A Passage to Adulthood: Ethnographic perspectives on transitional care for adolescents with epilepsy and a co-morbid learning disability

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Shelda-Jane Elizabeth Smith Rigby

Department of Public Health and Policy

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Abstract

A Passage to Adulthood: Ethnographic perspectives on transitional care for adolescents with epilepsy and a co-morbid learning disability – Shelda-Jane Smith Rigby

Transition is the planned and purposeful movement of adolescents with a chronic health condition into adult services. It aims to promote independence and self-management of young patients with regard to their ongoing health and care needs. However, particular challenges (including a reluctance of patients and families to leave the familiar paediatric environment and increased risk of psychological distress during the transitional period) have been identified as young patients move between these services. Consequently, this care practice has been identified as a key area for national improvement. In searching for ways to address these challenges, practitioners, researchers and policy makers have focused upon implementing care interventions that aim to build independence and responsibility amongst young patients. Given that young people who have epilepsy and severe forms of co-morbid learning disabilities [ELD] may not always reach complete independence from their carers, questions remain as to whether the aims of the transitional process are applicable to this population. Therefore, the aim of this thesis is to (re)specify the transition 'challenge' by documenting and analysing the institutional practices and lived experiences of ELD through a transitional care service.

This study is the first to ethnographically examine the practice of UK transitional care for young people with ELD. Through a multi-sited ethnographic approach, I show that the transitional care between two hospitals in the north of England (and wider 'social' domains such as the family home and social care environments), is a highly situated and negotiated practice. Furthermore, narrative and observational methods of data collection with clinicians, care professionals, families and young people with ELD reveal transitional care to be a practice that is bound up with assumptions about what it means to be an adolescent, tensions in cultures of care, expectations regarding rites of passage and normative conceptualisations of the childhood-adulthood dichotomy. Based on these findings, the central argument of this thesis is that, whilst UK adolescent healthcare is a complex and contested care practice that organises and orders patients based on chronological age, it is also a social practice that operates in the context of wider political agendas and social ideals. In situating ELD transition within its institutional context, this study exposes the sociocultural arrangements that shape contemporary understandings and experiences of adolescence and disability. Crucially, it shows how society and culture shape biomedical practices and understandings of the adolescent patient.

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Declaration

This thesis is the result of my own work. The material contained within this thesis has not been presented, nor is currently being presented, either in part or wholly for any other degree qualification.

I was solely responsible for all data collection and analysis.

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To see six years of hard graft, now in its final form, is boss. This PhD has accompanied me through some of the biggest events of my life, including my wedding day, the birth of my children, and a whole mix of psychological ups and downs. To see it come together brings a sense of achievement that, without the following people, would never have been accomplished.

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Dedication

This thesis is dedicated to the memory of my beautiful and wonderful nan,

Pola

(Gladys Smith).

From childhood you set me on a path of curiosity and so, no matter what questions I ask they were always going to be because of you.

And also, to the memory of Carol Ann McCarthy.

Acronyms and shortened words used in the thesis

A&E	Accident and emergency
AEDs	Anti-epileptic drugs
CBU	Clinical business unit
CCG	Clinical commissioning group
CHN	Complex health needs
CQUIN	Commissioning for quality and innovation
DAH	Developmentally appropriate healthcare
DOH	Department of Health
EBM	Evidence-based medicine
ELD	Epilepsy and co-morbid learning disability
ENS	Epilepsy nurse specialist
fMRI	Functional magnetic resonance imaging
GP	General Practitioner
LA	Local authority
LAC	Looked after children
LD	Learning disability
MDT	Multidisciplinary teams
MOSA	Medical Officers of Schools
NHS	National health service
NICE	National institute of clinical excellence
PFC	Prefrontal cortex
PSP	Parent skills passport
R&D	Research and development
RCT	Randomised controlled trial
SEN	Special educational needs
STS	Science and technology studies
TEC	Teenage epilepsy clinic

List of Tables and Figures

The Past— the dark unfathom'd retrospect!
The teeming gulf—the sleepers and the shadows!
The past—the infinite greatness of the past!
For what is the present after all but a growth out of the past?
(As a projectile, form'd, impell'd, passing a certain line, still keeps on,
So the present, utterly form'd, impell'd by the past.)

- *Walt Whitman*

Intellectually, true beauty is very difficult to distinguish a priori from the bloom of youth.

- *André Breton*

Chapter 1- Introduction

The case of Ashley X

In 2006, two Seattle-based endocrinologists published a paper in the Archives of Paediatrics describing recent medical interventions undertaken on a young female patient named Ashley who had ‘severe, irreversible neurological and cognitive impairment’ (pg. 1014, Gunther & Diekema, 2006). According to Ashley’s medical history, within a month of her birth she began to display symptoms of low muscle tone, feeding difficulties, choreoathetoid movements and developmental delays. Further evaluation by specialist neurologists, clinical geneticists and developmental paediatricians were unable to determine a specific cause for Ashley’s disabilities, however, static encephalopathy with marked global developmental delay was the eventual diagnosis. Her medical care team concluded that Ashley’s development would never progress beyond that of an infant. Therefore, between the ages of 6-9 years, Ashley underwent a series of growth attenuation treatments, including high-dose oestrogens to stop her growth, a hysterectomy to avoid menstruation and a bilateral mastectomy to stop her growing full breasts. Attenuating her growth - via prompting an early puberty - meant that Ashley experienced the end of puberty by the time she was 9 years old. The aim of this treatment catered, not so much for the needs of Ashley, as it did for those with responsibility for her care. In other words, growth attenuation was chosen to ease the difficulties of caring for a severely disabled young person; a task her parents and clinicians believed would become increasingly burdensome as her physical development continued into adolescence and adulthood. Consequently, the authors of the paper stated that:

> ‘Many parents would like to continue caring for their child with special needs at home but find it difficult to do so as the child increases in size. If growth could be permanently arrested while the child was still small, both child and parent would likely benefit because this would facilitate the option of continued care in the home.’ (pg.1013).

Ashley’s parents authorised growth attenuation therapies to keep her body in a state of perpetual childhood. According to Gunther and Diekema (2006) the reasoning behind these procedures was two-fold; i) to improve Ashley’s quality of life and ii) to ease the burden of care. Specifically, keeping her body size small meant that her grandparents and parents could keep her mobile – turning and lifting her as necessary.

The Ashley Treatment, as it came to be known, attracted much media attention, with prominent philosophers like Peter Singer responding in favour of a careful consideration of such treatment in cases of profound and multiple disabilities (Singer, 2012). Whilst this approach to easing the burden of care has attracted much debate, both supportive and condemning (Harnacke, 2016; Kafer, 2017; Kaveny, 2016; Romer & Crocker, 2006; Turnbull, Wehmeyer, Turnbull & Stowe, 2006), Ashley’s case highlights, not only familial concerns of caring for a severely disabled child that is physically maturing into adulthood, but also exposes the wider social challenges related to the ongoing care provision for those with disabilities. For example, in this case, looming adolescence triggered a moment to consider the future care provision for Ashley; the financial costs of paid-carers and, in its US context, potential medical costs. It is, perhaps, an extreme example of the problems attached to transitional care as children with chronic health conditions move into adulthood. Nevertheless, the case of the Ashley X presents new moral and ethical concerns when considering the complexities of care for young people who will never become independent adults. In this case, the adults surrounding Ashley X understood her body as en route to adulthood whilst her mind and cognitive abilities remained in childhood (Kafer, 2017). It is this asynchronous tension that will be considered in the course of this thesis.

The Ashley Treatment, with its aspiration to maintain a child-like body, is reminiscent of historical depictions of children with disabilities. With the publication of *Des Maladies Mentales Considérées Sous les Rapports Médical, Hygiènique et Médico-Légal, Volume 1* (1838), French neurologist/psychiatrist Jean-Étienne Dominque Esquirol categorised a certain group of people as 'idiots[1]' - roughly translating as those with intellectual and developmental disabilities. Esquirol proposed that this category of people would not benefit from training or education; according to him there was no method to change the idiot since they were '*arrêté dans son development*' (pg. 284). Esquirol's thinking on people with disabilities was further developed by Édouard Séguin, a physician and educationalist working with children who had cognitive impairments. Unlike Esquirol, Séguin believed education to be valuable in the treatment of children with intellectual disabilities, with his book *Traitment Moral, Hygiène et Éducation des Idiots et des Autres Enfants Arriérés* (1846) being dedicated to the diagnosis and treatment of such children. He believed educational and physiological tasks (such as physical exercises to strengthen the nervous system and vocational training) to be key to improving the quality of life for those classified as 'idiots'. Despite Esquirol and Séguin writing nearly 200 years ago[2], questions surrounding the care of disabled bodies have persisted into contemporary society. For

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[1] Esquirol is commonly considered to be the first to differentiate between lunatics and idiots; what today we would term as mental illness and learning or intellectual disability.

[2] Within the interim years, there have been significant social changes to the care of people with disabilities in areas of legislation and the demolishment of asylum type institutions. For an overview of the UK social history of disability I direct the reader to Davis (2006; 2017).

example, the Ashley Treatment (which simultaneously reflects Esquirol's depiction of arrested development and Séguin's hopeful interventions) show just one (much debated) approach to the challenge of continued care into adulthood. These debates force us to pay attention to experience and practices surrounding young people with disabilities as they grow into the expected status of independent adulthood. These questions, which ask what makes an independent adult and who can attain such status, is a central concern of this thesis.

Treating and caring for people with disability and chronic illness – past and present - reveals persistent tensions. These tensions centre around worries for the future health and social needs of these young people as well as the burden of care for families and social institutions. Furthermore, through the above examples we see the blurring of biological and social categories since it is difficult to determine whether these tensions are caused by a problem of individual physiology or sociocultural discrimination. The case of Ashley X brings into focus the wider social context that shapes how society cares for its most vulnerable, including changes in medical technologies or the provision of care and support for families of disabled children. It is apparent that the Ashley Treatment is tied up within a nexus of technological, political and social change. These changes (such as new medical technologies) have allowed for a re-conceptualisation of 'adolescence' and 'childhood'. This is clearly evidenced in the application of medical interventions that result in a state of childhood in perpetuity. An examination of the challenges associated with adolescent healthcare leaves wide open the question as to whether the Ashley treatment (and relevant child/adolescent disability care practices) is a response to an inherent biological problem, a reflection of sociocultural conditions that impact upon disability, or a combination of both.

The Ashley Treatment and subsequent debates demonstrate that biomedicine is not a neutral enterprise. Rather it is characterised by contestable assumptions concerning what constitutes a fit and well human being which are presented as authoritative truths governing care practices for disability instead of matters for debate and negotiation. In other words, the Ashley Treatment becomes a symbol of the biomedical hope that disability should be minimised, rather than accepted for what it is. In this case, society is forced to confront the question of what to do with an adolescent population whose ills are currently incurable but remain difficult to care for. It is this question that guides the practice of transitional care and that is the focus of this study. In order to situate the reader to the thesis that follows, I will first provide an overview of epilepsy transitional care; what it is, how it is practiced and why it is considered important before moving into Chapter 2, which provides a detailed literature review that grounds my ethnographic study.

Epilepsy Transitional Care

Transitioning between child and adult services, as a specific component of clinical care, is in its infancy, nevertheless it is characterised by a growing national and international research and policy literature. Whilst adolescent medicine is formalised as a distinct speciality in the United States, specific clinical literatures regarding ‘transition’, both within and outside of the US, only began to appear in the early 1990s. Within the UK, it was during the early 2000s that we began to see the transition of young patients to adult healthcare as a growing priority and a key area for significant clinical development (examples include *Transition: moving on well* [DoH, 2008]; *National Service framework for Children, Young People and Maternity Services* [DoH/DfER, 2004]; *Transition: getting it right for young people,* [DoH, 2006]; *Annual Report of the Chief Medical Officer* [DoH, 2013]; *From the pond into the sea*, [Care

Quality Comission, 2014]). Additionally, in 2015, transition was highlighted as a ‘top 10’ research priority by the British Medical Journal (Morris et al., 2015). Specific to epilepsy, it is now a recommendation of the Quality and Outcomes Framework that young people with epilepsy have an agreed transition period during which they receive care that is jointly reviewed by both paediatric and adult services (NICE, 2012).

One of the main reasons for positioning epilepsy transitional care as a priority is due to its prevalence as a neurological condition. Childhood onset epilepsy is reported as being one of the most prevalent neurological conditions in the UK and is understood to have long term implications for future health and psychosocial wellbeing (Appleton, 2009; Bacca, et al., 2012; Meearaus et al., 2013; Wallace, Shovron & Tallis, 1998). In 2014, a special issue of Epilepsia featured a series of papers relating to epilepsy and transitional care, which covered areas of pharmacology (Chiron & An, 2014); aetiology (De Saint-Martin, et al., 2014) and lifestyle (Nashef, et al., 2014) amongst others. This special issue was the outcome of an international symposium held for neurologists with an interest in epilepsy and as such, reflected concerns that neurologists held for their young epilepsy patient population. The overarching argument within this special issue was that epilepsy transition was now a global clinical concern.

As childhood epilepsy persists into adulthood three possible clinical outcomes have been identified (Borlot et al., 2014): (i) well controlled seizures and normal cognitive function, (ii) difficult to control seizures and normal cognitive function or (iii) intractable epilepsy associated with cognitive delay, of which intellectual disability is a sub-group. It is the latter outcome that Borlot et al. describe as the most challenging for neurologists when receiving a new patient from a paediatric service. This group of young epilepsy patients with co-morbid cognitive delay (as characterised by impairments in both intellectual and social/adaptive functioning acquired before adulthood) are the focus of my thesis. The prevalence of epilepsy in those with mild to moderate learning disability (IQ score between 50–70) is estimated at 15%, whilst in those with severe intellectual disability (IQ score < 50) prevalence is estimated at 30% (Lhatoo & Sander, 2001). Furthermore, the addition of a learning disability to the diagnosis of epilepsy [henceforth referred to as ELD] often results in poorer seizure control and increased rates of morbidity and mortality (Baca, Barry & Berg, 2018; Sillanpää,, 2004). Taken together, these understandings of ELD highlight that in the development of transitional epilepsy services, health professionals, researchers and policy makers must also consider the heterogeneous nature of this patient population. However, as will become clear in the first chapter of this thesis, this is not presently the case since the epilepsy transition literatures are largely concerned with 1) the psychological impact of transition, 2) age-appropriate care, and 3) multidisciplinary teamwork [see Chapter 2 for a full explanation of this].

Rationale and Overview of Thesis

Taking an ethnographic approach, this thesis investigates the practice of transitional healthcare by examining the clinical practice, sociocultural contexts and family experiences of transitioning into adulthood with ELD. The rationale for my study, is based upon the need to explore the experiences of ELD transition in order to clarify how care practices shape both carers and patients’ experiences of transitioning into adulthood. Whilst the case of Ashley X may appear an extreme and rare example of adolescent healthcare practices, it exposes underlying social anxieties regarding young people with disabilities and their transition into adulthood. These anxieties perceive the disabled adolescent body as a ‘disruption in time’ – where the body has become out of synchronicity with the mind (Kafer, 2017). This thesis explores how these anxieties play out on a mundane level: in the everyday working practice of the epilepsy clinic and the family home environment. As I will go on to show, the narrative of transitional healthcare has many threads, each revealing a key issue about what we expect from biomedical institutions (and the clinical practices that operate within in them) as well as how sociocultural understandings of adolescence, learning disability and long-term conditions come to shape young people's care. It is these intertwined threads that I wish to disentangle in the course of this thesis. This ethnographic examination of transitional care is important since, the findings of this study suggest that clinical institutions may benefit from an ongoing examination of the sociocultural and institutional context within which present-day transitional healthcare is situated.

This thesis draws from ethnographic fieldwork that centred on a Teenage Epilepsy Clinic [the TEC] in Northern England and the clinical, social and research activities associated with the TEC. I use the ethnographic data to illustrate and examine the tensions between how transition is described in the clinical literature, guidelines and policy with the experiences of families and young people with ELD – who are not only transitioning into an adult care environment but also into adulthood. Following this introductory chapter, Chapter 2 reviews the dominant clinical literatures of transitional care and examines how this perspective is taken up by social scientific studies of adolescence, youth and disability. Furthermore, I consider how hospital ethnographies in sociology and anthropology provide methodological openings to the unpacking of clinical care practices. In Chapter 3, I detail my research questions and the ethnographic approach that I have taken to the investigation of ELD transitional care. This is followed by six empirical chapters. These chapters can be grouped together in two parts. The first three empirical chapters (Chapters 4-6) focus on the institutional apparatus that supports the practice of transitioning. To start, I describe the implementation of the TEC and its subsequent development (Chapter 4). I then consider how proponents of transitional healthcare, both at the field sites and nationally, were involved in stabilising the TEC into a legitimate institutional practice, i.e. the formalisation of transitional care (Chapter 5). This is further expanded through my discussion of specific material artefacts (i.e. transition pathways and care information leaflets) that were used within the practice of transitional care and parents' interactions and use of such material objects (Chapter 6). The aim of these three chapters is therefore, to show how institutions seek to address the 'challenge' of transitional care. In the three remaining empirical chapters (Chapters 7-9), I privilege the experiences of transitioning to adulthood for the parents/carers of young people with ELD. To this end, I use the framework of rites of passage to explore assumptions underlying transitional care. These assumptions are concerned with i) the situations wherein child-parent separation does or does not occur (Chapter 7); ii) what does or does not change for adolescents with ELD during transition (Chapter 8); and iii) the degree to which these young people may or may not socially reintegrate as adults (Chapter 9). My aim in presenting these final three chapters is to contrast the institutions' preferred model of transitional care with familial experiences of caregiving. In other words, these chapters explore what I have termed within the thesis as 'the rhetoric versus the reality of care'. Together, these six empirical chapters draw upon a variety of fieldwork data (including interview extracts, fieldwork observations, and documentary sources) to build a composite understanding of transitional care as it pertains to young people with ELD, their parents and their health professionals. In the final chapter (Chapter 10), I bring together the findings and discuss the contributions of this study.

Chapter 2 - Problematising Epilepsy Transitional Care: A literature review

This literature review focuses on the so-called ‘challenge’ of transitioning young people with epilepsy and co-morbid learning disabilities [henceforth referred to as ELD] from a paediatric to an adult healthcare setting. Research on epilepsy transitional care has largely been conducted by those within the clinical or health-related sciences[3]. From this perspective, the ‘challenge’ of care provision for young patients with epilepsy is often discussed in relation to the condition’s associated high prevalence rates of cognitive and psychological co-morbidities. Consequently, the transition of patients with ELD is consistently framed as a complex concern for clinical practice (Robertson, Hatton, Emerson, & Baines, 2015; Wagner et al., 2016). The complexity of transitioning those with epilepsy and an additional co-morbidity is reflected in the large body of interdisciplinary clinical and health literature that underpin studies in this area (Appleton, Chadwick, & Sweeney, 1997; Appleton, 2009; Baker, Spector, McGrath, & Soteriou, 2005; Beecham, Snell, Perkins, & Knapp, 2010; Bacca, et al., 2018; Berg, Caplan, & Hesdorffer, 2011; C. Camfield, Berg, Stephani, & Wirrell, 2014; Chiron & An, 2014; Collins, 2011; Gray et al, 2017; Iyer & Appleton, 2013; Lewis & Noyes, 2013; Mu, 2008; Scheffer & Dravet, 2014; Schultz, 2013; Shanske, Arnold, Carvalho, & Rein, 2012; Thomson, et al., 2014). Therefore, I do not attempt to provide an in-depth account of epilepsy or experiences of this condition during the transitional period. Instead, I focus on exploring what is considered the challenge of ELD transitional practice in respect to the delivery of care. This approach to reviewing

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[3] As a condition, however, epilepsy has been widely studied from a variety of disciplines ranging from the natural sciences (Reif, Strzelczyk, & Rosenow, 2016) , social sciences (Good et al., 1994; Kleinman et al., 1995;Webster, 2019) as well as the arts and humanities (Mula, 2016; Temkin, 1971; Wolf, 2016).

the literature has inevitably meant that certain scholarly contributions have been curtailed[4].

Given the multidisciplinary nature of the epilepsy transition literature, I employed a wide-ranging search strategy to undertake this review. This involved examining medical and social scientific literature databases, identifying seminal works concerning transitional healthcare, following the work of key researchers and using ancestry search strategies[5]. Policy documents and medical guidelines were retrieved from online search engines and specific websites including the Department of Health, the Care Quality Commission, NICE and the National Institute for Health Research. The internet sites of charitable organisations such as Epilepsy Action, Mind, The

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[4] For example, there is an abundance of health-related qualitative research, which explores patient and caregiver experience of epilepsy during the transitional and early adult period (such as Audulv, Packer, & Versnel, 2014; Chong et al., 2016; Geerlings et al., 2015; Harden, Black, & Chin, 2016; Lambert & Keogh, 2015; Lewis, Noyes, & Hastings, 2015; MacLeod & Austin, 2003; O'Toole et al., 2015; Rapport, Clement, Doel, & Hutchings, 2015). However, I have not provided an explicit section on this work, rather I have chosen instead to incorporate it throughout the review.

[5] The literature was searched by sourcing electronic databases, including JSTOR, MEDLINE, CINAHL, Cochrane Library, Google Scholar and Web of Knowledge at regular intervals from October 2013-October 2016. Different search terms were combined in advanced search options and included: transition; transfer; epilepsy; neurological disorder; adolescent; young people; youth; teenager; paediatrics; pediatrics; learning disability; intellectual disability; mental retardation; and cognitive impairment amongst others. For the purpose of reviewing the literature, I adhere to each author’s preferred choice of terminology. Papers were retrieved and critiqued according to their relevance to the present study’s research questions and methodological approach, contribution to the transition debate, whether analytical and classificatory terms pertinent to the study (such as ‘learning disability’ and ‘transition’) were explained, whether the researcher’s perspective was made clear and, whether conclusions drawn were justified. Ancestry searching involved searching the reference lists of papers and documents for commonly cited studies in order to find an ‘ancestral’ basis for the current papers under review. Literature recommendations from study participants (both parents and health professionals) have also been considered for review as this indicates the sources of information that have direct influence on transitional care experience and practice.

British Institute of Learning Disabilities, and Epilepsy Research UK were also searched for unpublished grey literature.

This chapter provides a comprehensive summary of the literature search and is split into three parts. Given that clinical research dominates the literature on ELD transitional care, I start by clarifying how this care practice is defined and approached from this perspective. Here, I examine what the clinical literatures (including medical, nursing and psychological) describe as the main concerns when transitioning young people with ELD. I then go on to show how this clinical perspective organises care around a very normative and generalised understanding of adolescence. In part two, I discuss how this particular perception of adolescence at play has acquired medical and scientific stability via the disciplinary fields of developmental psychology and developmental cognitive neuroscience. I then go on to critique this literature using wider social scientific studies of youth, which argue that conceptualisations of adolescence vary, depending on its social, cultural and historical contexts. This literature leads me to focus part three upon the socially constructed practices of health and care. Here, I pay attention to ethnographic research that shows biomedicine and society, whilst often assumed to be disparate entities, are in fact in a dialogical relationship with each other. Furthermore, these ethnographies of biomedicine and clinical care from the fields of medical anthropology, medical sociology and science and technology studies [STS] highlight why a solely clinical approach to understanding ELD transitional care is limited.

In presenting ethnographic studies of biomedicine, I make the case for my empirical study, which seeks to not only further the practical enterprises of those involved in transitional healthcare, but primarily aims to understand the approach and structure of a care practice within its social and institutional context. In doing so, I highlight the knowledge gaps concerning the transition of young people with ELD and, consequently, provide a rationale for the current study whilst setting the scene for the later empirical chapters.

Part 1: A Clinical Perspective of Transitional Care

In writing about a ‘clinical perspective’, I am referring to the disciplines of medicine, nursing and clinical psychology. For example, studies of epilepsy transitional care are often undertaken by researchers who are themselves practicing clinicians aiming to improve service delivery (examples include, Appleton et al., 1997; Lewis & Noyes, 2013; Snead et al., 2004). In presenting these fields as one perspective, my intention is not to characterise a clinical or healthcare paradigm in any definitive or singular way, but rather, it is to acknowledge that there are particular trends and convergences within these disciplinary contributions that reflect a broad consensus on transitional care issues. The most significant agreement between these clinical disciplines is that transitioning to adult services is a challenging experience (for care providers, families and patients) with potentially devastating effects for a young person. It is these studies, with their efforts to improve the practice of transitional care, that I will henceforth refer to as ‘clinical’.

The literature search for part one of this chapter shows that the majority of studies focussing on transitional care have been conducted by European and North American researchers. This proliferation of European and North American literatures reflects what Nsamenang (2002) has called the ‘Eurocentric enterprise of adolescent psychology’, wherein adolescence is viewed as a time of stress, turmoil and challenge for young people. In reviewing a set of literatures that are embedded within a particular social, cultural, technological and historical milieu, we can see how the perceived challenge of transitional healthcare is an artefact of its context (Latour, 1987; Lupton, 2012). However, it is an artefact with very real consequences for those involved in delivering and receiving this care practice. Whilst I will extend this discussion later in the chapter, I begin this review by exploring the development of adolescent healthcare from its inception in the 1950's USA and the significance of this for the growing interest in the concept of transitioning.

Initial efforts towards improving adolescent healthcare can be seen in the set-up of an Adolescent Unit, first established in the United States in Boston's Children's Hospital during the 1950's (Gallagher, Heald & Masland, 1958; Munro-Prescott, 1998). This clinical unit focussed on providing healthcare specifically for those aged between 12-21 years and introduced the first academic training programme in adolescent medicine (Munro-Prescott, 1998). However, it was not until 1993 that a dedicated transitional healthcare service was proposed as a preparatory process for young people with long-term conditions moving to adult services (Blum et al., 1993)[6]. In a seminal position paper presented at the Society for Adolescent Medicine, Blum et al. (1993) defined and outlined the aims of a dedicated transitional healthcare service, stating that:

> Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems… The optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive. (pg. 570).

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[6] Due to medical advances, particularly in the treatment of cystic fibrosis, children who had once died during childhood were now beginning to survive into adulthood, subsequently inciting the need for these patients to move from a paediatric clinical environment to the adult one (Blum et al., 1993).

In the clinical literatures, this statement is routinely used as a rhetorical point of reference for defining what transitional healthcare is and what it aims to achieve. The statement emphasises some of the critical components of transitional healthcare, for example 'transition' is differentiated from 'transfer' of care in that transition aims to be a 'purposeful and planned movement', rather than a one-time handover from one service to another. It is this deliberate approach to healthcare that has come to determine the transition research and practice agenda. For example, the statement emphasises the need for transition to be: 'uninterrupted', 'coordinated', 'developmentally appropriate', 'psychosocially sound' and 'comprehensive'. These terms are crucial in that they have come to be the key guiding principles for how transitional care is organised, explained and championed by relevant stakeholders.

In consideration of this definition, and from reviewing the clinical literatures, I have identified three main characteristics of the study of transitioning young people with epilepsy from a clinical perspective. Firstly, the aim to be 'psychosocially sound' has prompted clinical researchers to examine the psychosocial risks surrounding this stage of life and to develop interventions to alleviate such risks (Baker et al., 2005; Ferro, 2014; Gray et al., 2017). Secondly, the aim of providing a transitional service that is 'developmentally appropriate' reflects normative and progressive characterisations of adolescent development (Colver, 2018; Colver & Longwell, 2013; Dovey-Pearce, et al., 2005). Thirdly, the aim of providing 'comprehensive' care that is uninterrupted and coordinated has resulted in a trend toward nurturing multidisciplinarity in adolescent healthcare (Goldstein et al., 2004; Nabbout & Camfield, 2014; Shanske et al., 2012). These aims, and their subsequent concerns, have resulted in a particular model of care that young people with ELD are confronted with; a model of care that casts them as a challenge to be overcome or managed. It is to a detailed examination of these three concerns within the clinical literatures that I now turn.

Psychosocial wellbeing, developmentally appropriate and comprehensive care: The clinical concerns of transitional healthcare

The first of the three identified concerns - that transition should be ‘psychosocially sound’ - involves minimising the risk of psychological difficulty during the transition from child to adult services (Corrigan, Broome, & Dorris, 2016; Fegran, et al., 2014; Ferro & Boyle, 2012; Gray et al., 2017; Thomson et al., 2014). The clinical practice guidance literature asserts that psychological risk of anxiety and low-mood is a wide spread problem for those transitioning with epilepsy and therefore clinicians should take steps to reduce any negative impact caused by this process (Care Quality Commission, 2014; NICE, 2012; 2016). Findings from a questionnaire-based study (Baker et al., 2005) indicate that adolescents with epilepsy have significantly higher levels of depression, social anxiety, stigma and obsessive symptoms than those without epilepsy. High levels of psychological co-morbidity are often attributed to epilepsy itself being a condition that is characterised by the unpredictability of seizures (Asadi-Pooya, et al., 2007), high levels of social stigmatisation (Jacoby & Austin, 2007), loneliness (Geerlings et al., 2019) and academic under-achievement due to varying cognitive impairments (Beghi, Camfield, & Camfield, 2014; Rodenburg, et al., 2011). Furthermore, consensus amongst the clinical studies of epilepsy transitional care suggest that young people (when moving into adult services) must learn to adapt to new responsibilities in managing their seizures, whilst simultaneously adjusting to the psychosocial expectations associated with becoming an independent adult (Geerlings et al., 2015; Reeve & Lincoln, 2002; Reger et al., 2018; Sbarra, Rimm-Kaufman, & Pianta, 2002; Smith, Myson, & Gibbon, 2002).

