017	1mth	
H1	10/06/2013	Y	31/03/2015	21/04/2015	1yr / 10mths	
I1	14/02/2017	Y	17/07/2017	17/07/2017	5mths	
J1	15/04/2017	Y	06/09/2017	06/09/2017	5mths	
K1	24/11/2016	Y	01/10/2017	25/09/2017	10mths	
L1	07/01/2017	Y	18/10/2017	18/10/2017	9mths	
M1	10/04/2017	Y	30/10/2017	30/10/2017	6mths	
N1	05/12/2016	Y	19/01/2018	08/12/2017	3mths	
O1	12/12/2017	Y	30/07/2018	30/07/2018	7mths	
P1	14/04/2018	Y	11/05/2018	11/05/2018	1 mth	
S1	24/07/2018	N	-	18/02/2019	7mths	
T1	24/08/2018	Y	01/10/2018	01/10/2018	2mths	
U1	12/09/2018	-	-	21/12/2018	3mths	

YEAR DISCHARGED	PATIENT	DATE DISCHARGED	LOS
2015	F	08/07/2015	11mths
	K	01/12/2015	7mths
	H1	21/04/2015	1yr / 10mths
Ave LOS of those d/charged in 2015		**40/3**	**13mths**
2016	A	25/04/2016	3yrs / 9mths (45mths)
	C	08/11/2016	8yrs / 10mths (106mths)
	H	09/03/2016	1yr / 2mths (14mths)
	I	18/01/2016	1yr (12mths)
	L	02/06/2016	2yrs (24mths)
	M	17/08/2016	1 yr (12mths)
	N	14/12/2016	9yrs / 2mths (110mths)
	P	01/02/2016	4mths
	Q	11/10/2016	2yrs / 1mth (25mths)
	R	04/12/2016	1 yr
	T	10/05/2016	1 mth
	U	29/06/2016	2mths
	V	22/11/2016	6 mths
	W	05/07/2016	1 mth
	C1	29/12/2016	4mths
	D1	14/11/2016	1 mth
	E1	06/12/2016	1mth
Ave LOS of those d/charged in 2016		**380/17**	**22mths**
2017	D	01/09/2017	3yrs / 9mths (45mths)
	O	16/01/2017	3yrs / 8mths (44mths)
	S	27/11/2017	3yrs / 5 mths (41mths)
	Z	06/04/2017	9mths
	A1	16/02/2017	7mths
	F1	03/03/2017	1mth
	G1	14/03/2017	1mth
	I1	17/07/2017	5mths
	J1	06/09/2017	5mths

	K1	25/09/2017	10mths
	L1	18/10/2017	9mths
	N1	30/10/2017	6mths
Ave LOS of those d/charged in 2017		**183/12**	**15mths**
2018	X	14/04/2018	1yr / 9mths (21mths)
	O1	30/07/2018	7mths
	P1	11/05/2018	1 mth
Ave LOS of those d/charged in 2018		**23/3**	**10mths**
Those remaining in hospital post Sept 2018	B		5yrs / 3mths (63mths)
	E		6yrs / 9mths (81mths)
	G		4yrs / 1mth (49mths)
	J		4yrs / 1mth (48mths)
	Y		2yrs / 2mths (26mths)
	B1		1yr / 11mths (23mths)
Ave LOS of those remaining in hospital post Sept 2018		**290/6**	**48mths**

Appendix 12. Initial codes and emerging areas of interest

Possible codes to be used – Stage 1.	**Emerging areas of interest – Stage 2.**
-Background & history to services -Professional organisations involved in formulating current service model -User & advocacy involvement in model -National policy & programmes that influenced service provision -Impact of historic scandals - Reception & implementation of Transforming care - Funding issues -Gaps in service	How model came about
-Health teams -Admission avoidance or prevention systems -Integrated Health & Social Care teams -Funding of community services -Housing situation -Community support services / providers	Community services

-Multi-agency working	
-Admission process -Local inpatient facilities -Out of area -Private hospital beds -Mainstream mental health beds -Cost of beds -Length of admission time -Monitoring & oversight -Discharge & repatriation	Inpatient services