Clinical studies also report that any psychosocial difficulties experienced during transition may persist into adulthood, drawing conclusions that adults with epilepsy will potentially experience a multitude of psychological difficulties including poor sense of control, depression, difficulties with peer relationships, low self-esteem, anxiety, social mal-adjustment and absence of friendship (Baker, 2002; McCagh, Fisk, & Baker, 2009; Gray et al., 2017). Additionally, and more importantly to the current study, the psychosocial impact of a learning disability has been reported to negatively influence condition management (Devinsky et al., 2015; Hirano, 2016). Tuffrey and Pearce (2003) argue that neurological conditions have a profound effect on young people's self-esteem and identity, highlighting that those with more severe neuro-disabilities may not have the social skills required to seek out and maintain services themselves. However, in comparison to the wealth of research concerning young people without learning disabilities, there are currently very few clinical studies examining the psychosocial profiles of those young people with co-morbid learning disabilities (Devinsky et al., 2015; Schultz, 2013). Nevertheless, what we do learn from these studies that examine the psychosocial aspects of transitioning between services, is that young people with epilepsy are viewed as a distinctive, complex and challenging patient group for the practice of care.

Aligned with this characterisation of young patients as posing a particular challenge to the practice of care is the second clinical priority, the delivery of a transitional care practice that is attentive to the specific and unique needs of adolescents. This echoes the suggestion of Blum et al. (1993) that transition should be 'developmentally appropriate'. Developmentally appropriate healthcare [DAH] is generally outlined as medical care that acknowledges both the psychosocial and physiological developments that occur during the life span and is considered a defining characteristic of adolescent medicine (Colver, 2018; Farre et al., 2015; Farre et al., 2016; Sawyer & Aroni, 2005; Sawyer et al., 2019). Proponents of DAH support the argument that adolescents are in the midst of 'biopsychosocial' changes which drastically differentiates them from children and adults, thus reiterating the unique needs of this age group (Dovey-Pearce et al., 2005; Farre et al., 2015; Farre et al., 2016; Viner, 2013).

With a commitment to flexibility and individual differences, DAH distinguishes itself from age-appropriate healthcare by emphasising development over chronological age. However, despite DAH being an approach where the 'what comes when' is to be indefinite and relative to the young person, it is, nevertheless, contingent on timing and (developmental) stage progression over the course of the human lifespan. This uncertainty surrounding developmental timing is most evident in debates around readiness to transition (Camfield, Bahi-Buisson, & Trinka, 2014; Nabbout & Camfield, 2014). For young people with epilepsy, the mean age cited for the transfer of care is 16.3 years, with a rather wide age-range of 12.8–21 years (Appleton et al., 1997). Other observational studies of epilepsy transition clinics have suggested between 16 and 17 years as an appropriate age of transfer to adult services (Jurasek, Ray, & Quigley, 2010). One reason for avoiding a prescriptive age of transfer in an epilepsy population is due to the cognitive and psychosocial variability within this population (Bhaumik et al., 2011). What this consideration shows us is that ambiguity, in terms of readiness to transition, can actually serve to provide flexibility when caring for young people with complex health needs, therefore allowing for discretion and the in-situ judgement of health professionals to guide the process.

Aiming to facilitate both DAH in epilepsy as well as supporting young people's psychosocial wellbeing, clinical interventions have been suggested to ensure all patients are knowledgeable of their condition before the point of transfer (Gray et al., 2017; Kurt, 2018). Suggestions include that clinicians provide condition specific education (Frizzell et al., 2011; Lewis & Noyes, 2013), enable self-management and compliance through medication awareness (Lewis et al., 2015; Modi et al., 2012) and provision of psychosocial interventions (such as peer support and formal 'resiliency building' programmes) (Snead et al., 2004; Wagner et al., 2011; Wagner et al., 2016). The content and aim of such interventions have been discussed by D'Agostino, Penney, & Zebrack (2011) with regard to young adult cancer survivors. They claim that the provision of consistent, coordinated healthcare is a key issue that impacts not just biomedical outcomes but a young person's 'achievement as self-reliant, independent and productive members of society' (pg. 233). This quote highlights the social processes the practice of transitional care is designed to effect. The desire to effect transition and initiate not just a change in care regime but a change in social status, as it appears within the clinical literatures, is thus predicated upon an unexamined assumption; that DAH will help to produce members of society who achieve the valued states of self-reliance, independence and productivity. Here we see normative depictions of adulthood at play, wherein independence and responsibility become the culturally default values defining what it means to be a functioning and participating adult in society. While the reinforcement of those cultural defaults could be criticised in several ways in relation to the expectations it places on neuro-typical individuals, particularly pronounced problems arise when this normative and outcome-based approach, which intends to produce valued members of society, is adopted as the model for care when working with the diversity of individuals who will comprise a local epilepsy population.

Addressing the lack of transition studies to include young people with intellectual disability, Schultz (2013) examined parental experiences of transitioning young people with epilepsy and severe cognitive impairment in the United States. The study described how parents are often the primary advocates for their child’s care during transition to adult services. Highlighting the complex interaction between parents and healthcare providers, this study suggests that implementation of DAH may not always mean striving towards independence and self-management since the parents of an adolescent/adult with epilepsy and cognitive impairment continue to play a vital role when providing care into adulthood. By acknowledging the diverse range of intellectual abilities that can be present in an epilepsy population, we can begin to question whether such a stage-defined model of healthcare (such as transitioning) is equally accessible to all young people (Coleman & Moore, 2006; Lubeck, 1998; Sawyer & Aroni, 2005).

Increasing emphasis on DAH, with its primarily psychosocial approach, is consequently shaping expectations regarding the role of medically trained staff and has implications regarding medical education, service provision and the requirement for specialist clinical psychological services. For example, Dovey-Pearce et al. (2005) propose that if young people are to be encouraged to look to the future and make informed decisions about their long-term health then they must receive healthcare that considers life aspirations alongside health related aspirations. Further suggestions regarding the delivery of DAH include that medical staff should work with young people to offer support in relation to the ‘continuing tasks of childhood’, such as maintaining friendships, building upon academic successes and fulfilling valued roles within the family and community (Dovey-Pearce & Christie, 2013; Price et al., 2011). However, these propositions leave unexamined how this type of transitional care service is to be delivered when budgetary limitations and time-management constraints are being increasingly experienced by many areas of health and social care services (Bailey, 2014; Devakumar et al., 2016).

The final concern for the clinical perspective of epilepsy transitional care is ensuring a smooth transition into adult services through effective multi-disciplinary teams [MDTs]. With transitional care aiming to be ‘co-ordinated and comprehensive’ (Blum et al., 1993), this has invariably been translated to mean care that is planned and inclusive of relevant disciplines such as medicine, nursing, psychology, psychiatry, social care and education. Specific to epilepsy transition, MDT work is encouraged due to the variety of psychosocial, cognitive and physical co-morbidities that young people may experience (Iyer & Appleton, 2013; Nabbout & Camfield, 2014), as well as for achieving patient-centred care (Goldstein et al., 2004; Kerr & Bowley, 2001; Shanske et al., 2012; Williams et al., 1995). Consequently, the role of the clinical psychologist has become a key factor in developing transitional services. Fegran et al. (2014) claim that adolescents’ experiences of transition are likely to encompass complex changes such as shifts in relationships with health professionals; moving from a familiar to an unknown care culture; and achieving responsibility and independence into adulthood which may negatively impact psychosocial wellbeing. It is through this assertion that psychology professionals have become intrinsic, if not to the practice of transition then certainly to shaping the transition research and practice agenda (C. Camfield et al., 2014; P. Camfield, Bahi-Buisson, & Trinka, 2014; De Saint-Martin et al., 2014; Fegran et al., 2014; Thiele, Granata, Matricardi, & Chugani, 2014; Wilde & Haslam, 1996)

There is a lack of research specifically examining working MDTs in epilepsy transitional healthcare, however, Snead et al. (2004) describe the implementation of a structured psycho-educational[7] group for adolescents with epilepsy. This piloted intervention required patients to attend a one-hour group session for six weeks that focussed on five topics: (i) the medical aspects of epilepsy; (ii) the promotion of healthy lifestyle attitudes and behaviours; (iii) the development of positive relationships with peers and family; (iv) stress management; and (v) the psychosocial concerns related to adolescence. The sessions were delivered by clinical psychologists and the study found no significant improvement in quality of life or reduction in depression and anxiety following the intervention. Out of the thirty-one invited participants, only seven took part in all sessions. The remaining were excluded for reasons of having an IQ lower than 70, experiencing psychological problems (despite these being two common co-morbidities of the condition) or, attending to school and social engagements. This study highlights the difficulties associated with psycho-educational based interventions as they are often delivered in addition to routine epilepsy care, which risks overburdening patients who already attend regular follow-up and monitoring appointments.

Another piloted intervention for adolescents with epilepsy suggests that education alone is more effective than psycho-educational based interventions for increasing knowledge of epilepsy and promoting psychological wellbeing (Frizzell et al., 2011). Facilitated by a nurse and a researcher, this education programme involved a discussion with the patient of their personalised medical record at a one-to-one, hour-long session. This was then followed by a later group session to discuss the impact of epilepsy on lifestyle issues such as driving, education and employment. It was found

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[7] May and Pfafflin (2005) differentiate psycho-educational interventions from that of education interventions as combining condition specific education as well as psychological information, including also coping strategies and emotional aspects of having epilepsy.

that in creating a personalised medical record for adolescents (including information on seizure type, results of investigations and medications), knowledge of their own epilepsy, knowledge of epilepsy in general and levels of self-confidence all significantly increased. Findings from the post-intervention focus group indicated that by increasing their knowledge of their condition the patients also improved their psychological wellbeing. Frizzell et al. suggest that by ensuring patients have adequate knowledge of their condition, health professionals may consequently ameliorate the psychological challenges associated with epilepsy in adolescence without the need for additional specialist professionals. These two intervention studies demonstrate the difficulties in designing multidisciplinary interventions for a condition like epilepsy where co-morbidities can vary greatly between patients. Furthermore, despite continual calls for multidisciplinarity in care, this consideration highlights limitations in implementing psychologically focussed programmes into routine care practice when resources are limited. In the face of such challenges, questions surround the value and effectiveness of MDT approaches (Atwal, Tattersall, Caldwell, & Craik, 2006; Ke et al., 2013).

Reflections on the clinical perspective of transition

From the account presented, we can see that within a clinical perspective the aim of epilepsy transitional care is to provide a service that supports psychosocial wellbeing, is developmentally appropriate to the needs of adolescents and encompasses a range of health professionals. These aims are shaped by a very particular understanding of what adolescence is – a challenging developmental stage that poses a risk to a young person’s present state of psychosocial wellbeing as well as their future health. Consequently, this implies that adolescents with long-term conditions require targeted management and intervention. Key to the requirement for management and intervention is the concept of psychosocial wellbeing, yet the term psychosocial is of itself problematic given that a shared understanding of what constitutes ‘psychosocial’ remains elusive and is a major gap in knowledge (Martikainen, Bartley, & Lahelma, 2002; Singh-Manoux, 2003)[8]. Reading across the clinical literatures regarding epilepsy transition, the term psychosocial is operationalised in a variety of ways by different researchers. For example, Baker et al. (2005) describe families, schools and wider society as meditating influences on the psychosocial, thus implying that these are considered external to what is meant in terms of ‘psychosocial’. Geerlings et al. (2015) describe ‘psychosocial issues’ as including ‘emotional functions and participation in daily life’ (p 130). However, what is understood as participation in daily life, both in this study and across the clinical literatures, is never made explicit. Furthermore, Geerlings et al. categorise concepts such as social support, stigma and peer acceptance, not as psychosocial but as environmental. This ambiguity regarding such a prevailing term, makes comparisons between studies concerning psychosocial risk problematic.

Despite this lack of clarity of definition, supporting psychosocial wellbeing remains a strong focal point for transitional care practice, for instance, it has prompted the design and evaluation of education, psychosocial and resiliency building programmes (Lewis & Noyes, 2013; Snead et al., 2004; Wagner et al., 2011; Wagner et al., 2016). These interventions are designed to be implemented at the patient-level. As a result, current solutions to the challenge of transitional care depend on individuals becoming better patients (i.e. more knowledgeable about their condition). By improving transitional

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[8] Investigating the term psychosocial as it is applied in health research, (Martikainen et al. (2002) argue that the unspecified use of ‘psychosocial’ is likely to diminish its effectiveness, stating that ‘It refers to everything and nothing in particular’ (pg. 1019].

healthcare through supporting young people to become better patients, these interventions are often designed with a ‘typical’ adolescent in mind, one that is likely to become a ‘productive member of society’. This may reinforce feelings of exclusion for those with intellectual impairments (Ferguson & Walker, 2014). The frequent exclusion of those with intellectual impairment from epilepsy transitional care studies appears incongruous when we consider that the condition of epilepsy is one that is characterised by high prevalence rates of physical, psychological and cognitive co-morbidity (Lhatoo & Sander, 2001). Consequently, the concept of transitioning remains largely unexamined with regard to how it impacts those who develop atypically (Munõz-Solomando, Townley, & Williams, 2010; Schultz, 2013; Taylor, Fauset, & Harpin, 2010; Young, Murphy, & Coghill, 2011).

Furthermore, in focussing on largely psychological and individualised interventions, the clinical literatures of transitional healthcare provide little consideration for how the social or structural influences - such as healthcare institutions, ‘Eurocentric’ cultural mores or biomedical advances - interact with our understandings of adolescent health and disability (Nsamenang, 2002; Singh-Manoux, 2003). Consequently, within the clinical perspective there is the assumption that individual young people, with sufficient intervention and attention, can be appropriately managed in order to adapt to the demands of a healthcare system. Arguably, it is understandable that the primary concern of the clinical literatures is the individual patient (rather than institutional and social contexts) when most of the literature comes from authors who are also clinical practitioners (Etherington, 1996; Navab et al., 2016; Rosenstein & DeRenzo, 2012; Yanos & Ziedonis, 2006). However, through a largely clinical approach, this perspective of ELD transition offers only a partial understanding of the challenge of care, wherein young people themselves are viewed as objects for intervention. On the other hand, a research approach that is committed to examining the social and institutional context, within which young people and their care are situated, is likely to contribute a broader understanding of this topic.

In conclusion, by reviewing the clinical perspective of transitional care we learn about the challenges associated with care delivery for young people with epilepsy and the current proposals to overcome these challenges. We also learn that the concept of adolescence is earmarked as a fundamental cause for this clinical challenge and consequently the patient becomes the target for change. For example, Wilens and Rosenbaum (2013) cite the 'incomplete' neurobiology of the maturing adolescent brain as reason why transition-aged youth struggle with decision-making, risk taking and emotional regulation – thus, requiring professional intervention. Additionally, Sawyer et al. (2012) discuss the importance of the adolescent phase as a foundation for future health, stating that the implications of 'adolescent neurocognitive maturation on policies and programming are only starting to be explored.' (pg. 1634). However, from this literature we do not learn about the institutional structures that currently frame UK transitional care practices, nor do we learn of the implications transitioning between services have for the family, nor do we learn of the complexities of adolescence for those with co-morbid disabilities. As such, I am now going to take a wider look at some of the underpinning constructions of adolescence from interdisciplinary literatures in order to understand the varied and relative nature of this prevalent concept. This will include literature from the disciplines of psychology, neuroscience, anthropology and sociology.

Part 2: Understandings of Adolescence: Perspectives from the psy, neuro and social sciences

For the most part, adolescence can be conceptualised in two distinct ways (Linders, 2016); as either a phenomenon that is neuropsychologically determined (as demonstrated through the neuroscientific and psychological accounts of adolescence, [henceforth referred to as neuro and psy[9]]) or as a phenomenon that is socially and culturally mediated (as argued through social scientific studies of adolescence). Whilst sociocultural contexts do not go completely unacknowledged in psychological accounts of adolescence (Arnett, 2011), they are often brushed over in favour of broadly defining this stage through its physiological attributes, including pubertal and brain development. In particular, it is through studies within the neuroscientific and psychological sciences that adolescence is given the status of being a natural object (Bowker & Star, 1999; Vidal, 2009). This approach to studying adolescence has resulted in a number of neuroscientific 'truth claims' (Rose & Abi-Rached, 2013) regarding human development that has enabled the period of adolescence to be viewed as something that is largely universal, natural and therefore normative (Casper, 2014). Conversely, sociocultural accounts consider adolescence as a category of people (Hacking, 1998; 1999); a category that is culturally, socially and temporally relative

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[9] I use the prefixes *neuro*- and *psy*- to refer to disciplinary combinations within the wider fields of neuroscience and psychology (e.g. neurolinguistics or psychoethnology). For the first half of the 20th century *psy* was the common prefix attached to many fields dedicated to the study of human behaviour. Where it was once *psy* that lent authority and expertise, it is now increasingly the case that the *neuro*-sciences are offering the dominant explanations of human behaviour (Rose & Abi-Rached, 2013). In referring to the neuro and psy sciences together, I do not claim that these disciplines are identical, rather it is to highlight that there is strong semblance between understandings of adolescence within 20th century western psychology and contemporary studies of brain development. Following Rose and Abi-Rached (2013), employ the terms 'neuro' and 'psy' to signify the wide family of disciplines that fall under these prefixes.

(Lesko, 2012). Given that the clinical transition literatures tend to rely on neuroscientific findings as an explanatory model of adolescence (Colver & Longwell, 2013; Sawyer et al., 2012; Wilens & Rosenbaum, 2013), it is important to consider this alongside social scientific scholarship on the topic. The discussion that follows examines these neuropsychological and social conceptualisations of adolescence.

A Natural Category: Neuro and psy studies of adolescence

In the introduction to his essay *Brainhood, anthropological figure of modernity*, Fernando Vidal (2009) argues that the expansion of neuroscience in explaining human experience has produced the notion of 'brainhood' – the idea that humans are ultimately their brains. In the case of adolescence, brainhood and the character of brain activity that occurs during this period have come to ground contemporary understandings of adolescent development (Bhabha, 2014; Kelly, 2012; Sercombe, 2010). Furthermore, sociologist Nikolas Rose (2007) has argued that the proliferation of the neuro and psy disciplines is responsible for reshaping social policies, practices and organisation. As a result, we are beginning to witness a rise in the application of adolescent neuroscience, not only in areas of transitional healthcare, but also criminal justice proceedings (Steinberg, 2017), public health discourse (Johnson et al., 2012; Romeo, 2017; Steinberg, 2012), and education programmes (Ballonoff Suleiman et al., 2015; Choudhury et al., 2012). Whilst Vidal and Rose write of the human subject as a whole, neuroscientific studies of adolescence actively reify the idea of brainhood. By explaining adolescent behaviour as a consequence of neuro-developmental processes, it is assumed that young people's development is organic and natural and therefore follows a typical and normative developmental path from childhood into adulthood. It is this assumption that distinguishes adolescence as a natural category and is a representation of human experience that has become the dominant perspective and one that appeals to ideals of science and rationality (Lock, 2001).

Whilst neuroscientific models of adolescence are relatively recent, theories of cognitive development have represented an enduring approach to building a psychological understanding of adolescence. Major contributors to this field include David Elkind (Elkind & Bowen, 1979), who developed the notion of adolescent egocentrism. Egocentrism views young people as incapable of differentiating between their own perception of what others think of them and what others actually do think of them. The concept of adolescent egocentrism was influenced by Erikson's (1959) theory regarding the stages of psychosocial development. Within this theory, Erikson (1968) described the gap between childhood security and adulthood independence as a 'psychosocial moratorium' – a time when adolescents rehearse different identity roles before reaching a stable sense of self. Both of these theories support the claim that adolescence is a time of challenge and stress.

However, the developmental theory of adolescence that has been most influential (and readily applied to contemporary findings in neuroscientific studies of brain maturation) is the cognitive stages theory proposed by Jean Piaget (Piaget, 1953; Piaget & Inhelder, 1958). Piaget's work, although an early theoretical model of development, reinforces the neuroscientific understanding of adolescence that grounds the transitional care literatures. According to Piaget's theory of development, individuals move through a series of cognitive stages. The cognitive stage most aligned with adolescence is the *formal operational stage* (Piaget & Inhelder, 1958). During this period, and having already developed logical reasoning in late childhood (proposed between 7-11 years), adolescents now acquire the ability to think more abstractly and engage in hypothetical reasoning. This signifies a crucial shift in adolescent cognition; moving from thinking about what is real to what is possible.

Piaget’s theories of cognitive development appeared some sixty years prior to today’s application of neuroimaging techniques to better understand the adolescent brain. Despite this, one aspect that has remained consistent through the years is the proposition that there is, indeed, a distinguishable age of adolescence - characterised as a period when the brain (or the self) undergoes a process of maturation. However, to young people with intellectual impairment the models proposed by cognitive developmental psychology cannot be so readily applied. Early studies attempting to map the Piagetian model onto atypical development concluded that this theory could in fact explain development if adjusted for cognitive delay or different cognitive learning styles (Fakouri, 1991; Saxe & Shaheen, 1981). However, this has not gone without criticism from social theorists and philosophers of disability where the idea that those with intellectual impairment have a deficit or development lag has been much debated (Carlson, 2010; Haegele & Hodge, 2016

). For example, a critical disability approach conceptualises the disability experience as an example of human difference and diversity, as opposed to it being an experience of deficit and delay (Carlson, 2010; Slorach, 2016). Despite its limitations, and far from being the most recent perspective of adolescent development, Piagetian theory is considered the closest psychological explanation of the cerebral maturation process[10]. It is this process of change and instability that the transition literatures posit as problematic.

Reinforcing these psychological models of adolescence, neuroscientific explanations began to emerge in the late 20th century[11]. Through newly available visual imaging methodologies, a neurodevelopmental understanding of adolescence has now become the dominant mode of explaining this period of life with the potential to influence policy and practice within domains of health, education and the juvenile justice system (Cohen & Casey, 2014; Johnson, Blum, & Giedd, 2009; Steinberg, 2009; 2011; The Royal Society, 2011). These changes in technological development and research methodology also correspond with the rise in interest for dedicated transitional and adolescent healthcare practices (Blum et al., 1993).

Examples of neuroscientific findings that are being translated into current clinical literatures of transitional healthcare, includes the inverted U-shaped trajectory model of brain development (Ment et al., 2009). According to the U-shaped trajectory, at the beginning of adolescence cortical grey matter volume increases, eventually reaching its peak during adolescence and declining thereafter (roughly between the ages of 12-

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[10] The cerebral maturation process is demonstrated through processes of synaptogenesis and synaptic pruning during the adolescent years (Crone & Ridderinkhof, 2011). Synaptogenesis is the rapid formation of synapses between neurons in the nervous system and synaptic pruning refers to the process of synaptic reduction.

[11] Lerner and Steinberg (2004) describes the 1990s as a time when research into adolescence ‘came of age’. This was a period when imaging technologies (such as functional magnetic resonance imaging, positron emission tomography and diffusion tensor imaging) facilitated non-invasive, large-scale studies of adolescent brain development. Prior to this, scientific investigation into child and adolescent brain development had largely been through small-scale, post-mortem studies to demonstrate neuroanatomical changes (Choudhury, 2010).

25 years). This results in the inverted U-shaped pathway[12] - a model that has been cited within the transition literature as a way of explaining the turbulent character of adolescence, and thus justifying the need for clinical intervention (Colver & Longwell, 2013; Sawyer et al., 2012; Wilens & Rosenbaum, 2013). For example, in an article featured in the Lancet's adolescent health series, Sawyer et al. (2012), refer to the inverted U-shaped trajectory as evidence of why adolescents are poor decision-makers and less intellectually mature. According to these authors, this model of development implies that the adolescent phase poses a considerable risk to a young persons' present and future health, making public health initiatives (specifically education in areas of sexual health, tobacco use, substance misuse, mental health and injuries) crucial during this stage of life. When considered in the context of ELD transitional healthcare, the U-shaped trajectory takes on even more significance as it is uncertain if these models map onto the brain development of those young people considered as developing atypically (Lawrence et al., 2019)

A further example of neuroscientific findings that are being considered in transitional healthcare practices is that of the protracted development of the prefrontal cortex [PFC] (Colver & Longwell, 2013). Longitudinal fMRI studies suggest that sub-serving primary functions (such as motor and sensory systems) mature earliest, whilst higher-order association areas, (such as the PFC) develop later (Giedd et al., 1999; Mills et al., 2016; Shaw et al., 2008). The protracted development of the PFC implies poor decision-making, decreased memory and lack of impulse control in young people (Sowell, Thompson, Tessner, & Toga, 2001; Sowell et al., 1999). Furthermore,

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[12] It has been suggested that this trajectory reflects dendritic outgrowth and synaptogenesis with subsequent synaptic pruning (Johnson, et al., 2012).

occurring in the later years of adolescence is myelination[13] (Johnson et al., 2009). Myelination is considered a brain activity that allows neurons to effectively communicate across the brain. Therefore, this suggests that brain activity remains inefficient until myelination has occurred; assumed to be once the young person has reached adulthood. The translation of these findings and their implications has been taken up within the transitional literature as evidence for a revision of UK healthcare policies. For example, Colver and Longwell (2013) state that the protracted PFC development is what provides evidence towards the poor decision-making capabilities of young people and therefore justifying the need for intervention. Consequently, the transition literature upholds a model of human development that supports a normative view of adolescence; a view that is grounded in very positivistic and naturalised processes.

The neuro and psy sciences regarding adolescence have significantly contributed to the understanding of brain and cognitive development during this period. However, these approaches have done so in a way that turns adolescents themselves into the problem that needs to be solved or the challenge to be overcome (Casey, Getz, & Galvan, 2008; Romer, 2010). A hasty application of psy and neuro findings have been problematised by sociologists in areas of adolescent clinical care (Boulton, 2015), child and adolescent health and social policy (Lowe, Lee, & Macvarish, 2015) and medical diagnosis (Roberts, 2015). From a sociological perspective, it has been argued that neurocentrism (as a current trend for health, social and welfare policies) has been overzealous in adopting neuro and psy findings into practical applications. In

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[13] Myelination is a process by which the fatty cell material that surrounds neuronal axons, act as an insulation to the neural connections. This insulation process allows nerve impulses to transmit across neurons more efficiently therefore facilitating integrated brain activity across regions and cortices.

consideration of the dominance of neuro explanations of adolescence within the clinical transition literatures, there is little research on how this applies to atypical development, such as severe cognitive impairment evident in an ELD population (Dennis & Thompson, 2013; Karmiloff-Smith, 1998). Preliminary neuroanatomical studies have suggested structural developmental differences between young people with diagnoses of autism (Ecker, Bookheimer, & Murphy, 2015; Hardan, et al., 2009) and ADHD (Shaw et al., 2006). Yet the developmental trajectories that are relied upon by the transitional literatures do not account for this variety and complexity of human development (Karmiloff-Smith, 1998; 2013), which brings into question their value in instances such as ELD transitional care or any other patient population where brain development is heterogenous.

A Social Category: Sociocultural studies of adolescence

The neuro and psy science's conceptualisation of adolescence positions adolescence as an organic and natural category that is grounded in brain development. These models of adolescence help to scientise[14] young people by providing neurobiological evidence to the specificity of the adolescent, thus making it largely static. However, in these approaches we do not see how the concept of adolescence is also a historical and cultural artefact (Choudhury, 2010). Studies in the social sciences and humanities have been prominent in discussing the adolescent as a figure that is culturally and socially contingent (Béhague & Lézé, 2015; Lesko, 2012).

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[14] As Stevens et al. (2007) explain, "Conceptualising maturation in defined stages made the formulation of theories and models of development more easily manageable, and the sorting of people within a type of maturational taxonomy was viewed as scientific" (pg. 164). These methods of taxonomising and categorising people are what characterises the scientisation of human development wherein 'truth' has been legitimised through scientific knowledge (pg. 165).

Scholars looking to advance a more situated perspective of adolescence - such as Epstein (2007), Lesko (2012), and Sercombe (2010) built their approach in critique of American psychologist G.S. Hall's seminal work *Adolescence: Psychology and Its Relations to Physiology, Anthropology, Sociology, Sex, Crime, Religion, and Education* (1904) and its lasting legacy on conceptualisations of adolescence. Within this paper Hall defines this life stage as *'strum and strang'* (storm and stress), which subsequently prompted scientific interest in young people (Lesko, 2012; Sercombe, 2010). However, this two-volume work did not occur in a vacuum rather it was developed during a particular historical period. Hall's work was influenced by popular evolutionary theory, particularly that of recapitulation. According to Haeckel's (1874) recapitulation theory, individual development recapitulated – or mimicked - that of the entire human species, in other words, moving from primitive and savage states towards civilisation. Specifically, Hall equated children to 'savages', adolescents to 'nomads' and finally adults as 'civilised' peoples. Hall referred to people of African, Indian and Chinese origin as the 'adolescent races', with European and American societies as civilised. At the beginning of the 20th century, recapitulation theory served to isolate adolescence as the pivotal moment when an individual 'leaped to a developed, superior, Western selfhood or remained arrested in a savage state.' (Lesko, 2012, p. 34). Through Hall's work, the concept of adolescence emerged out of western cultural and scientific concerns of race and social classification.

In this section, I present research that takes up a very different perspective from that of the neuro and psy sciences, one that shows adolescence to be socially, historically and culturally situated. In other words, these studies demonstrate that adolescence is variable and does not always mean the same thing across time and place. One of the first ethnographic studies undertaken in direct in response to Hall's characterisation of the adolescent is that of Margaret Mead. Challenging Hall's claim that adolescence is a universal experience of storm and stress, Mead's study, *Coming of Age in Samoa* (Mead, 1928) argued that adolescence is culturally relative. By describing how adolescent Samoan girls showed little indication of psychological turmoil, Mead explained that Samoan children experience smoother transitions from childhood to adulthood than their European and American counterparts due to having more social responsibility and domestic duties bestowed upon them at an earlier age. Despite this study itself being heavily critiqued[15], what Mead argued for was an understanding of adolescence as an outcome of cultural and social conditioning, suggesting that adolescence is, therefore, not rooted in nature; rather, it is fluid, contingent and situated.

In more recent ethnographies of youth, social and cultural context has been shown to be crucial in understanding how young people are perceived and understood by their societies. In her study *Coming of Age in post-Soviet Russia* (which includes interviews and observations with 103 students across Russia), Fran Markowitz (2000) examines how national instability influences conceptualisations of adolescence. As the world viewed *perestroika*[16] and the collapse of the Soviet Union as a tumultuous transition, Markowitz argues that, whilst well aware of the changes, Russian teenagers did not view these events in the same catastrophic way that adults around the world and in Russia did. In contrast, continual change was often described as providing opportunity

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[15] Mead's study has received much critique on methodological grounds [most notably from Derek Freeman (1998)]. However, it remains significant in propelling subsequent studies within psychology and anthropology that also claim adolescence is culturally determined (Blanchet, 1996; Schlegel & Hewlett, 2011; Schwarz et al., 2012).

[16] Perestroika was a political reformation movement within the Communist Party of the Soviet Union during the 1980s and 1990s. It is associated with Soviet leader Mikhail Gorbachev and his *glasnost* (openness) policy reform.

for psychological stability, in that being continual, change could always be relied upon. This demonstrates that what was perceived by the adults around them as disastrous for the present and future wellbeing of teenagers, was felt to be otherwise by young people themselves. Furthermore, Markowitz explains that young people constructed meaning regarding social institutions (such as school) as something that requires continual negotiation with their own, as well as official and unofficial adult ‘sensibilities and expectations’ of what adolescence is. Markowitz describes her work as challenging the ‘near-axiomatic theories of human development that take cultural stability as essential to the successful navigation of adolescence and the making of well-adjusted adults’ (pg. 4). Through Markowitz’s ethnography we witness how common narratives regarding national change, political or social uncertainty are perceived as conditions that negatively affect youth development. However, these perceptions are not necessarily reflected in the experiences of young people themselves. What Markowitz help us to see is that conceptions of adolescence are fluid and relative to the context within which they are studied. She shows us that times of social uncertainty may also incite resilience in young people, which challenges common perceptions about both social change and adolescence as troubling things in and of themselves. In this way, national regimes and political priorities cannot be removed from how we come to think of youth.

Political agenda, particularly within western neoliberal societies, has been shown to impact expectations of young people. Sociologists in education have shown adolescence to be a socialisation process wherein young people undergo social and economic transitions, effectively producing adults who are both contributors and consumers in society (Youdell, 2011; Youdell & McGimpsey, 2015). Tom Hall’s (2003) ethnographic account of British homeless adolescents, investigates the difficulty of navigating the transition from childhood to adulthood when young people are excluded, both socially and economically, from what is considered a typical adolescent experience. Through his descriptions of unemployed and homeless youth[17], Hall suggests that (although living independently) these young people were denied the civil, political and consumer powers of their peers. These homeless youth were well aware that they were unable to contribute economically, as both consumers and producers within society, and as such, the fully lived experience of transitioning to adulthood that was commonly attributed to their age-group was denied to them. This study demonstrates that moving into adulthood within modern day Britain also includes the expectation that young people will make social and economic transitions wherein they aim for financial independence and the ability to control their own resources. Crucially, this study emphasises the importance of paying attention to economic regimes in considerations of adolescence. Both Markowitz and Hall's ethnographic accounts demonstrate how notions of childhood and adolescence are not just bio-psychological manifestations of physical development, but are also shaped by wider social, national and political processes. Importantly, what ethnographies of our own and other cultures reveal is that the model adolescent, that we saw being characterised by both the clinical literatures of transitional healthcare and the neuro and psy sciences, is not the modal adolescent across the globe or through history.

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[17] Hall provides descriptions of how, despite social and political intentions to raise rates of employment amongst young people, some private bedsit landlords had a preference for renting to young tenants who were unemployed. This was a lucrative venture for property owners due to the reliability of housing benefits being paid directly to the landlord. Again, this highlights the struggle young people face between the choice of gaining precarious forms of employment or receiving reliable housing benefit. In this case, young people were caught in between the desires of the landlord for reliable rent and the socio-economic expectations of becoming independent of state welfare.

Of particular relevance to the current study, is the work of Rayna Rapp and Faye Ginsburg (2013). They demonstrate that acknowledging the experiences of young people with disabilities exposes a whole other range of concerns in the context of US post-education systems. Motivated by personal observations that youth with learning disabilities were often ‘transitioning to nowhere’ (pg. 187), Rapp and Ginsburg conducted the first ethnographic study into the education-work/college transition of young people with disabilities. They claim that, despite legal mandate for inclusivity in public services, transitioning from education is a fragile experience for young people with cognitive impairment. For example, in New York City, young people and their carers were unsure of what was available to them post-schooling since those who were not applying to college were left with few publicly articulated alternatives to this. Rapp and Ginsburg describe the contemporary American narrative of attending college after high school as holding a ‘hegemonic grip’ that has now become an aspirational norm for youth. However, it is a narrative that is not always attainable or even valuable to all young people. Stating that young people with disabilities are the ‘*promiscuous violators of the walls erected by medical manuals and school bureaucracies.*’ (pg. 192), Rapp and Ginsburg argue that through the experiences of people with disabilities and their carers we can see the normative and exclusive assumptions that underlie education-based transitional services. This finding is crucial when approaching the study of transitional healthcare for young people with ELD. Not only does it enable an understanding of how disability takes shape in concrete, cultural locations (whether this be a classroom or a clinic), but also how opportunity and social mobility (or lack thereof) are institutionally derived during the period of adolescence. In other words, it reveals how particular understandings of adolescence come to dominate and organise wider social practices.

Rapp and Ginsburg note that their aim in revealing such structural forces (such as legislation) at play through ethnographic methods, is to build new transition models where ‘envisioning alternative politics and institutions’ for life beyond high school for young people with disabilities is possible. As both parents of young people with disabilities and anthropologists, Rapp and Ginsburg describe their work as an *entangled ethnography*, which enables them to theorise their own experiences. In this way they bring an insider’s insight to what it means to be the parent of a young person with disabilities today, often highlighting the innovative and improvised practices of US families who are faced with changing disability and care policies and services (Rapp & Ginsburg; 2001, 2011). Not only do Rapp and Ginsburg show how public institutions impact the adolescent experience, they also emphasise the critical and continued role of the family in the care for youth with disabilities. This demonstrates that adolescence (in the context of disability) is something that is negotiated between and within families, as well as by society writ large.

Specifically, within a biomedical institutional context, Rayna Rapp’s (2011) ethnographic study of a neuroscience laboratory asks how both clinicians and parents are becoming increasingly willing to explain child and adolescent developmental variation in terms of brain differences, or neurodiversity rather than disability or impairment. Within this study, Rapp follows the laboratory work of two scientific groups: the neuroscientists who scan children’s brains in search of resting state differences between diagnoses, and psychiatric epidemiologists who make use of epigenetics to distinguish diagnostic populations. Exploring the translational research imperative[18], that has now become a condition for research funding in the United

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[18] Translational research, or bench-to-bedside medicine, aims to build basic scientific research in order to apply them in practice, largely for therapeutic ends.

States, Rapp argues that this initiates an overzealous hype for such research findings. Rapp argues that powerful medicalised and neuroscientific understandings of learning disabilities are now how parents come to understand and talk about the developmental differences of their children. The work of Rayna Rapp and Faye Ginsburg is important to the current study since it highlights changing trends within biomedical and social policy research, emphasising that understandings of the mind and how it works shift and change just as the institutions that support (and are supported by) research also shift and change.

In conclusion, part two of this literature review has shown that, on one hand the transition literatures are caught up in a very naturalised view of adolescence, whilst, on the other hand, we can see that these ideas of adolescence are much contested. Ethnographic studies of youth and adolescence have shown this to be a developmental life phase that is socially and culturally variant. Although the neuro and psy studies of adolescence scientise young people and characterise them as a challenging group, such studies should not be dismissed as they provide emerging theoretical models of typical western adolescent brain development, something that is important for building empirical understanding. Nevertheless, it is the diversity of human development that is often overlooked when translating such findings into policy and practice (Karmiloff-Smith, 1998; 2013). Bringing social scientific approaches into debates of adolescent development and adolescent healthcare, encourages researchers to turn their attentions to wider social or institutional policies and practices that may in fact ‘dis-able’ young people as they approach adulthood. This critical consideration is rarely engaged with in clinical literatures of transitional healthcare yet may prove beneficial - particularly where development is atypical. Therefore, in order to learn about young people, for the purpose of developing care practices around them, we need to acknowledge the contexts of their individual experiences. This brings me to the final part of the literature review where I will present examples of ethnographic work within the practice of biomedicine, which help to illustrate the connections between individuals, institutional practices and social environments. Since there have been no previous ethnographic studies of transitional healthcare for young people with ELD, with this current thesis being amongst the first, the following studies that I review relate to contemporary practices of hospital-based care and its dialogic, or interdependent, relationship with society.

Part 3: Understanding the Biomedicine-Sociocultural Nexus: The work of clinical ethnographies

Parts one and two of this chapter show that ideas about adolescence are variable and fluid, unlike the specificity that is given to the meaning of adolescence within the clinical transitional literatures. Furthermore, we cannot be certain that the current models of transitional care, which are based on such naturalised and normative understandings of adolescence, reflect the experiences of young people with ELD transitioning into adult care environments. This is because young people with ELD are not simply adolescents, but they are adolescents who have epilepsy and a co-morbid disability, therefore adding multiple layers of complexity to their transition experience. As such, I argue for the importance of attending to the context of the ELD transition experience. The context of interest in the current study is that of the clinic. Crucially, the clinic is a specific site that is not only biomedical and institutional, but is also social (Smith, 2005). Institutions are places where a network of positions, roles, norms and values are fixed into social structures and organised into relatively stable patterns of human activity, such as clinical practices (Giddens, 1984; Turner, 1997).

As such, it is important to have an ongoing discussion about healthcare practices where the social is not conceived of as separate from the clinical. Rather we must acknowledge that clinical practices are embedded within their cultural environment, social context and institutional frameworks. We need to understand how these interact with each other so as to fully appreciate the 'challenge' of transitional care. In the final part of this chapter, I present studies that have helped me to orient to the importance of attending to institutional contexts and that have also provided a theoretical and methodological base for me to move forward from.

Why ethnographies of biomedicine, hospitals and clinics?

The work of ethnography[19] allows for larger, and often taken for granted 'structural and institutional process to become visible and their true effect known' (Biehl & Locke, 2010, pg. 317). Whilst classic medical anthropology has tended to focus on traditional and folkloric medical practices of non-western societies, recent interest has shifted to 'studying sideways' (Hannerz, 2010). In other words, medical anthropology has turned its attention to include groups, institutions and practices that may be more familiar to the researcher, such as the work of biomedicine (Good et al., 2010; Lock & Nguyen, 2010). The past 30 years have seen a rise in ethnographies of biomedicine examining the often-unexamined assumptions that are embedded within biomedicine and clinical practices, such as the production of diagnostic categories and the delineation of patient groups (Lock & Gordon, 2012; Lock & Nguyen, 2010). One

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[19] Distinctions of what constitutes ethnographic research are abound (Hammersley & Atkinson, 2019). As such, it may be more helpful to think of the ethnographic studies that follow as an *imaginary* (Forsey, 2010). Within this imaginary, studies may be considered ethnographic if conducted with the purpose of providing a detailed description of everyday life and practice, therefore allowing one to understand the cultural context within which a community's actions unfold and their decisions are made.

reason for this is because ‘biomedicine, and the hospital as its foremost institution, is a domain where the core values and beliefs of a culture come into view.’ (Van der Geest & Finkler, 2004). Therefore, rather than viewing society and medicine as separate entities, through hospital ethnographies we can begin to see that clinical practices exist within a biomedicine-sociocultural nexus.

The following ethnographic studies of hospitals and clinics demonstrate the importance of paying attention to national, institutional and local practice contexts in order to understand the phenomena of ELD transitional care. Furthermore, these studies can be viewed as part of a broader body of work – that of science and technology studies [STS]. As a programme of study, STS investigates how cultural and social processes come to shape scientific and technological developments, and vice versa (Pickering, 1992; Sismondo, 2009). Beginning in the 1970s, and through a growing body of institutional ethnographies (such as Berg, 1996; Castel, 2009; Mol 2008; Pols, 2010; Singleton, 2010; Timmermans and Berg, 1997; 2003), STS has examined categories, practices and infrastructures of medical, technological and scientific endeavours. This work has contributed to an understanding of how things such as biomedical ‘facts’ or patient categories (such as adolescents) are produced and made to work within their institutional environments (Knorr Centina, 1999; Latour, 1987; Pickering, 1992; Rabinow, 1996; Rapp 1999; Timmermans and Berg, 2003; Woolgar & Latour, 1986). STS is an important field to attune to when studying clinical practices since it does not take biomedicine or knowledge production for granted and therefore can offer fresh insight into what constitutes medical or clinical ‘challenges’.

This biomedicine-sociocultural nexus is best articulated through one of the first hospital-based ethnographic studies. Coser (1962) described hospitals as ‘tight little islands’; places that are isolated from the continent of normal life and wherein the islanders (patients and staff) exist within their own society with their own rules and regulations. Similarly, Erving Goffman's classic sociological study *Asylums* (1961) reveals how the closed cultural institution of the psychiatric hospital shaped the core identity of its patients. However, in more recent years, rather than seeing hospitals as islands there has been a growing debate to view them as hubs of social relations - a microcosmic reflection of society writ small (Van der Geest & Finkler, 2004). We can see this microcosmic reflection in Kaja Finkler's (1991) ethnographic fieldwork. Finkler takes us into a large Mexico City hospital to demonstrate how 'biomedicine' – something largely considered an objective and acultural practice - gets reinterpreted in culturally and locally specific ways, despite the globalization of the biomedical endeavour. Her fieldwork shows how so-called 'objective' clinical judgements do not follow a universal or global standard. Instead, Finkler emphasises the importance of considering hospitals as reflections of their local context. Similarly, Helle Max Andersen's (2004) clinical ethnography, describes how social inequality in Northern Ghana is reproduced within the hospital setting through bureaucratic hospital organisation, hierarchy and structure. In this study, Andersen highlights how differential treatment of patients is made possible through the replication of class relations of the larger society. Shahaduz Zaman's (2004) study of an orthopaedic ward in a Bangladeshi government teaching hospital also demonstrates how hospital organisations reinforce the hierarchical structure and social relationships within the wider society's caste system. More recently, this capacity for biomedicine to reflect social processes has been taken up by Kierans (2015), for instance, to show us the interplay between state and markets and how they intersect to produce health inequalities around organ transplantation in Mexico. In articulating the medical space as a sociocultural hub, we can begin to discuss hospitals (and the people and practices within) as places that reflect and reinforce norms, mores and politics of the worlds within which they are embedded.

In highlighting the dialogical relationship between biomedicine and society, hospital ethnographies are crucial for thinking through what is traditionally conceived of as social problems or public health ‘challenges’. For example, low UK organ donation rates, particular those associated with so-called ‘BME’ groups, are often and incorrectly assumed to be problems of culture (Kierans and Cooper, 2011; 2013). Tackling this problem head-on, Cooper and Kierans (2016) turn their gaze inwards to examine the UK institutional practices involved in requesting organs from families of south Asian and African Caribbean descent. As such, they show that difficulties in providing organs for transplant are just as ingrained within clinical practice, often shaping the opportunities many potential donors have to donate or not. Organ donation debates rarely focus on such institutional arrangements – for example, how requests for donations are made or how brain death is established or how health professionals are trained in order to make organ donation requests.

Another public health initiative that has been examined through clinical ethnography is that of prompting patients to make informed choices regarding their health. In recent years, European healthcare systems have shifted from a largely paternal approach to medical care to a model that emphasises informed patient choice (Mol, 2008). This has resulted in healthcare practices and policies stressing the importance of individualised consenting care. In such care models, the decision-making responsibility is usually assigned exclusively to patients (Mol, 2008; Mol & Law 2004). Mol’s (2008) ethnography of diabetes clinical care argues against what she calls the ‘logic of choice’ in healthcare provision in favour of a ‘logic of care’. Under the logic of choice, healthcare is framed in terms of the ‘good’ and responsible patient-as-consumer, symptomatic of social processes that value economic efficiency, marketisation of care practices and care provision. However, for Mol, this has a profound effect upon patient experience.

Another key feature attended to in hospital ethnographies is that of infrastructure. Julie Livingston's (2012) ethnography takes us into the only dedicated public cancer hospital in Botswana during a time when the country was faced with a cancer epidemic. Her ethnography takes place on a single cancer ward, with only 20 beds that are continually occupied. This cancer ward lacked not only the specialist equipment that would be found in western hospitals, such as mammography machines, but also the basic facilities required to run a hospital, such as electrical power. This lack of infrastructure often resulted in clinicians having to improvise, rather than following standardised biomedical procedures. Subsequently, Livingston illustrates how cancer inequalities are embedded within a wider political economy and dependent upon available resources[20].

Similarly, Alice Street's *Biomedicine in an Unstable Place* (2014) is an ethnography that examines the often-invisible infrastructure that works behind the scenes of clinical practices. Describing the work of an overcrowded hospital in Papua New Guinea, Street argues that what we think of as biomedicine, a field renowned for its reliance on an objective, evidence-based body of knowledge, is not reflected so cleanly in

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[20] Furthermore, Livingston highlights that in the Euro-American imaginary, Sub Saharan African is so often associated with infectious disease, rather than envisaged as a site of cancer. For Livingston, this false notion of Southern Africa as a location of infectious disease only, must be viewed as a complex political-economic issue, which involves the 'production of invisibility' by the global health community. This shows us that within the public imagination there may lay common assumptions of what illness means to a given peoples and places, however, Livingston demonstrates that these assumptions cannot and must not be taken for granted.

locations where infrastructure is weak. For example, Street describes doctors who act without following formal protocols due to lack of resources such as staff, clinical equipment and time. Street provides a contrast between the clean and authoritative image of biomedicine that is presented to aspiring doctors during their training, with the realities that clinicians face during day-to-day clinical practice. Both Livingston and Street's work show the importance of attending to the infrastructure that supports the daily work of clinical practices.

What we learn from these ethnographies of hospitals and biomedical practice is that what may be perceived as 'challenges' of health, illness and disability may have been made problematic, at least in part, through institutional practices and social contexts. For example, through examining practices of care, we see that whilst institutional infrastructure is something that lurks in the background of clinical care, it is vital for biomedicine to function. Crucially, these ethnographies teach us the importance of not taking biomedical practice and knowledge for granted, but to understand biomedicine as an outcome of social practices and relations, of national and institutional infrastructures and policies, of political economies and of culture. Furthermore, these clinical ethnographies also share several guiding questions. The first is ontological: how do medicine and science conceive of their 'challenges'? The second is social: how do social relations participate in the production of those 'challenges'? Another is material: what infrastructures are necessary in order to stabilise medical/scientific challenges and make them perform as required? An exploration of these questions is what the clinical ethnography permits and what I aim to unpack in the current study of ELD transitional care. What we learn from the above clinical ethnographies, as well as the STS paradigm in general, is that clinical practices are not free from a privileged or objective understanding of the nature of things (Buchbinder, 2015; Pickersgill &

Keulen, 2011; Roberts, 2015). Crucially, we see that - rather than viewing society as something distinct from the clinic - there is a biomedicine-sociocultural nexus, which is reflected in the care practices, the organisation of care and its management of patients. In other words, exploring institutional practices brings forth the inextricable entanglements of the social, political and cultural spheres that work to co-construct clinical ‘challenge’ and medical ‘problems’.

Conclusion

In this review, I have demonstrated the importance of orientating towards a contextual study of the transitional care for those with ELD. I first discussed the dominant clinical perspective of transitional care, where we learnt that adolescents (as a patient group) are considered a challenge for clinical practice, largely due to the preconceived assumptions regarding what adolescence is. Since the conceptualisation of adolescence itself constituted a large part of this clinical challenge, I then focussed subsequent discussions on the various theoretical understandings of adolescence. From parts one and two of the review, we learn that the clinical perspective regarding transitional healthcare relies on a normative model of adolescent development. This, however, raises concerns for when we apply normative understandings of adolescence onto those who develop atypically, emphasising the importance of considering the concept of adolescence as one that is comparative and situated. Finally, in part three, I presented examples of hospital ethnographies as a way into exploring these so-called clinical challenges. Here, we see that the clinical ethnography is a valuable tool for elucidating the connections between the clinic, society and culture. These ethnographic studies of biomedicine and clinical practice demonstrate the importance of adopting a research approach that explores the wider context within which transitional healthcare is enacted, since such contextual bearings (including institutional goals, social expectations of youth, or government incentives) come to shape the experience and organisation of health and illness.

The work of clinical ethnographies contributes an understanding of health and illness as something that operates within the parameters of society and culture. Both the concepts of adolescence and disability are linked to physiological change and bodily difference, but it is important to recognise that the body is not separate from society (Kierans, 2015). With these insights in mind, I propose that the challenge of transitional care cannot be fully understood by simply looking at the 'challenge' of adolescents. Until we examine the institutional and social setting wherein the transition challenge occurs, the practices that make transition happen, and the people who experience these processes, there remains a gap in our knowledge concerning transitional care for young people with ELD. It is through an ethnographic approach, which connects both the clinical perspective's account of adolescence with the institutional elements of care, that we can begin to explore transitional care as a social practice. In the following chapter, I provide a detailed description of this approach by outlining the current study's methodological underpinnings and how I went about ethnographically studying transitional care for young people with ELD.

Chapter 3 - Methodology and Methods

The literature that I presented in the previous chapter demonstrated that the dominant clinical perspective regards adolescents themselves to be the challenge of transitional care. Crucially, the literature review showed that transitional care, whilst a relatively new yet complex concern, is organised around particular assumptions of adolescence that do not take into account young people's variability or contextual bearings. A contextual understanding, one that acknowledges the biomedicine-sociocultural nexus within which clinical practices are embedded, therefore constitutes a gap in current knowledge about adolescent health, illness and disability. By using ethnographic methods and paying specific attention to the transition of those with severe forms of cognitive and intellectual impairment, I aim to contribute to filling this gap by documenting ethnographically the various challenges that are bound up with transitional care provision for those with ELD. This chapter describes the ethnographic approach that I took to the study of ELD transitional care. I begin this chapter by outlining my research aims and subsequent study objectives.

Research aim

Focussing upon a Teenage Epilepsy Clinic [henceforth referred to as the TEC] in Northern England, I examined the 'challenges' of moving young people with ELD from a paediatric healthcare setting into an adult one. The principal aim of this study was to understand the experiences and practices of providing care for young people with epilepsy and severe forms of learning disability within the context of institutional care practices. Specifically, I wanted to understand how transitional care programmes structured the experience of transitioning for those in receipt of care[21] and in turn, what understanding these experiences teaches us about the provision of care.

In meeting this aim, my objectives were to:

(i) Examine the transitional journey of young people with ELD and their families by documenting clinical care encounters and practices connected with their transition;

(ii) Identify and examine the meanings attached to concepts of youth and disability (as expressed by both parents and professionals involved in transitional healthcare);

(iii) Link the experience of transitional care to the sociocultural values of the society within which this institutional practice is situated.

In focussing on the transitional encounter between young people, parents, and care professionals, these participants have guided me towards the variety of issues that were of importance to them in the process of transitioning from child to adult services.

The multi-sited ethnography

Ethnography is considered the hallmark of anthropological research[22]. Ethnographic studies produce rich, detailed descriptions of cultures through a range of methods, of which participant observation has become the distinctive feature of this methodology (Flick, 2014). These observations conventionally involve long-term stays within the culture under study (Flick, 2014; Malinowski, 1922). It is through such immersive work that researchers can distinguish cultural norms and practices and learn to see the

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[21] I take ‘those in receipt of care’ to include individual patients and their families.

[22] Initially, ethnography was the product of a shift in anthropological thinking. From 19th century colonial ethnology, ethnography became the method that moved the discipline away from a comparative approach that, knowingly or unknowingly, justified oppressive colonial regimes (Coleman, Hyatt & Kingsolver, 2017).

world as others do. Ethnographic work, is therefore, committed to producing emic accounts of everyday life; accounts that come from within, rather than outside, of the group in question (Evans-Pritchard, 1937).

In aiming to capture the situated nature of ELD transitional care, ethnographic methods do not limit their gaze to looking at care recipients and their experiences of care. Rather, ethnographic methods allow researchers to ‘follow the actors’ (Latour, 2007), in other words tracing the links between people, places, practices, institutions and objects. Ethnographies of science and medicine, including this study, treat every day social practice as entry points into social worlds. In the case of ethnographic studies of biomedicine, this involves acknowledging that biomedical practices, rather than happening in a specific and contained geographical place, become sites with multiple locales (Downey & Dumit, 1999; Marcus, 1998).

In a re-evaluation of anthropology’s traditionally holistic approach, George Marcus (1998) argued that the usual tactic of situating oneself within a bound community (e.g. a village or a hospital department) creates a ‘fiction’ of a whole and ‘fully-probed micro-world’, rather than that which is constructed for the purposes of inquiry (Marcus, 1998, pg. 33). In critique of the locally-focused ethnography, Marcus proposed a re-evaluation of the ethnographic approach in the form of a multi-locale (or multi-sited) ethnography. This involves the ethnographer widening their gaze to encompass different places, people, practices and institutions, so that neither side – such as transitional care (the macro) and young people with ELD (the micro) – is polarised with the other. Consequently, in a multi-sited ethnography I was able to be present in the various sites across which transitional care was enacted. This allowed me to better understand the conditions under which transitional care delivery worked (or failed to work) in the context of ELD. This multi-sited ethnographic approach further facilitated an understanding of how concepts such as adolescence and disability were co-constructed and made to work within the world of transitional care – a practice that existed between the seemingly concrete locales of paediatric and adult care settings.

Phenomenological underpinnings

My ethnographic work is underpinned by a phenomenological epistemology that involves studying the social world (or life word) as it is encountered by individuals or groups of peoples (Flaherty, 2009; Katz & Csordas, 2003). A central tenet to the study of social worlds concentrates on human - or social - practices as embodied, materially mediated and centrally organised around a shared practical understanding (Foucault, 1979; Garfinkel, 1967; Goffman, 1961; Lynch, 1994; Mol, 2002; Schatzki, Knoor Cetina & Savigny, 2001; Wacquant, 2003). In the case of transitioning, one way to investigate this shared practical understanding would be via the sustained activities (such as clinical encounters) between doctors and patients but also between the material conditions of the clinic, such as guidelines, protocols and its physical environment.

As a philosophical tradition, phenomenology has a much longer history than its more recent methodological application (Flaherty, 2009; Katz & Csordas, 2003). In response to the rise of empiricism as the dominant mode of scientific inquiry, Edmund Husserl’s phenomenology argued against the scientisation of human and social activity, invoked through empiricism (Husserl, 1910; 1970 [1936]). Husserl (1910; 1913) takes us into first-hand explorations of the life-world, which he treats as the basis of knowledge of the world. Through his later development of hermeneutic phenomenology, Martin Heidegger (1927) expanded the notion of the lifeworld through his conceptualisation of dasein (being-in-the-world). In a permanent state of dasein, humans are so immersed in their lifeworld that its existence only ever enters awareness through disruption or change. Examples of such disruptions include illness, disability or bodily difference, where ‘normal’ activities that constitute a lifeworld are no longer taken for granted (Good, 1994; Kleinman, 1988; Rapp & Ginsburg, 2001). Crucial to the current study, experiences of illness and disability are therefore of methodological value in that they show us what is taken for granted in our everyday social world.

Whilst Husserl and Heidegger provided little detail on how to do phenomenological research, the work of 20th-century philosopher Alfred Schutz (1944) is key to the methodological application of phenomenology to the study of the mundane activities of social life. Phenomenological estrangement, as a methodological approach for social scientific research, was developed in Schutz’s essay *The Stranger* (1944). Schutz invites researchers who are attempting to understand the social life of which they are a part, to adopt the role of a stranger. This role offers an orientation to examining the informal and taken-for-granted fabric of society, which he terms the ‘cultural pattern of group life’ (1944, pg. 499). Within this cultural pattern, there are schemas (or ‘recipes’ for conduct) that the stranger must learn if they are to be integrated into the new group. For Schutz, the stranger is one who has not been born or reared into the social group and therefore all peculiar valuations, institutions, systems of orientation and guidance are unknown to them. Namely, the stranger is one who does not share the basic assumptions that guarantee seamless social functioning[23]. Schutz shows us that the methodological value of being a stranger lies in making the

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[23] Through his analogy of the immigrant, Schutz claims that in everyday life we employ these social recipes, which, in turn, allow common sense knowledge to predict or know the typical interaction between others and ourselves.

invisible recipes and basic assumptions visible. For a phenomenological study of transitional care, adopting the role of the stranger is to acknowledge such things as clinical practices not as '…a matter of course but a questionable topic for investigation, not an instrument for detangling problematic situations but a problematic situation itself…' (1944, pg. 506). From this perspective, problematising the often taken for granted features of transitional care (for example the concept of adolescence) facilitates an understanding of caregiving as a social practice that has been developed in relation to its previously defined sociocultural context. Consequently, this methodological approach is suited to explore not only individual accounts but also how these accounts link to sociocultural, political and technological contexts (Wacquant, 2003).

In the current study, I adopt the role of a stranger in order to attend to the experiences of individuals and the practical ways in which they are involved in constructing care as young people with ELD move into adulthood. A phenomenological ethnographic approach orients not only to professional's accounts of transitional healthcare or to experiences of young people and their families in isolation, but pays attention to how they co-construct transitional care together. This also means paying attention to the use of material artefacts and infrastructure that are connected to the transitional care practice such as patient information sheets, transition protocols and clinical spaces. This is because, in an institution where the creation and circulation of materials is an everyday activity, artefacts become material, textual or visual (re)constructions of a particular social reality (Dant, 2005). Therefore, my aim in studying transitional care is not to evaluate or assess the effectiveness of this practice but rather, it is to understand it as a social activity. This necessitates an iterative approach that allows the researcher to learn what emerges as significant to the practices at hand. Through continually zooming in on relevant issues, as well as zooming out and attempting to collect contextual bearings, ethnography is a valuable methodology to delineate the complexity of ELD transitional care. As a method, a phenomenologically informed ethnographic approach allows for the range of human and non-human actors (e.g. health professionals, patients or material artefacts) to make themselves known through the process of fieldwork. Consequently, an ethnographic approach to understanding transitional care practices enables a 'better comprehension of health services at all levels of analysis' (Biehl & Petryana, 2013, pg. 13).

Ethnographic Methods: Field sites, participants and fieldwork

Multi-sited ethnographies involve recognising field sites as unstable and heterogeneous things, often without clearly delineated borders. This is exemplified in Kim Fortun's (2001) ethnographic study of the aftermath of the 1984 Bhopal disaster. Fortun shows us that to view the Bhopal disaster as a single bounded geographical site was inappropriate. She describes it as a disaster that was 'entangled in the local and the global, the historic and the future…' (pg. 1). In adopting a multi-sited ethnographic approach, my gaze included multiple peoples, places and institutions that came to represent the complexity of the phenomenon under study. With this in mind, I began my fieldwork with a Teenage Epilepsy Clinic [the TEC] as the initial focal point. The TEC was a representative site of where transitional care gets done. It was where patients, parents and care professionals gathered together to discuss, prepare for and eventually do transitional care.

The TEC took place weekly, within Carden Adult Epilepsy Service. However, as time went by, I soon became aware that transitional healthcare did not purely take place within bounded clinic rooms nor did it simply exist between doctors, patients and their families as the following description explains. Transition also took place within

Longwater Paediatric Hospital and the collaborative work that went on between these two NHS Trusts. Therefore, to fully appreciate transitional care, I needed to expand my gaze to include paediatric epilepsy clinics, adult epilepsy clinics, homes of patients, social care settings, and NHS research and development departments. The following section describes the two main field sites: Longwater Paediatric Hospital and Carden Adult Epilepsy Services.

The TEC: A collaboration between Longwater Paediatric Hospital and Carden Adult Epilepsy Services

Fieldwork primarily focussed on the practice of transitional healthcare between two NHS Trusts in England[24], Longwater Paediatric Hospital (specifically the neurology department) and Carden Epilepsy Services (adults only), with both Trusts being within five miles of each other. These two services provided specialist healthcare to those with neurological conditions, including epilepsy. Generally, in the UK, children with long-term health conditions will move from a paediatric healthcare provider to an adult one when they ‘age out’ of the paediatric system; usually between 16-18 years of age. However, that is not to say that all young people with epilepsy will enter specialist services such as Carden - many young people in England receive epilepsy care within a community setting such as through their General Practitioner [GP] (Iyer & Appleton, 2013: Rajendran & Iyer, 2016). During fieldwork, these two NHS Trusts ran a joint Teenage Epilepsy Clinic [TEC]. The TEC was considered a purposeful method of delivering transitional healthcare for young people[25].

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[24] In the UK the NHS is based on national taxation making most healthcare, including healthcare at these field sites, free at the point of use.

[25] This means that the present study is not a general representation of all epilepsy healthcare for young people across the UK since there are discrepancies on how chronic conditions are managed and by whom, depending largely on local government (Dickson, Scott & Reuber, 2015).

Longwater Paediatrics was a large children's hospital that employed over 2,500 staff. The hospital provided both general and specialist care for multiple health conditions. Most of my ethnographic observations in Longwater took place within the hospital's Neurology and Research and Development [R&D] departments. The Neurology Department was the site where five of the study participants were based: the paediatric Epilepsy Nurse Specialist's [henceforth referred to as ENS's] Penny and Eve; the paediatric consultant neurologists' Drs Roberts and Lewtas (both of whom specialised in epilepsy clinical care); and the neuropsychologist Sara[26]. Also active in epilepsy transition was Longwater's transition nurse, Suzy. Suzy was based in Longwater's R&D department.

On arrival at the Neurology Department, children and their families were greeted with a waiting area that seated up to eighteen people. Families were required to book-in with the receptionist who would then retrieve the patient's paper-based clinic files and alert clinicians of their arrival. The waiting area, designed with children in mind, was filled with large colourful plastic tubs that contained toys, books and magazines. In a corner of this waiting area, stood a vending machine that offered crisps, chocolate and soft drinks. The walls were decorated with frescos of a well-known cartoon mouse, they too were brightly coloured even if they were beginning to look a little worn and dated. During my visits, this waiting area was often hectic, with a cacophony of sounds ranging from children laughing to children crying, parents telling children to be quiet or to keep still, toy trucks being banged along the floor or plastic building blocks being scattered onto a table. It was the quietness that came only after the majority of patients

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[26] In using first name designation for all participants except the doctors, reflects how these participants referred to each other in the field sites.

had gone home that made me reflect upon just how busy, lively and colourful this hospital department was during the daytime.

Children and their families were called into their clinic consultation by the health professional that they were visiting. The clinic rooms were situated along a long, narrow corridor and were all positioned on the outer edges of the main hospital building. This meant that each clinic room had a window, which faced out onto either a car park or a small grassy courtyard. The windows allowed natural light to fill the large rooms for most of the day. These clinic rooms were spacious enough to hold an examining bed, desk, stacked chairs for large families and more toys, with some rooms even housing small play tables. Similar to the waiting area, the clinic rooms were also bright and colourful. The walls were adorned with various posters of epilepsy first aid, info-graphic style posters of antiepileptic drugs [AEDs], or cartoon illustrations of the human brain. In one room, there was a large foam stress ball in the shape of a brain with vivid colours representing four anatomical lobes.

At the very end of the corridor was the Neuropsychology Assessment room. This was where the neuropsychologist Sara who, although not ‘home-based’ in the neurology department, carried out most of her work (such as undertaking consultations and assessments with patients). This room consisted of a set of two adjacent rooms that were divided by a door and a one-way mirrored wall for psychological observations. In a separate part of Longwater Paediatric Hospital, a brisk 10-minute walk away, was the R&D department. This was away from the public’s view and was only accessible to staff via a key card security system. The R&D department was a corridor of eight generic office type rooms containing desks, computers and filing cabinets.

Located less than five miles away from Longwater was Carden Adult Epilepsy Services. Carden provided specialist epilepsy care servicing on a regional (and at times national) basis. It was housed within a larger neurology department, which provided ongoing medical care for multiple conditions including dementia, Parkinson's disease and motor neuron disease. Carden was the workplace of the adult ENS's Tina, Sandra and Paula and the adult consultant neurologists' Drs Barton and Keegan. When entering Carden, patients were usually met by an administrative assistant who would direct them to book-in to their clinic appointment via a touchscreen computer before taking their place in the large open plan waiting area of eighty-six seats. Although there was a reception desk that was continually staffed during operating hours, there was little need for patients to approach the receptionists since they would have already signed in via the electronic booking-in system. In this sense, there was little to no staff-patient interaction prior to entering the clinic room to see the doctor or nurse.

Since Carden's waiting area catered for a variety of neurological conditions, the age range of patients here was broad - young adults with their parents sat next to elderly patients with their children or carers. This waiting room was busy and, similar to Longwater, was also noisy. This noise, however, was different. Rather than the loud and concentrated sound of a small number of children playing or being scolded by their parents, the sounds that perpetuated here were more akin to a persistent soft buzz of hushed conversations from many people. The walls were bare in contrast to the children's hospital; save for a few text-heavy posters or laminated signs asking the public to 'Respect our Staff' and to put an end to 'abuse of NHS staff'. There were numerous TV screens positioned high on the walls of the waiting area. These screens alerted patients when they were ready to be seen by the clinicians by displaying their name and room number. Unlike Longwater, there was less staff-patient interaction until people entered the clinic room. Not every clinic room in Carden had a window. This meant that rather than natural lighting, these rooms relied on harsh, artificial ceiling lights. There were no posters on walls or toys in corners, the rooms were notably smaller than the children's hospital - with space for two or (maximum) three seats in addition to seats for the clinicians. The desks in Carden formed a barrier between patient and clinicians, unlike in Longwater where the open space meant there was no physical obstacle in the way of clinician-patient interaction.

The difference between Longwater and Carden was not simply that of paediatric and adult medicine. The environmental and spatial contrasts contributed to a feeling of stark divergence between the two settings. Whilst Longwater felt lively, open and playful, Carden appeared more stifled and sombre, with limited social interaction. Whereas Longwater decorated its walls with colourful images and informative clinical posters, Carden's walls were almost bare - save for the odd piece of blue tack and posters warning patients not to abuse employees. These physical and visceral differences are what a young person and their families encounter when they transition between these services.

Since the TEC was a joint endeavour between these two separate NHS Trusts, the practice of transitioning encompassed a loosely defined field site. After leaving Longwater, a young person would attend the TEC for two or three consultations. These consultations would have both a paediatric and adult neurologist in attendance. At the discretion of the clinicians, young people would 'graduate' into Carden's adult-only epilepsy service and no longer be seen by a paediatrician. Despite there being the specified TEC, transitional care also took place outside of this clinic. Additionally, I encountered a variety of professionals who were involved in transitional research and policy development within universities, community centres and NHS management departments. Furthermore, the practice of transitional healthcare extended to include not only varying places and peoples, but also things and events, such as care practice guidelines, local Trust and national policies, and a mutual research agenda across Longwater and Carden that aimed to improve their joint service. Moreover, as transition was not only a clinical concern, the field site extended into areas of social and domestic care, making transition not solely a clinical concern but also a social and private one.

Participants

Since epilepsy transitional care was a rather specialist concern at the field sites, I included all the Longwater and Carden health professionals that I knew to be involved in this area of care. This resulted in a very small group of clinical professionals whose work focussed on this care practice. However, as I came to spend more time in the field, I found there to be other non-clinical professionals who, although not directly involved in transitioning young people with epilepsy, still had some significant bearing on how transitional healthcare was practiced (this included transition nurse Suzy and filmmakers Ade and Nadia [see Table 2 for further details]).

Since the transfer of patients into the TEC did not happen at any specific age (rather it was based on the clinical judgment of a patient's health professional), I included patients (along with their family members/carers) who the health professionals described as being 'transition-aged youth'[27]. My patient sample included young people from the ages of 12 years to 21 years. Seven of these young people were

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[27] In my experience, 'transition-aged youth' often meant those paediatric patients whom health professionals deemed mature enough to be considering transition. For example, Penny the paediatric ENS told me that 'there are some twelve-year olds who understand transitioning better than some fifteen-year olds. We just approach the subject when it feels appropriate'.

registered as TEC patients in Carden, whilst the remaining five patients were registered at Longwater [see Table 1 for further details]. For these paediatric patients and their families, the issue of transition was a familiar one – often via discussions and/or leaflets given whilst attending clinic. However, they were yet to make the formal move into the TEC service. To present my findings in the following data chapters, I use family cases to tell ethnographic stories regarding the complexity of transitioning with ELD. The cases that are presented in each story were selected for their typicality, in other words, they usefully exemplified particular aspects of the transition process across the data as a whole. In total 12 family cases took part in the study, which produced a large group of informants that consisted of parents, siblings, professional carers and young people themselves [see Table 1]. Furthermore, I was concerned with the transitional care of those young people with a co-morbid diagnosis of severe cognitive disability. For this criterion, I relied upon the judgement of the health professionals to introduce me to the patients they felt best represented this population[28]. Tables 1 and 2 provide overviews of the participants. All participant descriptors (including names, places and job titles) are pseudonyms to protect anonymity whilst attempting to maintain integrity to the data.

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[28] The term learning, cognitive and intellectual disability are somewhat fluid classificatory terms. In choosing which young people to include/exclude I decided to make in-situ decisions based on parent's and doctor's concerns about adaptive functioning as the young person moved into adulthood. It was this population, who will not reach independence away from twenty-four-hour care, that I was committed to exploring rather than those with a specific and often arbitrary diagnosis.

Family	Young Person, age*	Diagnosis History**	Transition Status*	Associated health/social care professionals	Living status
The Hills	Sally, 19	Epilepsy Leukodystrophy Severe Learning Disability	TEC patient	Dr Roberts Dr Barton	Living at home with mother Jillian and father Alan.
The Holbrooks	Daniel, 17	Epilepsy Autism Spectrum Disorder	Longwater patient	Dr Roberts Penny	Living at home with mother Gail and father Mark.
Bates	Jason, 21	Epilepsy Global Developmental Delay	TEC patient.	Dr Keegan Dr Lewtas Claire Nic	Living in supported accommodation with full time carers, Nic and Clare.
The Murphys	Maddy, 17	Epilepsy Autism Spectrum Disorder (high functioning)	TEC patient	Dr Roberts Dr Barton ENS Sandra	Currently living with mother Denise and father Christopher, yet applying to live independently in a government funded supported accommodation.
The Hoopers	Maya, 19	Epilepsy, Acquired Brain Injury (at birth) and Global Developmental Delay	TEC patient	Dr Lewtas Dr Keegan ENS' Tina & Sandra	Living at home with mother Gwen and father Paul.
The Simpsons	Carlton, 19	Epilepsy Severe learning Disability, Cerebral palsy Autism Spectrum Disorder	TEC patient	Dr Keegan Dr Lewtas	Living at home with parents, including mother Dani, and 6-year old brother. Also had support workers for at least 10 hours per day.

The Browns	Kate, 18	Temporal Lobe Epilepsy Autism Spectrum Disorder	TEC patient	Dr Roberts Dr Barton	Living at home with mother and grandmother***.
The Bambers	Amy, 12	Epilepsy Angelman Syndrome Scoliosis	Longwater patient	Dr Roberts Penny	Living at home with mother, father and 23-year-old brother.
The Williams	Isaac, 19	Epilepsy ASD	Longwater patient	Dr Roberts Eve	Living at home with mother Mellissa and two younger siblings.
The McCarthys	Carys, 17	Epilepsy Severe Learning Disability	Longwater Patient	Dr Roberts Penny	Living at home with mother, father and two younger sisters.
The Irvings	Sophie, 16	Epilepsy ASD	Longwater patient	Dr Roberts Eve	Living at home with mother and father.
The Deweys	Hope, 18	Epilepsy Severe Learning Disability	TEC patient.	Dr Keegan Dr Lewtas ENS Tina	Living at home with mother, father and 16-year-old sister.
Notes: *At time of first meeting; **Taken from patients medical file and interview with parents; ***For readability and consistency, I have not provided pseudonyms for parent/carer participants if they do not feature in the data chapters.					

Table 1. Young people and their families

Health/care professional	**Job Title, Location**	**Other activities**
Dr Roberts	Paediatric Neurologist, Longwater and TEC 1	Original developer of the TEC.
Dr Lewtas	Paediatric Neurologist, Longwater & TEC 2	-
Penny	ENS, Longwater	-
Eve	ENS, Longwater	Original developer of the TEC. Lead on Transition Animation Project.
Sara	Clinical Neuropsychologist, Longwater	Transition Animation Project. Longwater Audit of epilepsy transition services.
Suzy	Transition Nurse, Longwater	Project Lead-Trust wide transition developer.
Dr Barton	Adult Neurologist, Carden & TEC 1	-
Dr Keegan	Adult Neurologist, Carden & TEC 2	-
Tina	ENS, Carden	TEC nurse up until 1995
Sandra	ENS, Carden	-
Paula	ENS, Carden	-
Ade	Filmmaker, Longwater	-
Nadia	Filmmaker, Longwater	-
Clare	A private social care company director	-
Nic	A private social care support worker	-

Table 2. Health/care professionals

Recruitment and Access

To approach young people and their families, clinical staff helped to initiate contact between the families and myself. During clinic appointments, the staff asked patients for their consent on my behalf (consent for me to observe the consultation as well as briefly introduce the study). I then proceeded to ask families if they would like to receive a study information pack[29] [see Appendix 1 for sample information sheet and consent form]. If they agreed, this pack also contained my contact details and I requested permission to contact them within a week with a follow-up phone call. The families who agreed to be interviewed and/or observed were recruited into the study [see Table 1]. Throughout fieldwork, I continued to approach new families until I felt that I had reached a saturation point – a point when, during preliminary analyses, no new insights were emerging from the data. This decision to stop approaching new families came nine months into twelve months of fieldwork. I felt confident doing this since, rather than aiming to capture a wide range of experiences (although I think this research does do that), I set out to gather in-depth stories of transitional care and moving into adulthood.

My approach to inviting health professionals to participate was more opportunistic. This was because, between Longwater and Carden, there was a small group of professionals that had both an interest in epilepsy and worked in transitioning patients. I had initially contacted Dr Roberts and ENS Eve who, in turn, eventually became my key gatekeepers for this study and facilitated further introductions with all other health professionals. They also played a crucial role in providing me with serendipitous

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[29] Information packs contained a letter of invitation, study information sheets, reply slip and pre-paid SAE.

opportunities, for example informing me of any clinical or research activities that they thought I may have been interested in.

Ethnographic Observations

Ethnographic fieldwork included over 200 hours of observation. This comprised of clinic-based activities, including: TEC patient consultations; nurse-led consultations (paediatric and adult); neurology team meetings and research team meetings in both Longwater and Carden. Observations away from the clinic included: a summer animation project (wherein young people were invited by the paediatric epilepsy team to design and film a short animation about their transition healthcare experiences); attending relevant epilepsy health professional meetings and conferences; attending day trips with a supported-living care company; visiting learning disability arts workshops; disability research seminars; and, visiting the homes of patients and their families.

In the early stages of fieldwork, I initially observed weekly epilepsy clinics (paediatric, adult and TEC clinics). This required attending either morning or afternoon clinic sessions and observing as health professionals conducted their consultations. These clinical consultations included a variety of follow-up (patients already known) and newly-diagnosed patients. During this clinic-based period – at this stage, I was attending clinics 4 days a week – health professionals informed me of all upcoming activities that they thought would be useful for me to observe (such as the summer animation project). They also alerted me to an epilepsy professional network, which brought together clinicians and researchers from across Northern England. Through this network I was able to both participate in and observe the regional epilepsy research meetings.

Away from the world of health professionals, clinics and formal meetings, I was able to observe social care through a supported-living care company. This involved me ‘shadowing’ care workers Nic and Clare as they supported their clients on a daily basis. Unlike the clinical world, where I often needed permissions or registration to access what it was that I wished to observe, the world of supported-living care was much more informal. I participated in day trips out to forests and parks, lunches in a pub as well as observing daily morning and bedtime routines. I was also invited to an art workshop for young people with learning disabilities. Furthermore, I was invited to attend Sally Hill’s school transition meeting as well as a monthly learning disability parents support group. These occasions were largely serendipitous and occurred due to the wishes of parents and carers who wanted me to see first-hand the variety of activities that encompassed caring for a young person with ELD.

Fieldnotes

All observations were recorded into fieldnotes. These fieldnotes attempted to not only capture what was said but also the action that took place in the observed event, and to emphasise the context and background of all observed activities. My primary aim, then, was to observe as much activity as possible and to translate that activity into the fieldnotes[30]. I found it best to split the writing of fieldnotes into two stages. Firstly, at the time of observation, I would use an A5 notebook to write down my jottings ‘snatched’ in the course of action (Hammersley & Atkinson, 2019). These would comprise important phrases, keywords, concise notes on action, and any other elements that seemed to be of importance to the situation. These jottings were to be

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[30] In order to record observations and informal interviews for the production of fieldnotes, I was initially guided by the works of Burawoy (1991), Okely (2007), Emmerson, Fretz and Shaw (1995) and Sanjek, et al. (1990) as well as reading ethnographic studies across disciplines.

used later that day in order to complete the second stage of writing fieldnotes. The second stage involved writing the fieldnotes ‘proper’. I used the initial jottings to trigger a string of memories - enabling me to write a more detailed reconstruction of the events. The process of writing fieldnotes was not a matter of writing down the ‘fact’ of what happened but rather the writing itself was an active process involving my own interpretation and sense-making. Consequently, what was produced was a textual document with specific purposes, sensitivities and concerns, in other words it was specific to my interpretation of events (Emerson, Fretz and Shaw, 1995).

Since I was also interested in the non-human elements of human interaction, my fieldnotes included reflections on what non-human things made this situation possible (for example digital or paper-based clinic notes, arrangement of furniture, safety harnesses used for young people in public spaces). In other words, I documented what material artefacts were relied upon to facilitate an event. My aim in doing so was to capture the interaction between people, devices, documents, and physical spaces.

In organising and managing my fieldnotes, each was dated and coded according to a referencing system which detailed event type and associated keywords. Each fieldnote included three sections: (i) *methodological notes* outlining time/date, duration, location, how this event was facilitated and by whom; (ii) *descriptive notes* with in-depth descriptive details of the observation in a chronological order of events, and; (iii) *initial analytical ideas* noting anything that related to past literature, theoretical ideas, emergent patterns, or contradictions. Both the descriptive and analytical notes ended up forming the foundation for the final writing up phase of the thesis.

Ethnographic observations allowed me to observe practices and interactions surrounding transitional care for young people with ELD; whether this be formal practices such as clinic consultations or informal interactions such as bedtime routines. Observations and fieldnotes enabled me to describe the kinds of practices that get done when caring for those with and without learning disabilities, what was said to some patients and what was not said to others (for example, family planning information) and it also enabled me to observe the relationality of people and things surrounding transitional care (such as hospital designs for children and adults).

Secondary Sources – Documents, images and archives

During fieldwork, I collected any material artefacts that had a direct bearing on the practice of ELD transition. These secondary sources of information and material artefacts, such as policy documents, patient information leaflets, photographs and archives, provided important contextual information concerning the problem under study (Hammersley & Atkinson, 2019). Moreover, these documents helped me to add specificity to the detailed stories featured in the data chapters. Furthermore, from December 2013, I began sourcing archived information regarding Longwater and Carden. This information was held at national public archives and a small collection of historical patient information leaflets were available through both Longwater and Carden's on-site libraries. This archival information served to inform my knowledge of the field sites and the development of the neurology departments from the 1980s to 1990s[31].

With the consent of parents and health professionals, I read over copies of young peoples' medical files and outpatient clinic letters. These were letters that documented patient consultations in Longwater or Carden and were addressed to patients/families

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[31] This archived information proved crucial in writing Chapter 3 where I trace the development and implementation of the TEC.

and their GPs. These documents contained information including medical histories, diagnoses, any treatments or medication, information on dates of transition and time taken from transition referral to first consultation in the TEC. This data served to map patient encounters with the healthcare system, from attendance at hospital to any surgical procedures they had undergone.

I also collected documents, both official and unofficial, that related to the local practices of transitional healthcare. This included a transitional healthcare policy that was in its draft stages, as well as patient transition information packs and a transition guide that was published by national charities and made available to patients through health professionals. These documents proved valuable for understanding how the hospitals communicated with patients and family members, as well as expressing their expectations concerning what patients ought to be able to do at what stage of their transition to adult services. With permission from all parties, I took photographs of the artwork from the summer animation project and of day-trips[32]. Photographs and videos also became part of the data gathering tools as fieldwork unfolded. Photographic and film data were not something I anticipated being relevant, but they became increasingly useful serving as visual reminders for when I was writing up fieldnotes. Finally, throughout this study I followed transitional, adolescent epilepsy and learning disability care in the media (from 2013 to 2018) and identified several cases that addressed the research questions; doing so provided a sense of public debate and opinion related to the present study.

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[32] Photographs were only ever taken of objects such as notes people had written or paper-based documents that I was not able to keep or reproduce.

Interviews – Narrative and Semi Structured

In addition to ethnographic observations and the production of fieldnotes, I conducted two types of interviews. Narrative interviews were used with the 12 parents and carers of young people with ELD and semi-structured interviews were used with health professionals [see Table 3]. In total, I conducted 39 pre-arranged audio-recorded interviews. This included 21 narrative interviews with twelve families of young people with ELD (12 primary narrative interviews, 6 secondary face-to-face semi-structured interviews, and 3 secondary semi-structured interviews over the phone) and 18 semi-structured interviews with twelve health and social care professionals.

Family/Participant	**Narrative Interviews Phase 1**	**Narrative Interviews Phase 2***	**Semi-Structured Interview #1**	**Semi-Structured Interview #2**	**Informal Interview****
Families	12	9	-	-	28
Health/Social Care Professionals	-	-	18	6	36
Notes: * 6 of these were face-to-face and 3 of these were over the phone. ** Informal interviews were not audio recorded but transcribed by hand and were often opportunistic.					

Table 3. Interview log.

Ethnographic observations were also extended to all interviews. For example, during interviews I would make fieldnotes of what I observed in action (e.g. during one interview, Denise [mother to 19-year old Maddy] showed me family photographs) rather than simply recording what was being said to me via the interview. As part of my ethnographic approach, I also made use of opportunistic conversational/informal interviews with every person that I came into contact with[33]. Primarily used within the initial weeks of fieldwork, informal interviews proved a useful way of settling into the observer role. This involved me 'hanging around' (Whyte, 1943) with the healthcare professionals, shadowing them as they worked. Largely relying on active listening, memory and brief jottings, informal interviewing allowed me to get to know the participants and for them to get to know me.

Narrative Interviews

Narrative interviewing involves a design that focusses on the elicitation and provocation of storytelling in contrast to more structured interviewing procedures, (i.e. semi-structured interviewing). Narratives, as well as being a way of temporally organising experience, are also vehicles for moving cultural and social values, mores and morals (Bruner, 1986, 1990; Riessman, 2008; Wengraf, 2001). Mishler (1986a) states that by asking interviewees to connect their responses into a story, narrative interviewing 'brings out problems and possibilities of interviewing that are not visible when attention is restricted to answer-question exchanges.' (pg. 67). This unrestrictive approach allowed interviewees to discuss what is important to them. Furthermore, I considered this to be an ethical choice when interviewing around the potentially sensitive subjects of disability and care.

For each of the 12 families, it was the parents who participated in the primary narrative interviews. This was because the young people in the study were largely verbally non-

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[33] Bernard (2011) characterises informal interviews by a 'total lack of control or structure' (pg. 211). However, this is not to diminish the effort and intentionality that lies behind these conversations. The importance of informal interviews is best articulated through Doc, in William F. Whyte's classic ethnographic study, *Street Corner Society* (1943). Doc, acting as Whyte's primary informant, advises him against rushing in with interrogation. Answers can be gained through simply 'hanging around' with the group, without ever explicitly asking the questions.

communicative or had limited capacity to participate. However, there were three occasions when a young person was present during the interviews and would participate, with the help of their parent, as fully as they could.

Adopting the biographical narrative interview guidance of Wengraf (2001), I adapted a two sub-session framework as a model of narrative interviewing [see Appendix 2 for interview guides]. The first narrative interview involved asking a single question designed to elicit the full narrative:

> I would like you to tell me the story of when you moved from the children's hospital over to the adult hospital so far, include all the events and experiences which are important to you. Start wherever you like.

During the storytelling, I would jot down phrases or keywords that I intended to revisit after the initial narration. Only if necessary, the interviewee was encouraged to answer this question with reassurances and prompts. The initial narration continued until the interviewee indicated that they had no more to say. Interviews were transcribed as soon as possible in order to undertake multiple readings of the transcripts. Where possible, second interviews were held with families. Based on their initial narration, preliminary analytical ideas and crude inferences were made in order to structure the second interviews.

In analysing the narrative interviews, I was guided by the work of Riesmann (2008) to understand the stories within the data. I first reviewed all narrative interviews and gathered examples of stories. Borrowing from Mishler's (1986b) policies for analysis (an adaptation of Labov's [1967] structural narrative analysis), I chose to identify the following features within my interview transcripts: the orientation of the story (which provided relevant background information); any complicating actions within the story (event/actions that disturbs norms and provokes a central narration); the resolution (following climax, conveys the result of the action); and any evaluation (the speaker highlights the point of the story)[34]. Once I had identified the narrative accounts, I began a more meaningful analysis of its content. Using Mishler's (1995) typologies of narrative interpretation, I searched for instances that exemplified the sociocultural context of what was being said along with identifying what the participant frequently referred to or reiterated as being important to them[35].

Semi-Structured Interviews

For interviews with healthcare professionals, I used a semi-structured approach. The interview guide aimed to prompt accounts of their practice - such as descriptions of their daily work or opinions of working with teenagers. In comparison to narrative interviews, these interviews were much shorter and, at times what I had intended to be one-to-one interviews, would become impromptu focus groups of up to three individuals at the request of the interviewees. Since interviews with the professionals were conducted during their working days, they saw this approach as being more time efficient for them. This occurred with the three adult ENS interviews over two interviews.

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[34] I abandoned Labov's (1967) suggestion of searching for abstracts and codas within narrative transcripts since these were often single phrases and the narrative was still intact without them. Furthermore, although a structured approach allowed me to organise the narratives with the ability to cross compare each of the components across individual stories, there were limitations. For example, I found difficulty in determining a resolution in all of the narratives. This may be due to there not always being a resolution that the interviewees offered, such as transition was often discussed as ongoing and the resolution was yet to unfold.

[35] For example, since my research aims were concerned with contextualisation, understanding the social and psychological context of participants stories was critical, however in a topic that is temporally ordered (such as transitional healthcare), it was important to consider temporality and the passage of moving from childhood to adulthood.

The concerns raised within the literature review became a topic guide for the semi-structured interviews and was developed before fieldwork had commenced [see Appendix 2]. The guide was used for all interviews with professionals. The interview guide aimed to elicit the following: descriptions of individual roles; descriptions of daily work; opinions of transitional care; opinions of MDT transitional care; perceived barriers or enablers to transitional care, and; any experiences they may have that related to transitional care. Interviews with professionals were conducted at various stages throughout the fieldwork. Interviews with Sara (paediatric neuropsychologist) and Clare and Nic (supported-living staff) took place in their homes and outside of their working hours. All other interviews were conducted in the interviewee's place of work and during their working hours. Semi-structured interviews were audio-recorded and transcribed. Participants would often express further insights after the audio recording had stopped. On these occasions, I would ask if they were happy for me to make note of what they had said for inclusion with the interview transcript. Only on one occasion did somebody decline this.

It is also important to note that interviews are not without their limitations. Adopting the notion of a 'dance of expectations' (Miller & Dingwall, 1997), for example, interviewees may wish to present themselves as competent members of their respective professional communities. As such, I do not take interview data to be unproblematic accounts of experience. Therefore, observing what people do alongside what they say affords a more contextualised approach to understanding social practices. Consequently, when analysing professionals' accounts of transitional healthcare, I approached them thematically looking for frequently occurring content, jarring topics or significant opinions.

Analysing Ethnographic Data: Pulling it all together

Ethnographic analysis is often described as an iterative and open-ended process (Agar, 1980). This approach is crucial for an ethnographic phenomenological inquiry that is committed to describing phenomena as it is experienced by the people within the study. Ethnographers begin to interpret data by starting with broad analytical ideas or hunches that are then further explored, expanded or discarded as time goes on. Consequently, themes, patterns and significances impose themselves upon the researcher, rather than the other way around (Okley, 2012). Following this, I acknowledge that from research design to research write up, this study has involved a simultaneous moving to and from, as well as around, activities of creative and systematic analysis. To adopt an iterative approach is not to completely forgo all other approaches to analysis; rather it acknowledges them as analytical *exercises* that are just one way for the researcher to work with and through data.

In addition to the more systematic exercises of narrative and thematic analysis of the interviews described above, I considered the concept of creativity to be crucial when pulling together my gathered materials into one coherent ethnographic account. Notions of creativity are often abandoned in methodological accounts of analysis (Koro-Ljungberg, 2015), however, I have found it to be a useful concept to work with when considering that ‘thinking analytically’ permeates all aspects of the research process. Approaching analysis as an ongoing creative (rather than prescriptive) process recognises that the separation of data collection and data analysis is an artificial one (Geertz, 1983)[36]. Consequently, rather than identifying one particular period that was dedicated to data analysis, I suggest that data analysis began almost immediately during fieldwork. Analytical thinking occurred within (and through) activities such as designing interview schedules, reading the transcripts and writing up jottings into fieldnotes proper.

Furthermore, critical to my analysis was wider reading outside of my research topic. Data was read alongside a wide variety of texts including academic and literary genres. Reading, especially reading widely, allowed for the provocation of ideas for observation and various insights and articulations to work with. I also took seriously the act of writing as a way of interpreting data and relied heavily upon keeping a research journal throughout the PhD and memoing during fieldwork. In her book *Alive in the Writing* (2012), anthropologist Kirin Narayan supports this idea that ethnographic writing is itself an analytical strategy, stating that ‘The process of writing invariably brings discoveries’ (pg. x). It was within my journals and memos that I undertook the more recognisable aspect of qualitative analysis, namely coding and categorising of themes, patterns, in vivo terms etc. Therefore, journals served the purpose of recording, developing and modifying any emerging theoretical ideas that occurred as I engaged with fieldwork, literature, transcripts and fieldnotes.

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[36] Attesting to the importance of creative and iterative analytical approaches, Atkinson (2013) claims that in contemporary ethnographic analysis emphasis is placed on more formulaic techniques of ethnographic data collection and management. Here, he explicitly refers to grounded theory, as a method that falsely passes for the work of analytical thinking. This, Atkinson claims, stifles the creative work done by ethnography. Similarly, anthropologists have debated whether ethnography demands such an ‘experimental moment’ in analysis and writing (Marcus & Fischer, 1986; Clifford & Marcus, 1986; Rosaldo, 1993).

Ethics and Reflexivity

Conducting ethical social scientific research is closely linked to a commitment to reflexivity, a practice wherein social scientists subject their own research approach to the same critical analysis that is used to examine their topics (Green & Thorogood, 2014). This slightly differs from the 'ethical concerns' outlined in the formal application procedures which permitted study within the NHS. There were some ethical concerns that arose in the course of fieldwork that were not so easily accommodated by formal ethical procedures, which were largely concerned with informed consent procedures, causing no harm and maintaining anonymity. This reflects a discrepancy between ethics in practice (the everyday dilemmas that are confronted by the researcher during fieldwork) as opposed to the procedural ethics that require researchers to apply to various governing bodies for approval and access to study sites and participants (Guilleman & Gillam, 2004). In the final section of the methodology chapter, I outline the ethical considerations that arose prior to and during fieldwork, followed by a reflexive account of my research approach and its findings.

Ethical Considerations

To begin fieldwork, a variety of ethical and access applications were required; notably an NHS Research Ethical Committee [REC] approval and local site NHS Research and Development [R&D] approval. The study gained ethical approval from Haydock REC in August 2014 and NHS R&D approval from the two NHS sites in September 2014 (see Appendix 3 for approvals).

Informed consent was gained by handing all participants the study information sheets as well as clarifying any concerns they may have had. Once they were informed of the study and their role in it, then they would sign the consent form. However, there were occasions when I found difficulty applying the stringent principles of informed consent to the participants. For example, before any observation, I would introduce myself to the person in charge and explain my intentions[37]. These points reflect Bosk's (2001) observation that conforming to the rigorous steps toward gaining informed consent is often disruptive to interaction, may increase self-consciousness in the participant and would be 'socially peculiar'. As such, I recognised this procedure of obtaining informed consent as something that may have overburdened prospective participants, and thus potentially reduced research participation.

Consequently, in addition to the institutional ethical concerns, the ethical considerations that I found most pertinent to the study were those of representation, minimising harm and disruption, and protecting anonymity. Research into disability is often highly ethicised, politically concerned and is often undertaken with an insider perspective (Rapp & Ginsburg, 2013). As I will go on to further explain, my insider insights into issues of care and disability were limited. I had not experienced any disability myself nor had I personal experience of caring for those with disabilities outside of the capacity of paid employment. Therefore, my major concern (as a young woman without disability or chronic illness) was how I was to represent the experiences of others when their encounters with health and society would be markedly different from my own. In this way, ethnographic research was an ethical methodological choice. With a focus on exploration of a practice, my study allowed

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[37] For example, upon informing the leading consultant or nurse of my intentions, they then 'informed' patients and family who entered the room of my purpose in being there. I write 'informed' because I was often described as being a student here to observe the clinic. Although not false, it was also not a full disclosure of my intentions as a research student. Not all families could be certain of the true capacity of my being there. I agreed with the health professional that there was no time or sufficient reason to burden families with heavy paperwork regarding consent forms unless they were to become participants in the study.

for issues raised to be participant-led and initiated from in-situ observations[38]. As fieldwork continued, I found myself relying on some participants more than others. The ENS Eve who, acting largely as the study's main gatekeeper, was willing to engage with my study more than other health professionals were. In response to this potential bias, I would continually question whether I had begun to form any moral obligation to the opinions of certain participants and reflect on my interpretation of their responses.

Secondly, I had to consider how I was to minimise participant harm since interview topics of health and disability were potentially upsetting. This is where narrative methods became invaluable. Narrative interviewing allowed for open-ended discussions, therefore minimising any harm or distress that may occur. Similar to the notion of harm, there was the consideration of intrusion or disruption. In my role as an observer, there were times when I became acutely aware of how uncomfortable and suspicious being observed could make participants feel. For example, when observing health professionals at work (especially during the beginning stages), I often felt that I was obstructing the natural flow of their practice or influencing their clinical interactions by simply being present. This was particularly evident when, after months of getting to know each other, one of the ENS' confided in me that she had initially thought I was observing her in relation to her clinical training assessment. In response to this, I found myself engaging in a sort of Goffmanian impression management (Goffman, 1959). I would often agree with comments and opinions of participants to continue the flow of information. Often termed as rapport-building (Green & Thorogood, 2014), this approach required what at times felt like a degree of

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[38] Furthermore, it can be argued that rather than attempting to represent people, this study of a clinical practice is representing a set of institutional arrangements which shape people's experience of care.

manipulation that allowed access to opinions, experiences and stories of participants. This was an ethical concern that I reflected on every day of my fieldwork.

Another ethical concern that I experienced throughout the fieldwork (and particularly during writing-up of the findings) was the principle of maintaining anonymity. Borrowing from Bourdieu (1999), social science research is often described as making private worlds public, with the potential of shedding light on aspects of private worlds that participants may find undesirable. The assurance of anonymity is a step towards remedying this. To respect preference for anonymity, I have used pseudonyms for participants and all research settings. Despite this, participants (should they read my account) may therein recognise themselves. I have therefore opted to change further minor details and key attributes of participants in all my descriptions[39], when not directly significant to the findings.

Reflexively researching ELD Transitional Care

I now turn to provide a reflexive account of my experience of this study. My purpose in doing so is that the reader may make their own assessment as to how my personal background has come to shape this study. Within empirical phenomenology, Schutz (1932) explains that data interpretation must be grounded in the first-order constructs of the participants (their own meanings and words) followed by the second-order constructions of the researcher. In other words, my phenomenological ethnographic approach is one that recognises that my own background comes to bear upon the research practice and findings. The concept of reflexivity acknowledges this and

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[39] Key attributes include gender or specific job titles. Additionally, if views were expressed by multiple participants of a similar standing (i.e. similar health professionals) I have chosen to consolidate these opinions into that of one person. This is for reasons of providing a more coherent account and also to protect anonymity.

rejects the idea that social scientific research can be conducted as if separate from them (Hammersley & Atkinson, 2019; Gluck & Patai, 1991). As with many pieces of social scientific research, this study aims to contribute to a body of empirical knowledge but is simultaneously a deeply personal pursuit. It is personal because, within such studies, the primary research instrument is the researcher and consequently partiality and bias become intrinsic to fieldwork, data analysis and presentation of findings (Okley, 2012)[40]. In this section, I have focussed on providing a reflexive account that concentrates on my own intellectual background and expectations. This was important for me since fieldwork involved going into a setting where hierarchal professional and intellectual boundaries were commonplace. Therefore, it is important to discuss how I engaged with this intellectual domain of biomedicine, how I was challenged by it and what I hope my research can bring to it.

The research question that I undertake in this study could have been approached from a variety of settings such as schools, the workforce, or the community; however, I chose to look at transitioning to adulthood for young people with disabilities from the domain of clinical practice. This decision was based on two reasons; first, and as shown in the literature review, there is increasing public and clinical attention on adolescent healthcare and, second, I was already familiar with this clinical practice. I first entered the world of transitional healthcare as a research assistant on a separate project at Longwater Paediatrics in 2011[41]. I came to this role from a largely

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[40] I do not view this partiality as a limitation of social science, but it becomes incumbent on researchers to situate their biases and link them to a body of theory and personal history in order to contextualise the research findings and guide readers through them.

[41] In this post, my role included recruiting participants into a cross-sectional study that examined knowledge of epilepsy in patients and their families, as well as assessing IQ, levels of depression, anxiety and resilience. These measures were intended to highlight what services (specifically psychological services) adolescent epilepsy patients needed to successfully transition into adult care.

positivistic background in psychology with specific interests in cognition and neuropsychology. During my time in this role, I became aware of two issues. The first was that when administering research questionnaires, young people and their parents would often provide significant insight into their healthcare experience that was beyond the remit of the questions. Methodologically speaking, there was no scope for analysing these interesting and sometimes contradictory accounts regarding transitional healthcare. My second issue was the explicit exclusion of young people with a learning disability, or specifically those with an IQ of below 70. This struck me as a strange exclusion since there was a high prevalence rate of young people with epilepsy who also had co-morbid learning disabilities or difficulties. During recruitment, I frequently encountered young people who had a learning disability that excluded them from participation yet were cognitively able to complete the tests. Nevertheless, sticking rigidly to protocol, these young people were not permitted to participate.

Furthermore, during my time as a research assistant, I could not help but become aware of the painful contradiction that rested at the heart of the transition message. I increasingly felt that the underlying rhetoric of transitional healthcare was about betterment and self-improvement, urging young people to develop as good and compliant patients, in order to become a ‘productive member of society’ (D'Agostino, Penney, & Zebrack, 2011). Yet young people with severe learning disabilities were unlikely to become completely independent as they moved into adulthood. How were they and their families experiencing the transition journey when they were faced with such betterment sentiments? I began to question for whom the transition agenda was benefitting.

At the centre of my study is the question of how institutions engage with groups of people that it deems challenging, for example, young people with long term conditions and learning disabilities. Therefore, I see it as important to point out a particular memory of my half-sister Danielle. Danielle, who is three years younger than me has refractory epilepsy, autism and is nonverbal communicative. Danielle and I were not brought up together, so I do not claim to have any close, personal experience of being around young people with disabilities outside of my work. However, as a child, my siblings and I used to come together at my grandparents' house at various times throughout the year. I remember when Danielle and I, along with our two brothers Calvin and Francis, were playing a game of Pogs[42]. Francis attempted to include Danielle in this game but Calvin (who was the eldest) sighed and said words to the effect of 'she can't play, because she doesn't know how to play'. This led to Calvin giving Danielle a box of colouring pencils and paper to keep her from joining in with the game of Pogs. This upset Danielle and she began to kick, scream and cry when she was repeatedly told to go and colour on her own. We soon found ourselves in trouble. Our grandmother (who had been listening from outside the room) came in, confiscated the stack of Pogs, and said 'If you can't play nice then you can't play at all.' Although we did not intend to hurt Danielle, the rules of Pogs meant that she could not play 'properly'. Eventually, the three of us agreed to play a game of Pogs that included Danielle. However, the game that we played was not the 'real' game but a modified one where the rules of play were abandoned for reasons of inclusivity.

This memory has guided my questioning regarding the social treatment of those with learning disabilities. In the simplest sense, this memory of my siblings could be passed

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[42] Pogs, a variant of milk cap games, was popular with children in the mid-nineties.

over as just an example of child's play - however, despite our age we were very much aware of processes of gameplay (what were the rules, who could win etc.) and each person's capacity to participate in such play (did everybody understand these rules, could they execute 'flips' and 'slams' effectively). This leads to the consideration of the underlying rules and tacit understandings of all social practices, whether in the context of children's games or national healthcare, and what it means for those who do not engage in the rules of play in the ideal ways. In other words, what is it that is said, and what is not said, about disability in the doing of such practices?

My approach to this study is influenced by my having a foot in two worlds regarding my understanding of disability issues. First, there is my personal experience of caring for those with disabilities and mental health issues as a support worker. From these positions, I developed a sympathy and identification with the emerging counter-argument of disability as neurodiversty rather than pathology. Second, I was previously trained in clinical psychological research with its aims of increasing wellbeing and mental health. In short, the two appear incompatible since one promoted self-acceptance whilst the other, self-improvement. This multi-textured and contradictory experience will be nonetheless present in the data chapters that follow. However, I am certain that its impact and my loyalties to the acceptance of neurodiversity will be apparent throughout this study.

In this chapter, I have described my approach to exploring the research questions alongside any practical and ethical issues that emerged during fieldwork. I have demonstrated why a phenomenological ethnographic approach and its constitutive methods allow me to interrogate the practice of transitional care as a social one. What I hoped to have conveyed in this chapter is that in producing my account of this topic, I portray myself, and other social scientists as instruments of interpretation. As such, this chapter is my way of accounting for the ways that I have worked with data in order to elucidate meaning. In the following chapters I present my research findings.

Chapter 4 – Bridging Cultures of Care: The rise, implementation and development of the teenage epilepsy clinic

To introduce the ethnographic field sites and provide a background to the study findings, this chapter outlines the development of the Teenage Epilepsy Clinic [TEC] between Longwater Paediatric Hospital and Carden Adult Epilepsy Services. By documenting the TEC's origins in 1991 and the subsequent development of services since this time, I provide the reader with an understanding of the changes (to both the TEC and the wider Trust infrastructure) that have shaped current care practices; these changes will also provide the background from which my fieldwork can be understood. The account that follows highlights how the work of the TEC is supported by a wider apparatus of government health initiatives, institutional structures, professional roles and statuses as well as medical specialists that collectively function to further substantiate the 'need' for transitional healthcare.

The chapter is organised into two parts. Following a brief overview of the history of adolescent medicine and UK transitional healthcare, part one describes the implementation of the TEC during the 1990s and highlights particular and significant local changes that have, up until the present day, influenced the daily work of the clinic. Finally, in part two I introduce the organisational division of paediatric and adult medicine and how they contribute to the 'transition challenge' through distinctive cultures of care. As I go on to show, the rise, implementation and development of the TEC since 1991 is characterised by a complicated trajectory, wherein multiple changes to the service have taken place. Using the Foucauldian concept of 'heterotopia' (Foucault, 2003; Foucault & Miskowiec 1986) I argue that, rather than a fixed and stable healthcare practice that was fully established within its local Trusts, transitional healthcare was a clinical practice that was itself transitioning and continuing to evolve.

Background to adolescent healthcare

Stemming from the parent specialism of paediatrics, adolescent medicine differs from other paediatric sub-specialisms because, rather than focussing on a specific organ or medical technology, adolescent medicine revolves around a particular age group. Since ‘age group’ is something that will inevitably come to pass, adolescent medicine has struggled to gain what medical sociologists have termed ‘functional autonomy’, or in other words, professional prestige (Elston, 1991; Shortell, 1974). Adolescent medicine has also been criticised for being too general - with emphasis on the emotional, behavioural and psychosocial issues of youth - and not sufficiently grounded in biology for it to be considered medical (Munro-Prescott, 1998). Therefore, up until recent years, it has been considered a sub-specialism of peadiatrics, rather than a specialism within its own right (Alderman, Rieder, & Cohen, 2003; Golub, Arunakul & Hassan, 2016; Jenkins, 2016). Furthermore, adolescent medicine (with its emphasis on the concept of the mature minor) has been criticised by medical ethicists for being a practice that promotes false ideas of maturity, autonomy and individual responsibility; leading to accusations of it being a health practice that attends to the concerns of the state (particular in areas of sexual health regulation), rather than that of the family or of young people themselves (Barina & Bishop, 2013; Partridge, 2013).

Roughly depicted as a mid-20th century development, adolescent medicine has strong North American roots. In *A Doctor of Their Own* (1998), Munro-Prescott extensively traces the sociological history of contemporary adolescent medicine in the United

States. She credits the work of J. R Gallagher[43], at the Boston Children's Hospital during the 1950s, to the formation of the medical specialism. In his own historical account on the origins of adolescent medicine, Gallagher (1982) attributes the precursor to his practice of adolescent medicine to the British Medical Officers of Schools Association [MOSA] - the first group of physicians to focus specifically on school-aged children. The establishment of the MOSA was first referenced in a joint letter written to the Lancet and the British Medical Journal in 1884 (Evatt & Smith, 1884). The letter maintained that there was a need for an organisation specifically devoted to the welfare of school-aged children due to concerns regarding infection control in places that housed a high number of similar aged peoples. As such, the creation of a specialist physician for adolescents grew from a public health concern. This is unsurprising when at the time of MOSA's formation, preventing the spread of communicable diseases such as measles, mumps and influenza was of high priority within the wider British medical community (Gallagher, 1982). Therefore, far from the postulation of biological and psychological difference that I presented in the literature review, adolescent healthcare began as a public health risk management strategy to control infectious outbreaks amongst those young people in close proximity to each other.

However, it is to the Boston Adolescent Unit that the medical community largely attributes the formation of adolescent healthcare, with Gallagher depicted as the first practitioner to create and maintain a clinical unit devoted solely to their 'unique' healthcare needs. The Boston Adolescent Unit was also the first to initiate an academic

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[43] Gallagher went on to form the Society for Adolescent Health and Medicine in 1968. As highlighted in the literature review, Blum et al's (1992) now prominent statement defining transitional healthcare was presented at the 1992 Society for Adolescent Health and Medicine annual conference.

training program of adolescent medicine in 1977. This was followed in the same year by the American Medical Association announcing adolescent medicine as meeting the criteria of a medical specialism (The Society for Adolescent Health and Medicine, 2013). Unlike the United States, the United Kingdom's medical association does not recognise adolescent medicine as an established specialism (Viner et al., 2015; Viner, 2013). To date, the UK medical community has largely focused on the specific area of transitional healthcare rather than the umbrella term of adolescent health or medicine (Iyer & Appleton, 2013). However, with more studies mapping the neurological development of children and adolescents, it is undoubtedly the case that adolescent health has achieved a higher profile in the UK in the last twenty years than in previous decades. The Labour Government during 1997-2010, was responsible for a large number of policy initiatives concerning young people. Three particular examples which have had a significant impact include, the *National Service Framework for Children, Young People and Maternity Services* (2004), the Public Health White Paper *Choosing Health* (2004), and the *Healthy Child Programme* (2009). In addition, 'Teenage transition' was also one of four priority areas named in *Improving Health in Scotland: The Challenge* (Scottish Office, 2003).

The burgeoning interest in adolescent health is more than simply a reflection of medicine's recognition of adolescents as having unique needs. As Munro-Prescott argues, 20th-century concerns for adolescent health and wellbeing grew out of profound reorientations in Western (particularly mid-century American) cultural attitudes toward teenagers; attitudes which responded to the apparent emergence of an autonomous youth culture. As such, the origins of adolescent medicine are tied to social, cultural and ideological reform movements that aimed to intervene in what was perceived to be an increasingly independent and self-alienating youth (Lesko, 2012).

Furthermore, and as previously mentioned in the literature review, later decades saw a scientific and technological expansion through the development of neuroimaging technologies. This prompted researchers to attend to the neuropsychological development of children and adolescents that has led to the creation of dedicated academic fields, such as cognitive and developmental neurosciences (Blakemore & Mills, 2014; Frith, 2011). Consequently, the accumulation of scholarly interest in this area has ignited an interest in the implications of such findings for child and adolescent service and policy development (Lowe et al., 2015).

Taken together the historical development of adolescent medicine within a western milieu demonstrates the context within which the focus of my ethnographic study (and its field sites) grew. It is important to highlight that ‘adolescents’, when defined as a unique population with specific healthcare needs, is a conceptual category that has been developed and maintained over the last century in order to make sense of a changing youth. This is a reflection of what Lesko (2012) refers to as the cultural construction of adolescence. In other words, medicine’s current concern for adolescent health is not simply the result of an increased understanding of this population’s needs (through the advancement of science and technology), but of an entwined and complex history, which has been produced through a variety of sociocultural influences. Subsequently, transitional healthcare becomes a way of bringing the historical and dynamic nature of biomedical practices into view wherein crucial patient categories such as adolescence are products of social, cultural and scientific entanglements.

Part 1: Initiation of a UK Teenage Epilepsy Clinic

In the previous chapter, I presented an overview of the transitional service between Longwater and Carden as it currently operates. I will now explain the different ways in which the TEC has developed and changed over the years since its implementation at the field sites. Drawing from interview accounts with health professionals, I direct the reader’s attention to the most significant of these changes to highlight the evolving status of the transition practice.

The TEC’s implementation within Longwater’s Neurology Department and Carden’s Epilepsy Services in 1991 was the result of a collaborative relationship between Dr Roberts (a paediatric neurologist) and Professor Allan (an adult neurologist). These two neurologists had a special interest in epilepsy and shared a vision of improving the quality of care for the teenage patients under their care. Over the course of my fieldwork, Dr Roberts would often explain to me that prior to the TEC the handover of care from child to adult services was disjointed, having the potential to cause damaging consequences to not only the patient’s epilepsy but their lives away from the clinic. Following guidance from international colleagues working within adolescent medicine, the two clinicians tasked themselves with creating a service that would involve a smooth handover of care and provide reassurance for patients that they would remain under specialist review. Along with the help of Eve (the only epilepsy nurse specialist [ENS] working between the two sites at the time), Dr Roberts and Professor Allan began an experimental endeavour to establish the TEC as a routine part of adolescent epilepsy care. At this early stage, the overall aim of the service was to ensure uninterrupted and ongoing care for teenagers with epilepsy as they moved out of paediatric services. Dr Roberts described the primary objective of their venture as addressing the ‘unique needs and concerns of this age group’ and, of highest priority, to facilitate a smooth hand-over of specialist epilepsy care.

Unlike the more recently developed transition clinics that are now being implemented across the NHS, this particular clinic was not set up in response to national and local policy or guidelines. Rather, it was a local attempt to mirror the type of adolescent healthcare practices present in other countries; specifically, the United States and Australia. During my interviews with Dr Roberts, he would often emphasise the pioneering aspects of the TEC, explaining that at the time there was no UK service model for them to emulate. Consequently, both he and Professor Allan relied on methods of service delivery they read about in medical journals and society papers, as well as communications with international colleagues at medical conferences concerning the issues of transitioning young people with epilepsy.

For today's health professionals at Longwater and Carden, the TEC was often spoken about as one of its success stories. Not only did the TEC develop in an organic and experimental manner - in that it was the clinicians' vision of a better service rather than one from policy makers or hospital managers - but a 2015 audit of the service found that the clinic had a 97% attendance rate. As a result, today's health professionals saw the invested time and effort made by Dr Roberts and Professor Allan as having paid off. These demonstrations of success, coupled with Dr Roberts' assertion that today's TEC has served as a model for other transition services across the UK and Europe, meant that many of the health professionals within this study took pride in being a part of what they saw as a pioneering accomplishment. Writing in a 2016 medical journal editorial[44], Dr Roberts claimed that through the years the success of the TEC had been dependent on a clear commitment to young people, the philosophies and personalities of the clinic staff and the willingness to engage teenagers themselves. Both Dr Roberts and Eve were proud to maintain that 'their

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[44] This editorial appeared in a well-respected British medical journal. I have not referenced this editorial or named the journal due to keeping the anonymity of the participants.

TEC' was not in response to top-down decision-making but instead grew from what the 'clinicians on the ground' saw as problems for young patients.

Changes to the TEC: One addition, two losses

When the TEC service began in 1991, patients would experience the move from Longwater to Carden, or transition pathway, in much the same way as they would during my time conducting fieldwork. The pathway was, and remains, a three-step approach wherein upon leaving paediatrics, a young person is then referred into the TEC and seen by both a paediatric and adult neurologist, before then 'graduating' into the adult clinic. Once in the adult clinic they would stay under the care of one adult neurologist; presumably for the remainder of their lives. However, over the years, there have been infrastructural and organisational changes to the TEC that have significantly impacted the service. Dr Roberts described the most significant changes as being 'one addition and two losses' to the transition service. In 2014 there was the addition of the second TEC that was currently held by Dr Keegan (adult neurologist) and Dr Lewtas (paediatric neurologist). The first loss for the TEC came in 2003 with the retirement of Professor Allan. Professor Allan was described to me by adult neurologist Dr Barton as his predecessor and mentor, to which the continuation of the transitional service owed a great deal. The second loss to the TEC was that of the Epilepsy Nurse Specialists [ENSs] to the transition service. According to the charity Epilepsy Action (2017), the role of an ENS is to provide 'high quality, cost effective care for patients with epilepsy and their families.' It was a post held by registered nurses who had a minimum of 5 years' experience.

Nevertheless, during fieldwork the nurses were actively involved with promoting transition as an area of concern (largely through research and public speaking), despite no longer working within a specified clinical capacity. However, in previous years there did exist a nurse-led transition clinic that ran in conjunction with the TEC. Paula, a Carden ENS since 1995, told me that this was no longer operating due to managerial-level decisions deeming the addition of nurses to the service as superfluous[45]. Paula described the history and development of the TEC as ‘evolving and then devolving’ over the years, with the loss of the nurses as most significant to this apparent decline:

> **Paula (Carden ENS):** The nurse-led TEC was shut down around the early 2000s. It’s [the clinic] changed over the last couple of years, it’s evolved and then devolved [sic][46], so I mean the service is always changing and evolving. The one the nurses ran was a good little clinic but the Trust managers thought it impractical to run two lots of transitional services, well a nurse-led one and consultant-led one. So that ended that.

Despite the reduced role of nurses in the TEC, a young person transitioning today could still have an appointment with one of the three Carden ENSs if this was thought necessary for their ongoing epilepsy care[47]. However, when the nurse-led teenager clinic was in operation, a patient who had finished their consultation with the neurologists had the opportunity to consult further with an ENS who would be waiting in a separate clinic room. Paula tells me that this drop-in service was particularly popular with young girls who may have had questions around sexual health but felt

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[45] Paula told me that this decision was based on the Trust (and NHS in general) having limited financial resources and inefficient use of nurse’s time.

[46] I do not take Paula’s use of the word ‘devolve’ in the transitory sense i.e. to devolve or pass on power, but simply as an expression used in opposition to the service ‘evolving’, therefore I have interpreted this as de-evolving.

[47] Appointments with ENSs would be scheduled to take place between their consultant-led TEC appointments. For example, instead of waiting twelve months to be seen again in the TEC, a young person might have an ENS appointment at the six-month mark.

uncomfortable raising such topics with the male consultants. The loss of the ENSs to the transition service demonstrates that the higher-level decision-making of the Trust managers did not necessarily reflect what clinicians themselves (or young people) believed to be best practice; the inclusion of a nurse-led clinic to the transition service.

However, and rather counterintuitively, the Carden nurses did not express any strong regret over this adaptation of their role. Although they claimed the transition service was better before, they (in comparison with the paediatric ENSs Penny and Eve) appeared not to see the loss of the nurse clinic as significantly detrimental overall to the young epilepsy patient population:

> **Tina (Carden ENS):** All through the years, the transition service has never been absent at any time, but it's just been missing the nurses. It's the nurse service that's changed and it's, you know, we tried to do it differently but now we're all full. It's gone and that's a bit of a shame, but at least there's still some sort of transition service even if it was better years ago.

Tina's response to the loss of nurses to the TEC is in contrast to that of the paediatric ENSs. Frequently during fieldwork, the paediatric ENSs (particularly Eve, who had played a significant role in the early years of implementing the TEC) told me that nurses were indeed crucial to a young person's transition into adult healthcare due to their intimate understanding of the patient:

> **Penny**: Nurses know the child better and engage with other aspects of their life such as school and social care.

> **Eve**: It's like I always tell the [nursing] students coming through - the consultants know the epilepsy, but we know the child. We see them more than

> the consultants do; our time with them is longer. We’ve watched them grow and we know the family dynamics. Not only do we know that but also, we acknowledge that this is important for caring and allowing someone to grow into adulthood.

The loss of the nurses to the TEC highlights a particular discrepancy between the paediatric and adult professionals. The contrast between the adult and paediatric nurses view on their role in transitional care was stark – it was one of complacency versus outrage. On the one hand, adult nurses agreed that whilst it was good practice to have nurses involved in the transitional service, pragmatically it could not work due to time and resource constraints. However, on the other hand, the paediatric nurses argued that the loss of nursing expertise was a significant detriment to the clinic and therefore to individual patients. The above quotes from Penny and Eve point to the many years of investment and support that they had given to young people, thus the paediatric nurses may be more inclined to view their involvement as crucial. However, adult nurses (who are not yet familiar with the young people) may have different priorities. For example, the adult ENSs readily acknowledged the consequences of running a large, busy epilepsy service, and as such tailored their working practices to help reduce what was described as a back-log of patients. This discrepancy between views shows that not only are there differences of opinion between managers and clinicians as to what makes a good transition service, but also between the health professionals themselves whom collaborate within a joint paediatric and adult healthcare setting, such as the TEC. Taken together, these points hint at an underlying tension between the expectations of paediatric and adult medicine, which will be discussed later in the chapter.

The Learning Disability Clinic

Around the midway mark of my fieldwork, I learned of a specialist Learning Disability Clinic that was previously held in Carden. Although this clinic was not a specific part of the TEC, it is of significance to my research questions to understanding how learning disability services have been operationalised over the years. This is an important consideration for the current study since, as I will go on to show, many health professionals and parents expressed frustration with what appeared to them to be a diminishing of care services for those with ELD. In the early 1990s, there was an attempt by Carden Trust managers to make more of a commitment to their ELD patients (of all ages) by running a dedicated learning disability clinic. This was led by a consultant neurologist with a special interest in learning disability medicine, however by the mid-1990s, this clinic was no longer in operation:

> **Tina:** It was just him seeing patients with learning disabilities alongside the normal clinics. It just stopped, when he left the area. It just stopped because there was nobody else who could actually put in the time or anybody with a special interest in learning disabilities. It was good for a time because we knew he was around, you could speak to him about a patient if there was a difficulty, but now we just liaise with external LD services.

> **Paula:** There's actually a psychiatrist with a LD special interest in another Trust but he hasn't got the time to come in and visit us and obviously Carden won't pay him for his time and that additional service. That's where the issues are, the services that are delivered they need to be funded and so if there isn't a good reason to fund it won't get funded. Somebody's got to pay for it to happen.

These quotes depict the learning disability service as an appendage to the ‘normal’ clinical work of Carden. Tina and Paula explain that there was not a good enough reason (although what constituted a good reason was never discussed) for Carden to continue with this additional clinic when resources such as funding and lack of expertise were limited. This sentiment is echoed at a separate point in our discussion when Tina explained that the care for ELD patients is often more complex and burdensome - involving a multi-transition, with ELD patients frequently transitioning from multiple child-orientated services into the respective adult ones:

> **Tina**: Learning disability isn't dealt with in specific learning disability paediatric services. You'll only get to go into those LD services when you're an adult, so they have to transition into those services as well so you've got a bit of a double hit of transitioning with their epilepsy and their LD stuff. There’s additional stuff, like they’ll get a new social worker involved looking at adult services. They think about where they will move from school, and obviously the transition from education to adult centres is delayed until they’re 19 years. So, they have had their health transitioned at 16 years, but they’ve still got social care and what they're going to do in your day services still not yet transitioned. Any area of care for LD I think is ad hoc. I think it works well if they’re in certain areas and you get certain services running well, but there are other times where you would argue, it doesn't run very well and it’s a lot more fragmented. Also, with patients who have these additional needs, there’s more work involved for us. You're always having to chase things up with lots of different people and external services. But [the] truth is there’s not a lot of funding for LD.

Phrases such as ‘normal clinics’, ‘additional service’, ‘ad hoc’ and ‘more work’, all contribute to the portrayal of ELD transition, as well as learning disability care generally, as something surplus or excess. Here we see what sociologist Simi Linton (2010) calls the ‘linguistic conventions that structure the meanings assigned to disability’ (pg. 161) in action. For example, Tina explained that rather than lobbying for increased ELD service provision, care is often implemented as necessary; on a case-by-case basis. However, it is interesting to note that throughout fieldwork, and knowing that my research interest lay within the learning disability population, both Longwater and Carden health professionals would often stress the importance of paying attention to ELD transitional healthcare since they were such a large percentage of their patient population[48]. The discontinuation of the learning disability clinic and the ensuing lack of support to take it up again, indicate that (unlike adolescent medicine) enthusiasm for specific learning disability care to be incorporated into the epilepsy service was missing. In this particular case, Carden stopped funding a learning disability specialist because care for this patient group appeared to be sufficiently addressed by external services, such as community health services, despite this subsequently increasing the workload of its own health professionals.

Considering the above changes to the practice of transitional healthcare, we can see that since its implementation in 1991, the TEC has undergone various shifts. Consequently, the local practice of transitional healthcare has never been one stable entity, nor has it ever followed a fixed way of doing things with specific rules or

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[48] Exact numbers of ELD population were difficult to discern due to variance in terminology. However, for a general idea Penny estimated that ELD constituted ‘over half of Longwater’s epilepsy population’ and Dr Keegan (Carden neurologist) suggested that ‘around a quarter are completely free of any cognitive co-morbidities, learning disabilities, difficulties or even memory problems’.

guidelines to direct it. Instead, it has been a practice that has developed through contingent processes of professional relationships, institutional support (and lack of) and historical shifts in how society understands youth. Nonetheless, the TEC has been an experimental process that has seen some things work and others not. These experimental, innovative and almost trial and error like developments are often disregarded in best practice guidance literatures and even by the clinicians themselves in favour of linear ideologies of medical innovation (Morlacchi & Nelson, 2011). This is important to bear in mind since, in the following chapter, I discuss attempts made to formalise the practice of transitional healthcare through the introduction of a standardised transition policy and care pathway. This included new policies where the opinions of clinicians and young people were phased out in favour of top-down decision-making.

I have chosen to highlight these particular examples as they best exemplify the situated and local character of the TEC; demonstrating just how specific healthcare practices are to their respective contexts. In light of this, it is useful to consider Foucault’s (1986) concept of heterotopic spaces. In such places, the complex relationship between order and disorder is what defines hospitals and clinics as contemporary institutions of knowledge, governance and improvement (Street & Coleman, 2012). To view the TEC as a heterotopic space is to acknowledge its fragility alongside its attempts at providing a sense of order and stability to the practice of moving from child to adult services. However, these examples of the changes that have taken place around the practice of transitional care (such as the loss of the ENSs and the Learning Disability Clinic) demonstrate that the TEC is itself, a transitioning and a continually evolving practice. I now turn to examine what it is that the clinicians think are the reasons behind these various changes that have ultimately shaped the TEC into what it is today.

Shaping the TEC: Infrastructure, motivation and professional relations

In making sense of the TEC's development, Longwater and Carden health professionals expressed what they saw as three significant factors that have contributed to shaping the transitional service into what it is today. These included 1) both sites gaining Foundation Trust status and its consequences, 2) a lack of motivation for service improvement and 3) an underlying tension between working health professionals. I will now turn to look at each of these contributors in closer detail.

Foundation Trusts were introduced to the NHS in 2002 and function as semi-autonomous healthcare institutions within UK public healthcare (Exworthy, Frosini, & Jones, 2011). A critical consequence of the TEC being housed between these two specialist centres, is that both gained Foundation Trust status between 2008/9. This resulted in a widening of the geographical area that the clinic served and, consequently, increased its patient population:

> **Paula:** This isn't standard around the country. We're a regional, Foundation Trust, so we cover quite a large area.

The exact reason why the geographical area had widened was not known by Paula and the other ENSs. However, Tina speculated that since Carden had adopted the Foundation Trust status, the Trust managers and board of directors were concerned with increasing the Trust's reputation as a specialist epilepsy centre. Therefore, rather than focussing on the health needs of the local community, Carden focused on attracting regional epilepsy patients. The adult ENSs estimated that Carden provided care for approximately 10,000 epilepsy patients, yet they pointed out that the clinical team was too small to cope with the demands of such high patient numbers. A result of having such a high patient population was that many young people who were referred into the transitional service came from diverse clinical and regional backgrounds. As I will expand upon later in the chapter, this meant that many young people attending the TEC were unknown to both paediatric and adult neurologists. Consequently, for these patients the move into adult services constituted a transfer, rather than a transition, of care:

> **Sandra** (Carden ENS): We've gotten so big that the adolescents that come to us [PAUSE] only some of them have come from Longwater but there's a majority who are coming from their GP or these small district hospitals. So, patients can transfer into the TEC in different ways.

Sandra explained that another consequence of the Foundation Trust status is that the hospital board of directors decided for nurses to 'see patients in their own right' due to increased patient numbers. She informed me that, when she first took up her post as an adult ENS, her role was very much in the capacity to support doctors with nursing expertise; to be 'on hand' during clinics in case the consultants had specific issues that they considered to be best handled by the nurses. In practice, this meant that after the consultation with the doctor, and if considered necessary, the patient could then be seen by an ENS in a side room:

> **Sandra:** …but this wasn't deemed helpful or an efficient use of nurse time by the Trust managers. We had to constantly justify our role, and to be seen as just attaching yourself to a clinic looked bad. But Carden is so busy anyway

> there's no longer any spare side rooms. Bums on seats in clinics - that's what they want for nurses.

Here, Sandra is speaking of all epilepsy clinics including the TEC. Since having to see patients in her 'own right' Sandra has seen a shift in care practices. In such a way, the adult ENSs viewed the current function of their role as 'reducing appointment waiting lists', rather than being available for any epilepsy patients who wanted to see them. Additionally, the physical capacity of Carden's building meant that there were not enough clinic rooms to spare for this practice (nurses being 'on hand') to continue and as such, the adult nurse's clinical role in the TEC has all but been eliminated. Consequently, Sandra described her current role as 'taking a load off the doctor's hands'.

Similarly, the paediatric ENSs also spoke of the detrimental consequences of becoming a Foundation Trust and facing increased patient numbers. Eve described the current transition service as 'crisis management' - with care provision being sub-standard compared to when nurses were more involved in the clinical work of the TEC:

> **Eve:** We've expanded to become a Foundation Trust and you know it's a phenomenal caseload that's coming through and I feel often we work to crisis management. We're not delivering the service we have delivered at times. Now we can't deliver because of the success of the service, we are promising something that we can't deliver, and often it is crisis management.

By crisis management, Eve was referring to the lack of time spent with individual patients as they transitioned, despite the reputation of the TEC being founded on this premise. She further informed me that, ideally, young people should see a paediatric neurologist and an ENS for at least a year while they are under the TEC but now ‘they [patients] are just in and out - job done’. Both the paediatric and adult nurse’s responses highlight what they saw as the detrimental effects of obtaining Foundation Trust status; largely concerning a rising patient population. However, for Dr Roberts, the efforts to improve transitional healthcare has seen some advantages come with the status and reputation of being a Foundation Trust. During an interview, he describes transitional healthcare as a practice that has thus far struggled to achieve legitimacy and to be taken seriously by Trust managers:

> **Dr Roberts:** I think to put it bluntly Carden [managers] would be quite happy if the current service for teenagers was to be abolished. The management feel that their consultants’ time will be better spent seeing more new patients than follow-up patients with a joint neurologist from Longwater, they think it’s a bit of a luxury. Fortunately, Dr Barton and I completely disagree, we think it’s a crucial service and I think now Carden management have accepted that. About five years ago they tried to suggest we should get rid of it, but we challenged them firmly and they agreed, but the fact that they even bothered to challenge us was a bit concerning, that they didn't see it as a priority.
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> **Shelda:** On what grounds did they challenge it?
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> **Dr Roberts:** That transition could be done without the need for a joint clinic, but we’ve garnered a lot of support over the years. We all partake in some form of research and that helps raise the profile of the issues we’re trying to establish; we’ve drafted protocols and pathways and now Longwater is drafting its first transition policy. It’s all becoming really official. I think for the moment it’s going to stay our model.

> **Shelda:** Do you think it’ll be challenged in the future?
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> **Dr Roberts:** No, I think they've been through that ritual and process and I think now there’s so much support for it, from the adult neurologists as well, which is important. There’s a lot of backing within the NHS about transition anyway, getting it right, and you know we’re located in two well established Trusts, Foundation Trusts, and I think that has helped with our reputation and establishing transition as a critical care component. I think Carden management would be foolish and narrow minded to challenge us and abolish that service, I think it’s here to stay.

From this, we can see that there was an elevated prestige for the institution that had been granted a Foundation Trust status. In addition to the health professionals being active in areas of research, the reputation of the institutions within which they worked helped the clinicians to solidify transition as a ‘real’ issue; something that could now be drafted into official documents such as policy, pathways and protocols, which will be discussed in further detail in the following chapter.

A second contributor to the changes within the TEC was what Eve called ‘transition stagnation’. By this, she was referring to the attitudes - particularly that of the neurologists - who had been unwilling to change the model of transitional healthcare since 1991. For many of the clinicians, particularly the paediatric nurses, the difference between transfer and transition was a vital one. Despite claims of the success of the TEC owing to the pioneering and experimental approach of Dr Roberts and Professor Allan, my interviews with the paediatric ENSs painted a different picture. Throughout fieldwork, the paediatric nurses Penny and Eve frequently stated that the service was suffering from a ‘standstill’ with no feasible way to improve, and more importantly, they emphasised that they believed the service to be a transfer at its heart. To exemplify this point, I draw from field notes during a lunch break with Penny prior to observing one of her afternoon clinics. I had previously noted her overall dissatisfaction with Longwater's care for teenagers and so I decided to ask her 'What's wrong with the current model of transition?' and she, quite vehemently, replied:

> **Penny:** It is a transfer. If the patient's been seeing Paediatrician So and So for the past fifteen years, and he then refers them over to the Carden, they're seen either by Dr Roberts or Dr Lewtas neither of which know that patient, how is that transition? Is it just because there is a paediatrician present? I think it's fair enough for those patients that are already seeing Dr Roberts and Dr Lewtas, there's an element of transition there, but they are not the only paediatricians that see epilepsy patients. It is transition but only for the minority. It's a transfer for the rest.

Following this, I then asked her to describe what an ideal transition model would look like. Penny's response focussed on adult services taking a more active role in supporting the young person:

> **Penny:** If resources weren't an issue and time wasn't an issue, then ideally, I think the first meeting should be the adult neurologist coming over to the children's hospital. The teenager is then kept in their own environment, somewhere that they're used to, somewhere they have grown up in, and then it's not suddenly a big change. So, if the adult neurologist came over, and I mean this is your absolute ideal, this is never going to happen, he would come and do a joint clinic with the individual paediatrician here. Maybe once or twice to get them used to it and build up a relationship, and *then* it's the

> paediatrician that goes over to Carden. That's more of a transition, there’s an element of moving and not these jumps[49] and I feel that nurses certainly have a role to play in that as well.

Similarly, according to Eve, the original model where an ENS was present within the TEC ‘worked better, felt better and flowed more’. However, even back then it was not the perfect system as it was still a transfer but, instead of improving upon the model, the service has remained the same. This stagnation is the result of not adapting to the changing infrastructure within the hospitals (i.e. obtaining Foundation Trust status) and therefore the transitional service has suffered the consequences of high patient numbers and increased service demand. It is in this way that Eve describes the TEC as deteriorating. For Penny and Eve signs of deterioration included: lack of young people seeing a familiar paediatrician once in the TEC; the phone calls they continue to receive from parents post transfer[50] and; the general anxiety expressed by patients and parents prior to transition. Taking these considerations together, the paediatric nurses concluded that what could have been a great service is now a mediocre one at best, and crisis management at worst.

According to Penny and Eve, this stagnation was also rooted in the neurologists having an under-appreciation for the many professional roles (ENS, psychologist, social worker and educators) that come together when working in a multi-disciplinary environment such as the TEC. This finding comes as a contradiction to the transition literatures that extol the importance and relevance of MDTs during the transitional

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[49] Penny moves her hand and arm in a wave-like motion when she mentions moving between services, and makes leaping gestures with her hand to demonstrate staccato-like ‘jumps’.

[50] Both Carden and Longwater nurses had a dedicated telephone service where patients could call and leave a message asking for clinical advice. The response wait time was 24hrs for Longwater and 72hrs for Carden (exclusive of weekends).

period [see Chapter 2]. When nurses were present in the clinic, Eve informed me that it made for a smoother transition as there were more expertise available to cover a variety of topics or to ‘fill in the blanks’ as she put it:

> **Eve:** When it started off in the early days, even then it was a little bit of a transfer but there would be the paediatric neurologist, myself and there would be the adult neurologist, so three of us. So, we had a chance to hand over the information and care, we could fill in the blanks, but because of the pressures of work and the development of services, because everything mushrooms once it is set up officially – so that couldn't continue. I think the biggest failing is lack of nurse involvement. It’s just the doctors now. I always say this glibly, but it is true - doctors are there to cure and nurses care. We have a lot more of the background to the patient’s life and that’s important to acknowledge the ongoing, involvement, knowledge and care of the patient and family.

Eve sees the cure/care dichotomy as central to establishing the importance of nurses in the transition process. The concept of ‘knowing’ the patient (as opposed to knowing the illness) is important from the nurse’s perspective in ensuring a smooth and holistic transition. According to Eve, this now disjointed practice has roots in an underlying tension between the professions, specifically between doctors and nurses (as well as Trust managers - who claimed that nurse time would be better spent elsewhere). For Eve, an apparent lack of communication has contributed to the stagnation of the service. There is a general apprehension of stepping on peoples toes in their areas of expertise and not wanting to offend the ‘original ideas’ of those who initiated the clinic:

> **Eve:** People don't talk to each other. The staff never talk about the service and how we can do it. For instance, some of the consultants haven’t been as open to my project[51] as I would have liked. One of them said to me ‘What are you doing this for, we have a transition service?’ I said, it’s not like we’re putting something backwards, it’s putting it forwards but people feel as though you're stepping on their toes and that can be really difficult trying to get your point across that I’m not criticising what they’re doing, we’re trying to actually add to it, and complement the whole service.

Consequently, the differing aspirations and values for the service - as well as the tensions in professional relationships - have acted as a barrier to the development of the transitional healthcare. The critique of the TEC as being, ultimately, a dressed-up transfer was continually emphasised by Penny and Eve over the course of my fieldwork. The above examples highlight the professional relationships and professional statuses that have contributed to service (under)development from one group of professions perspective. The healthcare that a young person is met with in today’s TEC is one that has developed in a complex way. At these particular field sites transitional healthcare is not simply the application of evidence-based clinical guidelines but something that was enacted through government and managerial health agendas, motivation of staff to pursue alternative models of care and micro-level professional interactions.

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[51] Eve was working on an arts-based project that involved young people storyboarding and filming a short animation about how it felt to transition into adult services.

Part 2: Bridging the Gap: Whose challenge is it anyway?

The question of whose responsibility it was for ensuring a good transition - paediatrics or adult services - appeared frequently in interviews with health professionals. Specifically, for the staff at Longwater Paediatrics, transitional healthcare was described as being a problem for adult services, yet a concern for paediatrics in general. This deferring of responsibility of the transition challenge to adult services was often based around the fact that since young people are under paediatric care for a limited time, it is adult services that ultimately suffer the consequences of poorly transitioned patients. As highlighted by the clinical and health services literature in Chapter 1, an uncoordinated and disjointed transition is thought to contribute to poor psychosocial development for those with long term conditions; which in turn had the potential to negatively impact physical condition management into adulthood. Despite these assertions, the outcomes of a good or bad transition are little understood within the clinical literatures with regard to young people with co-morbid learning disability (Bhaumik et al., 2011; Tuffrey & Pearce, 2003). For Penny, the lack of research on the transitional healthcare for those with ELD was surprising since prevalence rates of learning disability and/or difficulty were considered high within a general epilepsy population. Penny estimated that at least half of Longwater's epilepsy population had some form of learning disability or difficulty; ranging from the very mild to the very severe. It was this co-morbidity, she informed me, that made for a 'different transition with its own unique set of problems'.

To highlight this point further, I now present an observation of a patient named Daniel Holbrook. I met Daniel and his family at the beginning of fieldwork; he was 17-years-old and described as having severe global developmental delay along with generalised seizures. Coming through the consultation room door, Daniel's mother Gail was clearly unhappy as she sat down shaking her head. Meanwhile, Daniel stood in the doorway with his father Mark firmly holding onto his son's shoulders. Gail explained that only minutes earlier, Daniel had a 'kick off in the hospital restaurant and didn't want to come…' into the clinic. With gentle persuasion from Penny, Daniel eventually entered the consultation room. Keeping his back facing the rest of us, Daniel sat on the floor and played with toy cars from a large yellow tub that sat in the corner of the room.

The remainder of the consultation continued in this fashion; with the interaction largely between Penny and Daniel's parents. After they left, Penny told me that she often worried for teenagers who, like Daniel, had to transition to an adult service that may not be as accommodating or understanding of his and his family's 'differences':

> **Penny**: The toys calmed him down. The family know, that with us, they don't have to apologise for his behaviour but in adults it's a clean cut, clinical environment. You know you're in, you're out. I suppose in these cases you *could* question transitioning but even people like him eventually have to move on. You can't stay in paediatrics forever.

Although Penny expressed some reservation about the transition of young people with a learning disability, she continued to accept the practice as part of a larger tradition of care wherein the distinction between children and adults is maintained. This tradition of seeing children and adults as requiring separate domains of healthcare provision brings me to the question of to whom does the challenge of transition belong to? Since adult services will inevitably be the ones left with a bigger and longer surviving caseload of patients, the paediatric nurses maintained that, ultimately, the challenge of transition and its potential consequences belonged to adult services.

Therefore, it was those clinicians and Trust managers who needed to ensure a transition pathway that was appropriate for those with ELD. Nevertheless, considering an alternative transitional healthcare practice for those with ELD was a slightly more problematic point of discussion as shown in the following interview extract with both paediatric ENSs:

> **Penny:** It could be more about changing how we provide care for those with learning disabilities but then you’ve got to be careful. That might be verging on going back to the asylum-type institutions, which would be awful. The model of having a paediatric, then teenager, then adult clinic for kids with severe learning disability - I am just talking moderate to severe, nonverbal, non-communicative cases - is not always appropriate, but that’s the way it is, we have child doctors and we have adult ones and you’re seen accordingly.
>
> **Eve:** I don't think it is right at all, it needs to be looked at more for individual groups rather than generically, especially for really complex cases. This is what we *try* to do. Transition ticks a box for some, but certainly not for all. You see we have the kids for a period of time, but adults they could have them for the rest of their life. So realistically they’re the ones who should show more concern for these issues.

Since the 1970s, the disability rights movement and its enduring messages of equality, diversity and inclusivity have been incorporated in NHS practice, with health professionals trained to be conscious of such issues (Milton, 2016). However, what may be considered equality in healthcare may come at the expense of equitable healthcare. For example, in treating all patients with epilepsy as equal, is transitional healthcare disadvantaging those who do not develop in alignment with the normative models of adolescence? Penny's concern of going back to 'asylum- type institutions' reiterates these culturally pervasive ideals of equality, diversity and inclusivity. However, this not only calls into question the practice of transitional healthcare for those with more severe learning disabilities, it also problematises the seemingly concrete concept of normative adolescence as a period for developing independence and responsibility.

The issue of adult services not taking responsibility for transition appears to have its roots in a common story that I frequently heard from those working within paediatrics. The belief was that thus far, transition practice and research had largely been advanced from a paediatric base; and from what I observed during fieldwork, this claim was not without justification. Although the TEC itself was housed on-site at Carden, there were other ways of practicing transitional healthcare. For example, at both Longwater and Carden, several transition-based studies were being conducted. Throughout my fieldwork, I was aware of four studies at Longwater that included transitioning epilepsy patients, yet only one study (that was in the proposal stage) at Carden. There was also one study (at the time of fieldwork) that was being undertaken between both Carden and Longwater psychology departments. Since the majority of these studies were initiated by the paediatric hospital, both Penny and Eve took this as evidence that transitional healthcare and transitional research was mostly initiated by a paediatric effort.

At another nurse-led clinic in Longwater, I observed a consultation between Penny and a 17-year-old boy with epilepsy and mild autism who was accompanied by his mother. This was to be the boy's final appointment at Longwater before he transitioned to Carden. When the consultation was finishing, Penny asked the mother and son if they had any questions. The boy shrugged and sheepishly smiled whilst his mother opened a note pad that she had been holding since she entered the room. On the notepad she had written a list of questions. I had heard these questions being put to health professionals in previous clinics where a teenager was involved such as: Will the ambulance know where to take us? Can I still call the paediatric team if I have any concerns? Can I stay with him on the adult wards if he is admitted into hospital? After they left Penny explained to me that these were typical parental worries of transition:

> **Penny:** It’s always the same old things that people say to us. Y’know, adult services only need to provide us with a leaflet or even the answers because to be fair we don’t even know what they do over there, then we can say [to patients and families] look here is what’s going to happen when you get there.
>
> **Shelda:** Maybe she feels it’s inappropriate to put him in an adult ward, with other sick people, she said he can be disruptive and loud.
>
> **Penny:** And I agree with that, but really, and this sounds terrible now, but I think Carden needs to address it. I think if you look at the transition work that's been done over the years, time and time again, it’s always from a paediatric base, it’s rarely brought from adults to paediatrics to say we need to sort this out. I think they have to get on board before you're going to see any changes. I think us, as children’s nurses, are willing to make them changes but I’m not necessarily convinced that the adult side are. I don't mean to sound harsh on the poor adult services but I think we are more accommodating and we need to pass that over to them.

These questions of what it means to be a paediatric or an adult clinician is significant when establishing the importance of transitional healthcare. Why is it that differently aged bodies require, not just different practitioners, but completely distinct cultures of care? The paediatric/adult distinction stands not only to distinguish groups of professionals, but also to shape professional identities and values. When I speak of cultures of care, I am referring to the two sides of the TEC having adopted what they see as fixed positions and specific perspectives, attitudes and beliefs about theirs and other's professional practices. Whilst the paediatric clinicians often claimed that adult clinicians did not do enough to improve transitional care, staff from Carden would use phrases such as 'too cushy', 'too soft' and 'unrealistic' to describe paediatric medicine as a whole. Subsequently, the importance of transitioning was often emphasised as a need to no longer mollycoddle young people as they move into adulthood but to prepare them for the reality of adult life. I offered this perspective of paediatrics to Penny and Eve. Penny recalls a conversation she had with an adult neurologist around a similar topic:

> **Penny:** They say it as a joke but there's always a bit of truth in jokes, he said 'I blame paediatrics 'cause they're too cushy, parents expect that over with us and it's just not happening.' I just thought there's our problem. Well, rather that's *your* problem mate.
>
> **Eve:** Well the other I've heard is 'You wrap them up in cotton wool'.
>
> **Penny:** Or 'Paediatrics doesn't help the situation by providing too much of a good service.' I don't think you can get too much of a good service. Personally, I think that's sad that they view us like that. I know they view us that way, I hear it constantly.

What Eve and Penny's accounts demonstrate is that, whilst transition aimed to facilitate a smooth handover of care for a young person, there are often in-built infrastructural, traditional and cultural discrepancies between paediatric and adult medicine. Consequently, a stark distinction is made between the two and the need for a transitional service is required in order to make this move less stark. These distinctions are phenomenological in nature. In other words, for the health professionals, having distinct care domains shaped how the clinicians viewed themselves and others. For example, Dr Lewtas described to me the role he plays as a paediatric neurologist in the TEC:

> **Dr Lewtas [paediatric neurologist]:** I sit there quiet [LAUGHS], all sage-like trying to look wise [LAUGHS] but it is really important he [Dr Keegan] leads the consultation so the patient knows that it's no longer me they're dealing with. He's the boss now. That way I can give insight to the patient's case if I know them, or any paediatric stuff if I don't. It's not just a transition for the patient but also a way of thoroughly and carefully handing over the patient to the adult doctors so that he's prepared for the patient. It works both ways.

Dr Lewtas' account is an instance of what Schutz (1944) refers to as 'recipes of knowledge', i.e. the tacit understandings regarding the appropriate ways to act in given situations. In the TEC, Dr Lewtas' role was less active than in his Longwater clinics, in order for the adult clinician to take the lead. However, he also saw himself as playing a significant archetypal role - the sage- lending an almost ritualistic character to the transition process; in handing over the patient to the adult doctor and Dr Lewtas ensured that both parties (adult clinician and patient) were as best prepared for each other as possible. On both sides of the TEC, the clinicians internalised their roles and practiced their care accordingly, with Dr Barton jokingly commenting that he was an adult doctor and therefore would treat all his patients as such. This produced what are two lifeworlds of care whereby different methods, practices and beliefs about what constitutes caring abound. The question of to whom does the challenge of transitional healthcare belong was not simply resolved by shifting the responsibility solely onto the shoulders of adult's services. Rather, a deeper explanation would acknowledge that there was a lack of phenomenological or experiential transition between the cushy, idealistic paediatric hospital and the stark realism of adult services. This is something that is unlikely to be mediated by preparing (or adapting) young people to face what is ahead of them in adult services.

Conclusion

By presenting the local development and subsequent changes since the TEC's initiation in 1991, this chapter highlights the heterotopic character of the TEC. In other words, we see the clinic's complex relationship with order and disorder. For example, the order that is implied within the biomedicine project alongside the disorder and messiness of the mundane work of clinics and hospitals - wherein worlds exist within worlds. Consequently, as an attempt to bridge two distinct cultures of care (paediatric and adult medicine) the world of transitional care takes on a recursive character, Through understanding child and adult medicine as two distinct cultures, I argue for an understanding of the 'transition challenge' as something that can only exist by virtue of the medical practices and boundaries that shape such distinctions.

My primary intention in outlining the rise, implementation and changes that have taken place around the TEC has been to highlight how transitional healthcare at the time of fieldwork, was in a state of flux. Therefore the object of my thesis, a clinical practice, was in no way a stable or definitive entity but was, instead, a human practice that influenced and was influenced by multiple factors, such as Foundation statuses and professional relationships (Rabinow & Bennett, 2009). Specifically, this chapter has shown that the TEC, as a heterotopic space, was made up of multiple relationships between institutions and people whose priorities changed over time. The findings of this chapter, therefore, problematises the certainty with which the transition ‘challenge’ was discussed (both within the literature and during my fieldwork within the TEC). The dominant clinical perspective on the ‘challenge’ of transitional care is problematic since it fails to consider the limitations of its own rhetoric - one that is drenched in appeals to independence, self-management and normativity. Consequently, this leaves little room for considering the impact this rhetoric of transitional care may have upon those who do not fit the normative model of adolescent development. Crucially, this chapter highlights the contingent nature of the transitional care practice, e.g. the influence of professional relationships on the development of the practice. In the next chapter, I focus further on these contingencies to explain how Longwater and Carden were making attempts at stabilising and formalising transitional healthcare, largely through the writing of a transition policy and continued clinical research.

Chapter 5 - Acts of Stabilisation: The role of policy, management and research practice

In the previous chapter, I presented an overview of the TEC; tracing its implementation and subsequent development within its local and national context. In doing so, I highlighted that, in spite of the TEC having been in operation for over two decades, transitional care was not yet a stable nor formalised clinical practice within the local NHS Trusts of Longwater and Carden. Therefore, in this chapter, I move on to focus on Trust-wide efforts made to establish transitional healthcare as a formal, institutional practice. In particular, I am concerned with the specific activities of policy development, management and research that were crucial to the stabilisation of the practice. In my use of the phrase ‘acts of stabilisation’ as an organising principle for this chapter, I am influenced by Science and Technology Studies [STS] scholars in their analysis of how acts of quantification, standardisation and classification, shape our everyday, social and cultural lives and how they come to order and stabilise human activity (Bowker & Star, 2000; Lampland & Star, 2009; Singleton, 1998; Suchman, 2007, 2014).

In what follows, I first consider the development of Longwater’s *Transitioning to Adult Services* policy document. Through the perspective of the Lead Transition Nurse, Suzy, I examine what type of care is mobilised by this healthcare policy. I then move on to discuss how Suzy’s job as a ‘Transition Nurse’ was created, specifically, to manage the formalisation of transitional healthcare. Finally, I consider the research activities that provided an evidence-base for the development of this policy (as well as providing evidence for the ongoing service development of the TEC). I discuss this evidence-base alongside a consideration of the preferred models of clinical research as inferred from interviews with neuropsychologist Sara. It is these activities of policymaking, management and research that stabilised transitional care into an established and institutional practice at the field sites.

Acts of Stabilisation: A definition

Before analysing the use of policy, management and research at the field sites, it is important to clarify what it is that I mean by the term ‘acts of stabilisation’. To understand the importance of formalising transitional care, I asked health professionals to explain why policy, management and continued research were valuable to their daily work. Most responses concerned increasing the quality of care, reducing risk to patients and holding the institution accountable for its services. However, Dr Roberts provided an alternative response to these explanations. Unlike the other health professionals, he bluntly replied that having a transition policy would ‘legitimise their concerns’:

> **Dr Roberts:** There is a tension between the health professionals, who see transitioning as a critical approach to providing adolescent healthcare, and the NHS managers, who see it as an ad-hoc or luxury service.

To put simply, policy, management and research supported the need for their transitional service. Therefore, through these acts, what may have been considered an insignificant clinical practice was given an air of stability and reinforcement. Dr Roberts and his TEC colleagues perceived a persistent threat from the ‘suits above’ to the continuation of the practice of transitional healthcare. Subsequently, stakeholders in this care practice, including Dr Robert’s, were continually engaged in activities that supported its claim as a legitimate clinical concern. For example, Dr Roberts claimed that he was always trying to ‘raise the profile’ of the clinical significances of epilepsy transition through speaking publicly at national and international events and writing about epilepsy transition for a variety of audiences (including parent groups, charities and professional societies). He informed me that, along with continued research into the health needs of adolescents with long-term conditions, the development of a specific transition policy would standardise clinical care practices, something he saw as necessary for transitional healthcare to gain a strong foundation within the Trusts:

> **Dr Roberts:** There's a lot of red tape and it can be a time-consuming process. These policies take forever to draft then redraft and so forth because you're going back and looking at the latest evidence all the time. However, it's inevitable if you want to make your case stick and provide quality care that has the full support of the Trust. So now transition can be taken seriously.

Dr Roberts acknowledges that establishing transition as a clinical concern takes time in order to garner support from higher management who, ultimately, decide on what care is provided by the Trust.

Rather than simply echoing the responses of other health professionals regarding the importance of standardisation in care (largely that of improving quality, reducing risk and maintaining accountability), Dr Roberts suggests that standardisation can be a means to another end - that of formal establishment. By formalising clinical care practices (through the development of a policy), quantifying a clinical concern (through ongoing research), and by formally representing the aforementioned concern (through the creation of specific job roles) this has the effect of raising the profile of transitional healthcare. Once it becomes a 'legitimate area of growing clinical significance' it would be, Dr Roberts claims, increasingly difficult for higher management to dismiss their work. In other words, these acts are what lend transitional healthcare the impression of being a stable, unified entity (Singleton, 1998). This point speaks to discussions within STS about how clinical practices achieve longevity. The Actor-Network approach suggests that human practices maintain themselves through scientists and practitioners successfully defining and aligning a diverse network of human and non-human entities to form a specific network of associations (Callon, 1986; Latour, 2007). For example, Dr Roberts brings what he sees as transitional issues to a wide audience, mobilising transitional care through the practices of writing, research and policy development. In making the work of stabilising healthcare practices visible, I show how these activities were purposely employed to take transitional healthcare from its state of ambiguity into an institutionalised and stable care practice.

Part 1: Policing practice: The role of policy in stabilisation

In the summer of 2016, Longwater health professionals were finalising a brand new, all-condition transition policy. This policy, *Transitioning to Adult Services,* aimed to provide a standard transitional service for young people with complex health needs [CHNs] (amongst which included learning disabilities) as they left their familiar paediatric hospital. Prior to this, both Carden and Longwater did not have any written policies or protocols specifically around 'transitional healthcare'[52]. During the last few days of my fieldwork, I was told by the Transition Nurse Suzy that the policy was in its final draft stage, however, it was to be at least another 12 weeks away from being

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[52] To my knowledge, there were no plans to develop a mutual transition policy at Carden, as opposed to the already established receiving new patients (of any age) policy. Once again, this supports Penny and Eve's claims to the paediatric effort for improving transitional healthcare (see Chapter 4).

implemented into the Trust[53]. The *Transitioning to Adult Services* policy was largely developed following an in-house questionnaire that was emailed to relevant clinical Longwater staff. This included medical consultants, registrars, general paediatricians and nurses who worked with young people transferring to an adult hospital for continued care. The questionnaire aimed to understand the views and opinions of paediatric clinicians on how best to deliver transitional care. Since this questionnaire was only ever given to internal clinical staff at Longwater, it is important to note that the views and opinions of adult clinicians, young people and carers of young people were absent within this policy. The main findings of the questionnaire showed that clinicians were most concerned with developing a clear outline of steps towards point of transfer over to adult services. It was Suzy's task to ensure that the developing policy allayed such concerns through establishing new transition practice standards. These practice standards, such as the Ten-Step Pathway outlined below, were underpinned by national documents regarding transitional healthcare (including *Getting the Right Start: National Service Framework for Children* [DoH, 2004], *National Framework for Children and Young People's Continuing Care* [DoH, 2010], *Transition from children's to adults' services for young people using health or social care services*, [NICE, 2016]).

Throughout the pages of the *Transitioning to Adult Services* document, emphasis was given over to terms such as 'fostering empowerment', 'increasing patient knowledge'

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[53] I was unable to find out how, or even if, this policy was eventually incorporated into the TEC since it was continually debated by Trust managers and Suzy whether or not to disrupt the current organisation of this clinic. In the eyes of those health professionals who had developed the new transition policy, the TEC was considered a 'superior transition service' to what the policy itself was attempting to establish. However, due to the time and effort it had taken to implement the TEC (see Chapter 4) this was deemed a model of care that would not be feasible to apply across the Trust in the short-term.

and ‘providing psychosocial support’, demonstrating the influence of psychological understandings of adolescence, i.e. a period of growing social and psychological independence for all young people. As discussed in Chapter 2, such a psychologised model of adolescence often assumes the capability of young people to understand and negotiate their own healthcare, which effectively increases their responsibility as they move into adulthood. However, questions remained as to whether such a responsibilised approach to care is suitable for those who develop atypically (Karmiloff-Smith, 1998; 2013). The responsibilities that were expected of young people as they moved through the healthcare system can be seen in the ‘statement of purpose’ within the policy’s introduction (see Figure 1).

> To ensure that young people are empowered to manage long term conditions and take responsibility for their own healthcare, including knowledge and understanding of their condition(s), self-management, healthy lifestyle and navigation of adult health services including access to their GP and primary care.

Figure 1. Excerpt from Transition to Adult Services policy’s statement of purpose

Within the policy, this statement of purpose was followed by a description of the Ten-Step Pathway. The Ten-Step Pathway was a central feature of the document, as it was envisaged by Suzy that this would become the ‘standard product’ of the Longwater policy; something to be used across all paediatric health conditions. However, as I now move on to show, this pathway held crucial underlying assumptions regarding adolescence that were to be applied to young people with co-morbid CHNs.

(Re)Presenting Complexity: The Ten-Step Pathway

As outlined by Lampland and Star (2009), the process of standardisation is intrinsic to the establishment of formal human practices. For example, the presentation of information into easy to digest forms, such as graphs, tables or narrative types (examples include clinical guidelines i.e. NICE Guidelines *Transition from children's to adults' services for young people using health or social care services*, or child development stages). In the case of the *Transition to Adult Services* policy, such representation came in the form of the Ten-Step Pathway (see Figure 2). After collating the data from the in-house questionnaires, Suzy condensed this to produce the infographic-style pathway. The pathway was designed for both patient and clinician use – for young people and their families to understand the context of their transition journey and for health professionals to be guided within their clinical work. This pathway was presented in the form of an A4 leaflet intended to be given out at the beginning of a patient's transition journey[54]. In bold, comic-sans text the leaflet posed the question: **What does a good transition look like?** The answer provided was: **Ten Steps**. This was followed by a paragraph describing the 'normal' psychosocial development of young people as one that is characterised by increased decision-making capacity leading to adult independence. The document stated that decision-making was one way for young people to gain control over their condition and, ultimately, their own healthcare management. It further claimed that through a

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[54] The timing as to when a patient's transition journey was to start and/or end was only ever suggested. Suzy was certain that young people should begin their transition journey no later than 12 years old, whilst other clinicians would use their knowledge of the patient themselves and the family context to guide their decision as to when discussion of transition should begin.

process of 'ten simple steps' transition becomes an important, yet smooth, journey into independent adult lives.

These 'ten simple steps' were not the way transition was practiced within the TEC (between Longwater and Carden). For example, the health professionals of the TEC described their practice as being a three-step model, within which paediatrics was viewed as the only preparatory period for young people prior to transitioning to Carden. However, the Ten-Step Pathway was inspired by a pre-existing transition programme at Southampton Children's Hospital called *Ready, Steady Go*[55], an approach based upon a traffic-light system, incorporating three steps. When I asked Suzy why specifically ten steps (and not three like the TEC and Southampton), primarily she informed me that this was the outcome of the questionnaire - that there were ten salient aspects of transition that Longwater clinicians felt were intrinsic to providing healthcare for young people. However, Suzy also emphasised the simplicity of the number ten:

> **Suzy:** It's a nice number round, it's simple and effective. It's easy for clinicians to follow and it speaks for itself. Since it's similar to *Ready, Steady, Go* it'll hit the ground running because it's based on something already out there, people know about this. You don't want to reinvent the wheel. Hopefully it'll be a standardised simple preparation tool that everybody will be using.

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[55] Transition to Adult Care: Ready, Steady, Go is a copyrighted transition programme developed in Southampton Children's Hospital. The approach is to consider transition as a traffic light system with red meaning not ready, amber meaning the patient is preparing to transition and green meaning the patient has or is about to move into adult services.
http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx

Since the pathway was based on the results of a questionnaire, Suzy considered it an example of evidence-based medicine; where the opinions of paediatric clinicians, informed the ‘effective and efficient delivery of care’. Relying on simplicity and familiarity in the initial design of the pathway, the ten steps were as follows:

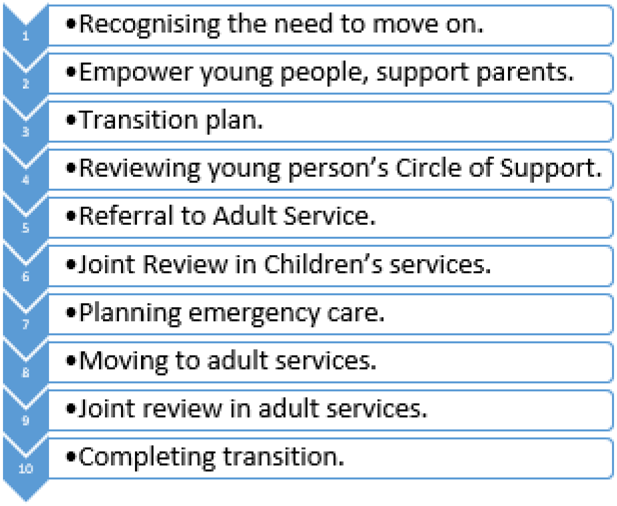

Figure 2. The Ten-Step Pathway

If we pay attention to the descriptions provided for each step of the pathway, we can begin to understand the intentions and values of the policy’s developers (i.e. the institutions) that generated this policy. Whilst the first step assumes an inevitability in the need in transitioning, the last step takes for granted that transition will be completed by a certain point. Step two assumes the need for empowerment and support, whilst steps three, four, six, seven and nine emphasise regular management and planning in order to execute this pathway. As such, the Ten-Step Pathway values a linear and incremental transition that is carefully planned and supportive of both patients and family’s needs, as young people become adults.

Directing my attention to the visual aspects of the Ten-Step Pathway, Suzy stressed to me the importance of acknowledging the use of a flow chart as the chosen format of visual depiction. Suzy noted that the direction of the pathway imitated that of adolescent development itself – it was incremental. Since both the pathway and adolescence ‘flowed in one direction’, complete independence from parents, she informed me, was the ultimate aspiration for all young people whilst under Longwater’s care. In other words, young people (according to Suzy) aspired to reach one goal, that of self-sufficient adulthood. In her emphasis on this goal, Suzy highlights a variety of assumptions held by the developers of this policy – whether that is Suzy alone or the institution writ large. First, there is the assumption that all young people wish to become independent, self-sufficient versions of themselves. This assumption discounts the importance of shared caregiving responsibilities within group living settings (such as the family) and emphasises a largely westernised individualistic view of human psychosocial development and our relational capacity to receive and provide care (Rapp & Ginsburg, 2011; Wilkinson & Kleinman, 2016). Secondly, the one-way flow towards adulthood reiterates the underlying assumption that adolescence itself follows a one size fits all trajectory. This ignores the complexity of development and maturity for patients with CHNs, despite being the precise population the policy was intended for.

Furthermore, the stress placed on the numerical value of ten indicates the ease and efficiency of the pathway rather than acknowledging the complexity of moving into adulthood:

> **Suzy:** It means moving forward in life and in care, to a new position. Y'know 1, 2, 3, 4, 5, 6, 7, 8, 9, 10. We're not going backward here, young people need to move forward with their lives.

Suzy was careful to note that although the pathway was sequential, she was reluctant to map each step onto a specific age[56]. However, despite her own emphasis on the fluidity and dynamic nature of Longwater's approach to transitional healthcare, I could not help but think that it was only fluid and dynamic to a certain point. The desired outcome was always the same; for young people to be prepared enough to attain Step Ten and eventually complete the transition. This is important to note because, despite being written specifically for those with CHNs, the Ten-Step Pathway did not attend to the individual trajectories of those patients who would not follow a simplified process of development (psychosocially, physically or cognitively) or have the capacity to understand the ten-step approach:

> **Suzy:** Knowledge is power. The more these kids know about their condition the better they'll handle any bumps further down the road. The more the parents know the better. They can do things themselves; they don't have to be waiting around for phone calls from the nurses or doctors or coming to A & E. They will know how to handle their own care.

This quote shows that the pathway was developed to aid those capable of self-management (such as, understanding their condition or making their own phone calls) and it restates the initial aims of the policy, which were to help young people to become more responsible for their own healthcare. The impact of responsibilised

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[56] Despite this, the day before a patient's nineteenth birthday was suggested as a timeframe for the completion of step ten, with the patient being discharged from paediatric care.

approaches to care provision is something that will be returned to in later chapters, however, what was apparent from the Ten-Step Pathway was that having clear, standard and easy-to-digest practice guidelines was a central component in the formalisation of transitional healthcare. Developing this pathway gave the impression of stability, authority and reliability to a healthcare practice that, on the face of it, may have appeared new and unfamiliar. The Ten-Step Pathway demonstrates a preoccupation within biomedicine towards producing standards and (re)presenting care processes in simplified formats (Kierans, Kingdon & Bell, 2016; Lock & Nguyen, 2010). Whilst the policy clearly acknowledged the complexity of human healthcare needs, by virtue of the population it was created for, it also addressed the very same complexity through methods aimed at simplification. Such a prescriptive approach to healthcare is likely to miss salient features of young people's lives; in particular the lives of those that do not conform to standards nor follow simplified developmental trajectories. Alternative approaches could consider a more fluid and dynamic pathway that did not assume self-sufficiency as the end goal of transitional care. Through insisting, that such tools can be universally applicable, as if all young people with CHNs were somehow homogenous, this approach to transitional healthcare reflects ideologies of business - for example, economic efficiency - within healthcare; a system that, as I will go on to show in the following section, values efficiency and reduced financial burden.

Part 2: Creating the Transition Nurse: The role of management in stabilisation

I now move on to present another important aspect of formalising the practice of transitional healthcare - that of creating new roles for managing the establishment of the practice. Suzy had been a paediatric nurse for over twenty years before accepting her new role as Transition Nurse at Longwater Hospital. In this role, she moved away from clinical nursing duties to developing the Trust's transition policy. This was the first time somebody had held the role of Transition Nurse at Longwater and, through its creation, Trust managers hoped to determine the needs of transitioning youth with the potential to formally implement transitional healthcare within the Trust. In effect, the Trust-wide transition policy was being executed on a trial basis. However, Suzy assured me that transitional care was 'going nowhere' and it was unlikely that Trust managers would dispute the significance of it:

> **Suzy:** We have so many of the doctors who see this [transitioning] as a vital issue. It would be extremely unlikely for them [the Trust managers] to say that it wasn't needed or to say that it wasn't a problem because it is. They're obviously going to give it the go-ahead.

Echoing the earlier viewpoints of Penny and Eve who regarded paediatrics as being more engaged in efforts to improve transitional healthcare than their Carden counterparts (see Chapter 5), Suzy also claimed that the work of furthering the transition agenda had, both locally and nationally, been a paediatric effort. However, this was not simply a reflection of one medical domain being more proactive than the other; as was frequently emphasised to me by Penny and Eve. It was, unsurprisingly, a reflection of available financial resources.

The job title of 'Transition Nurse' was the result of a Commissioning for Quality and Innovation [CQUIN] programme. The CQUIN payment framework was introduced to the NHS in 2009 and aimed to make a proportion of the healthcare provider's income[57]

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[57] Income that is largely generated from public taxation and limited direct patient payments such as dental, pharmaceutical and ophthalmic services (Marshall, Charlesworth & Hurst, 2014).

conditional on demonstrating improvements in quality and innovation in specified areas of care. Subsequently the push towards transitional healthcare at Longwater meant that it had now become incentivised. It is important to note that at the time of fieldwork, a CQUIN transition role was not available at Carden because, as speculated by Dr Barton, there was a lack of support for this service by its local Clinical Commissioning Group [CCG][58]. In other words, since different CCGs had different priorities, Longwater (as of 2016) had both the funding resources and dedicated staff to push the transition agenda and effectively formalise it into an established practice - whilst Carden did not.

As a consequence, Suzy felt that her role focussed on bridging the gap between child and adult services. Until the time came when adult services could fund their own formal transition CQUIN role, she would continue to 'act on behalf of both services by making sure adult services were adequately equipped' to receive these young people[59]. In light of this, Suzy felt that dedicated managerial and administrative roles were required, if not a necessity, to enable transitional healthcare to function and continue as a practice. In Suzy's view, the role of the Transition Nurse was therefore effective in both establishing transition as a legitimate clinical concern and formalising it into a Trust-wide legitimate service:

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[58] Following the Health and Social Care Act (2012), CCGs were created to replace Primary Care Trusts that had been in place since 2001. CCGs are clinically-led statutory NHS bodies that are responsible for the planning and commissioning of health services within their local area. At the time of fieldwork, there were 207 (191 as of April 2019 – at time of writing) NHS CCGs in England and together they are responsible for two-thirds of NHS England's budget – approximately £73.6bn (£79.9bn in 2019/20) (accessed from https://www.nhscc.org/ccgs/ on 04/10/2017 and again on 29/05/2019).

[59] Admittedly, Suzy acknowledged that she could only ensure that the paediatric clinicians maintained complete and up-to-date medical records of all transition-aged patients. This meant that the future adult clinicians would always be fully informed of a patient's medical history.

> **Suzy:** If it gets left to the on the ground staff nothing would happen. They are so busy they don’t have the dedicated time to go through these things – I do.

The role of the Transition Nurse was, therefore, a management strategy to establish and maintain this practice of care. Echoing Dr Roberts’ earlier point, for a clinical practice to gain a firm ground, managerial support was required for it to be taken seriously, legitimised and ultimately become a stable and widely accepted practice.

In addition to developing Longwater’s transition policy, Suzy’s role in managing the ongoing formalisation of transitional healthcare included strengthening what she called its ‘business case’. This meant demonstrating that the policy (and the Ten-Step Pathway within it) were both feasible and cost-effective. This was achieved through submitting what is called a Proof of Concept application to Longwater’s Clinical Business Unit [CBU]. The CBU’s at Longwater were each led by a senior clinician, a senior manager and a senior nurse. Together, they were responsible and accountable for the overall clinical, workforce and financial performance within their clinical area. Suzy’s Proof of Concept detailed the outcome of any piloted clinics (such as the TEC), feedback from any clinicians regarding transition and projected costs and savings of developing a formal transitional service. Since her Proof of Concept had been approved, the CBU deemed transitional healthcare was indeed a crucial issue with feasible solutions and something that they were willing to fund. Consequently, Suzy now focussed her work on strengthening the business case in order for the Trust to implement transitional care further:

> **Suzy:** This Proof of Concept is based on the audit/research work carried out in previous years. If a Proof of Concept is approved the Trust gets funding to run a programme. Without this approval and without the CBU we can’t make

> transition a standard care practice and then it's just left to individual doctors to do what they see fit. Like in epilepsy, it's great they took the initiative but not all clinicians do.

Suzy explained that the requirement of managerial and administrative roles meant that all forms of healthcare must therefore adopt a business approach – as opposed to a caring or wholly altruistic one - when formally establishing a relatively new practice. This method of legitimising transitional healthcare differs from the one earlier explained by Dr Roberts. Whilst Dr Roberts' activities involved writing about, speaking of and practicing transitional healthcare to increase the level of support for it, Suzy, however legitimises the practice through policy development and standard forms of care (such as the Ten-Step Pathway) that are then verified and funded through local commissioners. For Suzy, it was through proposed business models and proof of economic value that a sense of stability and formality to the transitional healthcare case was achieved. To view clinical care in economic and financial terms is significant in the context of the increasing austerity measures within UK public services (Slorach, 2016). Consequently, a business approach to healthcare has the effect of making institutions subject to an intensification of auditing and performance management (Strathern, 2000). For example, accountability was demonstrated through continual audits of the TEC to ensure it was meeting 'quality standards'. Therefore, the clinician's expertise, years of experience, and embodied knowledge were no longer sufficient markers of reassurance for Trust managers.

From this, we can see that efforts toward formalising and standardising transitional healthcare are symptomatic of wider sociocultural trends within medicine that are concerned with risk avoidance, institutional liability and denounce any references to improvisation in medical practice (Mol, 2006; Moreira, 2005; Timmermans & Berg, 2003). With transitional healthcare increasingly structured on grounds of pursuing efficiency, standardisation requirements that are introduced by organisational cultures become examples of how institutions shape patient behaviour to conform to their standards, values or targets (Timmermans & Berg, 1997). I now move on to present the final act of stabilisation, that of evidence accumulation through scientific principles, upon which policy and management were predicated.

Part 3: Evidence-Based Medicine: The role of research in stabilisation

Continued research into adolescent development and service provision were fundamental parts, of not just the TEC development, but of the transition agenda more generally at Longwater and Carden. According to Suzy, ongoing studies into the ‘many needs’ of adolescents were vital to the process of formally establishing a transitional healthcare practice:

> **Suzy:** It’s a way of proving its [transitional healthcare’s] value to young people but it also informs the clinicians on how best to run the clinic in order to meet the needs of the patients.

The TEC clinicians who were engaged in epilepsy transitional studies often emphasised to me that there was a preferred way of practicing research, or as Dr Barton concluded, there was ‘a right way to conduct the right kinds of studies’. This supposed ‘right way’ of undertaking research concentrated on conducting studies that were believed to appeal to particular epistemological, or more specifically knowledge-production, ideals. The first knowledge-production ideal was that the value of a research study should be judged according to a hierarchy of evidence. The second ideal was that all aspects of the research process should be democratic, meaning that research (and subsequent services developed from such research) should represent the needs of its patient population. Simply put, it was evidence-based medicine [EBM] that satisfied both these prerequisites. With this particular mode of knowledge-production being the empirical foundation upon which the transitional policy and transition nurse role were created, I now turn to discuss the epistemological base and the resulting assumptions that underpinned adolescent healthcare at the field sites.

In his essay, *Beyond the Standard Human*, sociologist Steven Epstein (2009) highlights the combination of 20th century developments that have converged to encourage, what he terms, ‘a relentless standardisation of medical practice’ (pg. 40). These developments include the rise of pharmaceutical drug testing and regulation, the growth of epidemiological studies based on notions of statistical risk, and the rise of evidence-based practices within biomedicine and clinical research (Timmermans & Berg, 2003; Timmermans & Kolker, 2004). In the social sciences, standardisation and its related concepts of quantification and formal representation[60] are processes by which various kinds of standards are established in order to efficiently manage and organise people and their activities. This underlying assumption of standardisation as a method of organisation is echoed in the practice of EBM wherein models of science are increasingly mobilised to inform medical practice (Kierans, Kingdon & Bell, 2016). Increasingly viewed as the go-to model of care within UK medicine, EBM

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[60] The following quotation from Lampland and Star (2009) best denotes the processes involved in standardisation and quantification: “Quantification is the representation of some action, being, or model through numbers. Formal representations are those not tied to a particular situation or set of empirical data but, rather, are a synthesis of data and a presentation of rules for combining and acting. These are often conveyed in visual form, such as graphs, tables, or formulae. They may also be conveyed in narrative form, such as conventional sayings or standard characterisations of phenomena.” (pg. 9).

relies on ‘proven’ diagnostic and therapeutic guidelines to organise and negotiate care (Ham, 2014; Timmermans & Berg, 2003).

Hierarchy and democracy

In presenting me with Longwater’s *Transitioning to Adult Services* policy, Suzy took pride in the fact that this work, her work, was an example of EBM. Additionally, the research on which the policy was formed (as well as upon which her job role was created) appealed to what is commonly termed as the ‘hierarchy of evidence’. The hierarchy of evidence reflects the authoritative assumption that various types of biomedical research (such as randomised controlled trials [RCTs]) are considered the gold standard of clinical research and are more valuable to EBM than, for example, qualitative interviews (Kierans, Kingdon & Bell, 2016; Timmermans & Berg, 2003).

During fieldwork, the meaning and value of a hierarchical approach to clinical research was best exemplified through my discussions with Sara. Sara was a Clinical Neuropsychologist at Longwater. Although she was not currently active in research, she had previously studied for a PhD in cognitive science and co-authored several empirical papers within the area of child and adolescent neuropsychology - therefore, providing Sara with a very positivist background. To help me understand the importance of this hierarchy of evidence to the development of transitional healthcare, Sara sketched a commonly-used illustration that she had encountered over the course of her clinical and academic training [see Figure 3]. As she sketched, she muttered to herself that she was unsure of what to put in the middle steps. Not willing to commit, but also not wishing to leave the spaces blank, she scribbled ‘cohort studies’ and ‘cross sectional survey design’ alongside a question mark. However, what was undoubtedly clear to her was that RCTs and secondary (meta) analyses of statistical, experimental

RCTs were at the pinnacle of the hierarchy whilst, ‘case studies, expert opinion, anecdotes and editorials etc’ belonged at the bottom. Concerning transitioning, this meant that RCTs were required to better understand this relatively new form of care.

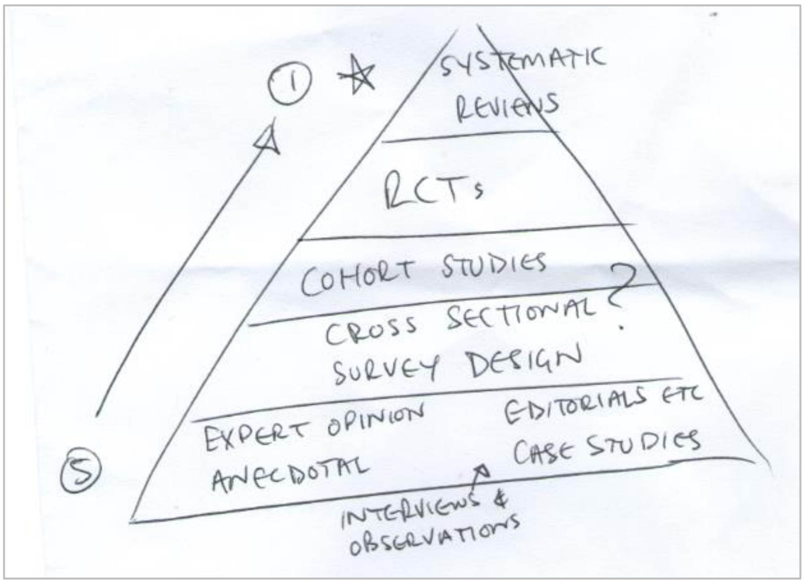

Figure 3. 'Hierarchy of Evidence' sketched by Sara-Fieldnotes [March 2015].

Sara explained to me that there was a constant scrutiny upon transitional healthcare within the Trust. She described the Trust managers as ‘not believing’ transitional healthcare to be as important as she and her colleagues saw it to be. In such a way, Sara felt that it was vital to conduct ‘proper research’ into transitional healthcare where science and hard evidence justified the need for such action:

> **Sara:** It’s all well and good doing observation type studies where we get to know our population but it’s proper research, intervention, piloting services that will get the ball rolling. Transition - it’s already backed up by what we know about the human brain during adolescence. It can be a terrible time and we should act on what knowledge we already have about it. We’re not here to satisfy our intellectual curiosities, we’re here to make people better.

In this sense, ‘proper research’ as Sara states, is used not only as a form of knowledge-production but also as a method of persuasion and as a moral course of action. For health professionals at Longwater and Carden, formalising healthcare often meant creating strong scientific foundations for their clinical practices by focussing on the meanings of evidence. For example, Sara legitimises the need for transitional care through ‘real’ neuroscientific truth claims regarding the ‘terrible’ nature of adolescence (Rose & Abi-Rached, 2013). Taking the nature of adolescence for granted, Sara calls for clinicians to do what she thinks clinicians ought to do, that is to ‘make people better’ and to continue improving and pushing for a formalised transitional healthcare.

The second way in which research was considered ‘proper’ was if it was deemed democratic – in other words, inclusive of all patients. At Longwater and Carden, research efforts focussed on quantitatively assessing young people’s views regarding transitioning. However, all of the ongoing epilepsy transition studies at the field sites explicitly excluded the views, opinions and proxy reports of those with moderate to severe learning disabilities. Sara offered what she saw as potential contributors to this noticeable exclusion of young people with learning disabilities. Speaking of her past clinical research experience, Sara informed me that when recruiting patients into a study, she would often stress to them the importance for them to ‘speak up and let their voices be heard’. Sara would emphasise that their voice was necessary because the NHS ‘belonged to everybody’ and all citizens should have a say in how its healthcare is delivered. However, she explained that there was an added complication when recruiting people with limited intellectual capacity into research studies due to R&D governance and ethical approval. For example, to include people with learning disabilities, researchers were required to compose and complete extra pro forma prior to study approval from Trust and research ethics committees. Sara explained that this 'extra work' had the limitation of prolonging the overall length of a study, and consequently, clinicians may opt to exclude this population from their studies. Therefore, people with learning disabilities (whether explicitly stated or not) were construed as posing a burden to the increasing appeal to workforce efficiency between the two Trusts.

Furthermore, Sara told me that young people with learning disabilities were unable to contribute directly to what she called a 'democratic approach to science', without the proxy report of their parents or carers. Within the NHS there is a sustained effort towards patient-centred services that are open and accountable (Mockford et al, 2012), this was an ingrained part of Longwater and Carden culture and was reflected in Sara's use of stock-phrases such as 'We want you hear *your* views' or 'This is *your* NHS you should have *your* say'. However, the views of those with learning disabilities were noticeably absent from all of the research projects upon which TEC development rested but also the views of patients and carers were absent from the development of Longwater's policy on transitioning to adult services. Nevertheless, this meant that what was considered 'proper research' often produced what could be considered as undemocratic results - results wherein the views of one group of people were continually excluded based on individual capacity to understand how to participate in particular standards of research.

Taken together, the principles of hierarchy and democracy reflect the authoritative assumptions that surround biomedical research, e.g. RCTs were considered superior to qualitative modes of research (Timmermans & Berg, 2003). As such, the research that underpinned the transitional practice at the field sites was a product of wider trends toward standardisation in biomedicine (Adams, 2013; Colvin, 2014; Goldacre, 2013; Petryna, 2009; Bhiel & Petryna, 2013; Timmermans & Berg, 2003). Health professionals at Longwater and Carden were addressing what Adams (2013) claims as the problem of ‘non-standard variation in clinical practice’. Furthermore, the manifestation of EBM within the TEC, particularly with its ‘democratic’ grounding, is an example of the fair and equal mode of care delivery that is promoted by institutions such as the NHS. In other words, a healthcare system that emphasises universalism, beneficence and equity and operates within a specific entanglement wherein certain social actors (such as clinicians, researchers, or patients) have social obligations to each other (Kierans, 2018). In short, the *Transition to Adult Services* policy and the research that underpins it, reflect important cultural assumptions about how people and institutions work together.

Conclusion

The purpose of centring this chapter upon acts of stabilisation has been to make visible the often-unseen work that goes into establishing and formalising a relatively new clinical practice. The central argument has been that in order for transitional care to achieve durability, a complex association of components, or actors, must successfully align and hold together. For example, the creation of the transition policy was predicated on the work of management as well as the results of past and ongoing research. This shows that care policies, pathways and practices do not come out of a vacuum but are instead drawn from a whole cultural context and history of knowledge production within biomedicine that emphasises a stronger evidence-base. Consequently, we can view the *Transition to Adult Services* policy and the Ten-Step Pathway as artefacts of particular knowledge-production practices and as the logical outcome of the methods used to create them.

Through policy development, the creation of dedicated managerial roles and having been founded on EBM principles, transitional healthcare was increasingly being handed a more stable existence within its local clinical landscape. This has implications for how recommendations to produce a healthcare service that reflects the needs of *all* young people are made to work at the local, institutional level. Consequently, we can begin to see that the 'challenge' of transitional care goes beyond questions that look outwardly - for example, how to make adolescents more responsible and independent. Moreover, questions can now surface regarding whether the institution can look inwardly, at their own practices and assumptions, to assess whether or not they may be contributing to this very challenge - for example, how may the distinction between paediatric medicine and adult medicine contribute to widening the transition gap?

The process of stabilising clinical practices through policy, management and research, not only helped to legitimise it, but it also shed light upon the values of the institution at hand. In other words, by examining policy and research we are able to see what it was that Longwater and Carden valued in its patients, and how it envisaged them becoming responsible for themselves. As Lucy Suchman (2007) shows us, planning models (such as the *Transition to Adults Services* policy and in particular the Ten-Step Pathway) are statements of intent. These statements reflect instructions for action however; rarely do they address the question of situated actions in any level of detail. Therefore, a statement of intent, plan or a clinical practice guideline says little about the actions and experiences that follow. By addressing what it means to make standardised practices an everyday part of clinical care, this chapter has examined the institutional efforts made towards managing complex populations by shaping them to conform to a general, idealised standard. As such the development of the transition policy for young people with CHNs is an attempt to provide a standardised care pathway for those conditions which, by virtue of their classification (complex health needs) are unlikely to be uniform or standard.

By focussing this chapter (and the previous) on the institutional and infrastructural aspects of transitional healthcare, I make way for the following chapters that show how the plans and intentions of the institution may fall apart when patients do not conform to standardised practices, pathways and policies (Street, 2014; Suchman, 2007, 2014). In the next chapter, I continue to explore the implications of standardised care practices for those who have a markedly different experience of transitioning to adult services. In particular, I discuss what it means to pass through adolescence and into adulthood within the context of a medical culture that valued and idealised young patients who were independent and responsible.

Chapter 6 – Producing Idealised Subjects: A journey into an independent and responsibilised adulthood

Building on the previous chapter's examination of policy development, managerial roles and research that have helped to formalise the practice of transitional care, this chapter discusses how parents/carers of young people with ELD experience such formalised care. To this end, I examine the content and subsequent use of a transitional care document, the *Transition to Adulthood Table: A Guide for Parents*, published by the neurological charity Cerebra in 2014 [see Figure 4]. Ethnographic scholarship on bureaucratic and institutional documents (Hull, 2012) explore how material artefacts come to construct subjects and socialites (Callon, 2002; Mol, 2002), and therefore, shape interactions between the people and the public institutions of health and social care (Buse, Martin & Nettleton, 2018). As such, this chapter explores the generative capacity of these mundane institutional documents and their capacity to 'make things come into being' (Frohmann, 2008). This is important to the current study because, to borrow from Lucy Suchman, I take the institutional 'plans of intent' (2007; 2014) – in the form of material artefacts such as patient information sheets and care plans - to show how institutional intentions were integrated into family life and shaped their daily experiences of caregiving.

This chapter is organised into two parts. Through a series of ethnographic stories, in part one I make explicit and central the ways in which material artefacts were used by service users. In part two, I present a threefold typology of the ELD transitional care experience. This typology is based upon analysis of the families' stories shown in part one but also informed by interview and observational data with other participants. Furthermore, I reflect upon what this typology means for the wider phenomena of transitioning to adulthood with severe learning disabilities.

Part 1: Materialities of Care: Shaping the experience of adolescence

Whilst material artefacts can encompass many different objects from hospital architecture (Jones, 2018b; Martin et al., 2015) to biotechnologies (Locock et al., 2016), in the current study it was the modest leaflet - an object routinely handed out by health professionals or left lying around clinics for patients to pick up at will - that was prominent in showing how care was practiced through 'things' (Puig de la Bellacasa, 2011). By chronologically mapping out the key activities within a process, care guides and pathways (like the one used by the families below) demonstrate the institutional expectations at play in a given healthcare practice (Llewellyn et al., 2018). Consequently, the *Cerebra Transition Guide* represents the 'plans' (or idealised intentions) as described by Lucy Suchman (2007) in her study of human-material interaction between people and Xerox machines. Suchman (2007) explores the rift between institutional plans and 'situated actions'. Emphasising the tensions that exist within human-material interaction, Suchman argues that plans must incorporate unpredicted contingencies and respond to the actions of others and the circumstances they find themselves in. However, this 'slippage between a standard and its realisation in action' (Lampland & Star, 2009, pg. 15) is where we can better appreciate how standard care pathways, guides and leaflets interact with services users.

My intention in focussing on the use of the *Cerebra Transition Guide* is twofold. First, it is to acknowledge that materials are key actors in the network that holds together care provision. For example, Buse, Martin and Nettleton (2018) define 'materialities of care' as heuristic devices that 'make visible the ordinary, tacit and non-verbal aspects of care practices' (pg. 245). Second, it is to understand how the institution's plans of intent, when represented in such a clear visual form as this particular guide, were taken up by service users. To attend to the materialities of care, as I have approached it, is to focus on the mundane physical ‘things’ or ‘objects’ that constitute caregiving. Rather than taking such artefacts for granted, this chapter shows them to be objects with agency that directly influence how transitional care is experienced. To demonstrate the ‘slippage’ between plans and situated actions, the following three ethnographic stories discuss as follows: 1) the Hill family’s application of care guidelines into their daily life; 2) the Holbrook family’s account of anxiety and alienation prompted by guidelines and, 3) Jason Bates and his paid carer Nic’s[61] adaptation of guidelines.

Ethnographic Story 1 - The Hill Family

I initially met Sally Hill whilst observing my first TEC at Carden Epilepsy Services in November 2014. Sally was 19 years old and this was her second TEC consultation. Prior to Sally and her family entering the TEC room, both Drs Roberts and Barton had agreed that this would be her last time in the TEC before she ‘graduated’ into the adult epilepsy clinic. Sally, whose medical file stated that she had epilepsy, leukodystrophy and severe learning disability, had been a patient of Dr Roberts since she was diagnosed with tonic-clonic seizures aged 11 months old. As such, Sally was one of those patients who had received the much-sought after continuity of care[62], or in Dr Roberts’ words ‘the full transition experience’. This consistent care relationship with

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[61] As will later become clear, Jason Bates (who lived away from his family) was cared for by paid carers, 24-hours per day within a supported-living accommodation. It is to these live-in carers that I refer to as his family because, despite Nic providing paid care for Jason as a client, their situation also resembled something of a family unit.

[62] In the context of the TEC, continuity of care was described by Dr Keegan as, ‘a seamless integration of paediatric and adult care.’ In other words, having one paediatric neurologist who cared for a patient in both Longwater and the TEC before handing them over to adult services was seen as the ideal transition. For further discussion of the term see Gulliford, Naithani and Morgan (2006).

Dr Roberts was palpable through his easy and relaxed interaction with the family. Dr Roberts left the clinic room to greet the Hill family in Carden's busy waiting area[63]. When he returned, he was chatting with Jillian and Alan (Sally's parents) whilst Sally linked his arm for support. The family were clearly at ease with their doctor - a result, no doubt, of knowing him for a lifetime. Unsurprisingly, Sally's parents were saddened to hear that this would be the last time that they would see Dr Roberts. When leaving, Jillian commented, 'So it's over, just like that'. She embraced Dr Roberts, thanking him for his support over the years and he reassured her that Sally would receive care that was just as supportive in the adult neurology clinic. As they left, and Dr Roberts took up his seat behind the desk, he said to me 'It's a bittersweet thing, after knowing them for so long'.

The following week, I interviewed Jillian at home where she also invited me to join her in collecting Sally from school. In a few months, Sally would be enrolling into an adult college for young people with learning disabilities. It was planned that Sally would attend a day college where she would register with a life and social skills cohort.

> **Jillian**: It's not like real college, with subjects and that, she'll learn how to interact in a shop. Y'know she'll learn how to handle money, how to use a bus, make a cup of tea that kind of thing. Daily interaction and stuff.

As she was packing her bag to leave the house, Jillian checked the contents of an A4 document file she carried in her hand. However, as she leafed through the assortment of papers it became apparent that something was amiss. Jillian rushed upstairs

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[63] An act in itself that was special. The usual practice for calling in TEC patients was to alert them via the five TV screens that were placed on the walls of Carden's waiting area. This was the only occasion that I observed something this intimate with genuine care and affection between the health professional, patient and family.

explaining that she needed a specific document, one that had ‘all the right questions on’ – questions that she wanted to ask Sally’s school teacher. Returning downstairs, she waved the document in her hand. This single piece of paper that she was so frantically searching for was the Cerebra *Transition Guide*. The table graphically depicts what it called ‘the responsibilities of education, social services and health agencies in the transition process’ at specific points from ages 12 to post-18 years. For Jillian, it provided a clear, chronological outline as to what could be expected from the various services at different stages of her daughter’s adolescence. Of importance to Jillian was that this document aided her in asking the right questions, at the right time, across different service domains.

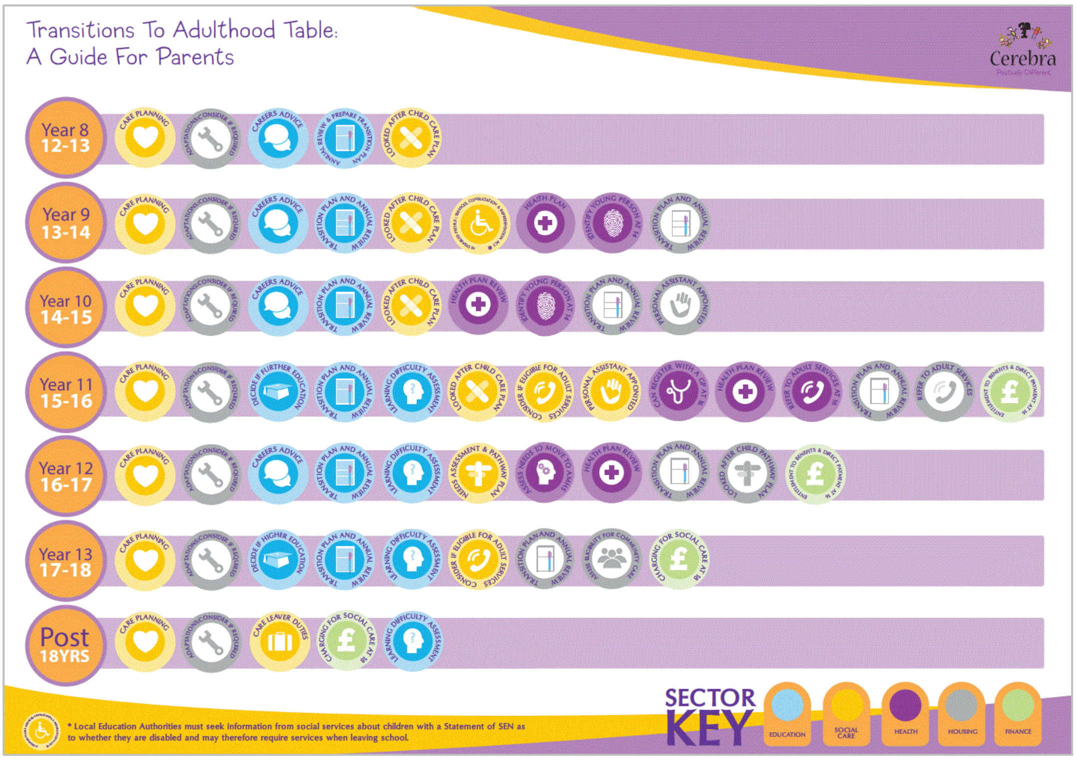

Figure 4. Cerebra Transition Guide (2014)

Since her daughter’s disability was so profound, Jillian interacted with multiple health, social and education services on a daily basis. Therefore, she described this document as ‘saving her from having yet another thing to think about’ in her communications with a myriad of health, social and education professionals. In total, Jillian kept seven copies of this document - one for each different appointment that she needed to attend regarding Sally and her transition to an adult based service. Jillian organised these documents as follows: 1) EPILEPSY, 2) LEUKODYSTROPHY, 3) LD 4) PSYCHOLOGY, 5) SCHOOL, 6) SOCIAL WORKERS 7) DISABILITY/FUNDING.

She would take each applicable copy along to its corresponding appointment and jot relevant notes around the edges. It was the copy she reserved for 'SCHOOL' that she was searching for before we left the house:

> **Jillian:** It keeps me on the right path and can be used across all of Sally's appointments – it's basically the same questions for all those things. It makes what is an already mad, busy life a bit more simple. I know where I'm up to then, what application form we've already filled out, what we have covered X, Y and Z at such and such appointment. It's really good and keeps everybody on the right path

Jillian told me that the document was popular amongst other parents of teenagers with neurological conditions. The seven copies that Jillian owned were given to her by another parent who attended a local support group. This parent had photocopied her own guide, which she had received directly from the TEC, and handed them out to other parents at the support group. Jillian informed me that because the document was no longer available via Cerebra[64], she too would photocopy it for other parents of children with disabilities to use however they saw fit. These blank copies were then reproduced numerous times when handed to other parents or shared across social media.

In addition to showing me the ‘SCHOOL’ transition Cerebra document, Jillian also handed me the version marked ‘EPILEPSY’. This paper had many markings on it; scribbled words such as ‘Carden’, ‘dr barton’ and ‘cancel’ along with phone numbers that were scrawled along the top and other fragments of writing that I could not quite make out. I asked her what the various writings meant:

> **Jillian**: I can’t even understand my own scrawl [LAUGHS]. I must have known at some point. The epilepsy transition is finished with - she’s with Dr Barton now. I guess that can go in the bin now.
>
> **Shelda**: How was that? Your final appointment in the TEC.
>
> **Jillian**: Oh gosh it got quite emotional for us even though we were prepared for it [waves the transition guide]. We’ve known Dr Roberts for years and I can honestly say we owe him our lives, so to just end that relationship is heart-breaking for us. Everyone says how great Dr Barton is and when we’ve met him, he seems nice enough but it’s just not the same is it. We knew it was

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[64] Since this document was so significant to Jillian, I wished to obtain a copy for my own interests. However, when I contacted the charity Cerebra, I was informed that the guide was now considered ‘outdated, irrelevant and non-standard.’ Before emailing me a copy of *Transition to Adulthood Table: A Guide for Parents,* Cerebra asked me to confirm that I agreed to not share this document with patients or parents but to use it solely for research and demonstration purposes. I was also informed by Cerebra that there were no plans to re-develop this document for future publication. Nevertheless, and in spite of the publisher’s intent to stop the distribution of the document, that did not stop the document being re-produced by the parents.

> coming [she waves the ‘EPILEPSY’ document] so we should have been more prepared. But Sally, my word she wasn’t half upset in the car on the way home - we had to stop on the motorway because she was carrying on so bad.
>
> **Shelda**: In what way?
>
> **Jillian**: Well in the car Alan stupidly said ‘Oh that’s the last time you’ll see him,’ and she just started crying. Then we were trying to explain ‘it’s ok he still works at the hospital’ but she was still crying - really hard like. We pulled into the [motorway] services, got her a drink and cake [LAUGHS]. In the end, we said she’ll get to see him at her next appointment, and silly dad got it wrong. I just hope she forgets. Somehow, I think she won’t – it’s a shame isn’t it.

When we left the house, Jillian gathered a pile of rubbish, mostly papers, to put in her outdoor wheelie bin. On top of this pile she placed the EPILEPSY cerebra document, ‘End of an era’ she said to me before putting the pile of papers into the bin and heading off to pick up Sally from school.

Ethnographic Story 2 - The Holbrook Family

The above account demonstrates how the Cerebra *Transition to Adulthood Table: A Guide for Parents* was a preparation tool and simplified what was an already complex time in the Hill family’s life. However, in the case of the Holbrook family, the same tool did not prove as useful. I first introduced Daniel Holbrook in Chapter 4 as a way of highlighting the physical distinction between a paediatric and adult healthcare setting. There, I described how the child-friendly environment of Longwater, with the availability of toys, reduced 17-year-old Daniel’s anxieties when entering the clinic room. Furthermore, his ENS (Penny) had expressed concern that adult services would not provide Daniel with such calming measures. Likewise, Daniel’s mother Gail held fierce assertions against moving her son away from the ‘familiarity of paediatrics and into the inappropriateness of Carden’. Similar to Sally Hill, Daniel had also been under the care of Dr Roberts since his infancy and the family had subsequently developed a trusting and close relationship with him. During one particular home interview with Daniel’s parents Gail and Mark, they recounted a time when they felt comfortable enough to question Dr Roberts’ opinion regarding their son’s medical care:

> **Gail:** There is no barrier with him [Dr Roberts]. If I disagree with his opinion, rather than dismiss me as a paranoid mother, he listens. I know that’s rare in doctors and I don’t expect to find it again when he [Daniel] goes over to Carden. It’s a level of comfort that takes years to build.

This close relationship with Dr Roberts was important for Daniel’s parents as they began to tell me of the constant struggle that being a parent of a child with learning disabilities encapsulates. Therefore, having confidence in the professionals made the life of the families less demanding. This sentiment - feeling as though young people with learning disabilities were disregarded by health/care institutions - was a common feature amongst other families I spent time with. Similar to the Holbrook’s, families would often speak of their interactions with adult health, social or education professionals with terminology reflecting violence and struggle. Figurative phrases such as ‘fighting tooth and nail’, ‘bleed yourself dry’, ‘constant battle’, and ‘a fight for care’, were prevalent within the interview transcripts. These phrases became common ways of describing access to health and social care services when moving from a child to adult environment - but none more so than within the interviews with the Holbrooks. Their frequent, almost daily interactions with doctors, social workers and the local authority[65] was described by Gail as being half the battle of having a son with learning disabilities. Consequently, the Holbrooks' relationship with Dr Roberts was a vital relief – something that they anticipated the end of once Daniel transitioned into Carden:

> **Mark Holbrook [Daniel's father]:** There's some [professionals] that you've got to question. They just don't have the know-how or the confidence to deal with kids like Dan, or they're just not interested. When he was younger things ran smoothly but now everything seems to be getting taken away from him and, in a way, we either have to be ready to fight for that care or learn to let it go. You have to pick your battles, for example one, nurse at Carden didn't know about specialist LD services in our area and I mean at times we've felt that we're doing their job for them.

At this interview, Gail and Mark showed me an example to highlight their concerns about transitioning to adult services. From a pile of papers stacked high on the kitchen table, Mark retrieved the Cerebra *Transition to Adulthood Table: A Guide for Parents* and handed it to his wife. Holding the document, Gail explained that Daniel was never going to reach these goals but was expected to 'at least try'. According to Gail, the 'battle' that parents of children with learning disabilities face relates to their children being viewed (by others outside of the family unit) as abnormal:

> **Gail:** Rather than another aspect of being human, of the human condition, Daniel is seen as abnormal. Something that is undesirable. That's the battle. If

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[65] In the UK, local authorities are the official government organisation responsible for all public services and facilities in a given area. Many families in the study who were accessing post-18 disability social care had to petition their local authority in order to fund such care.

> everyone saw him the way we do and were more accepting of him rather than wanting to eradicate people like him, then there’d be no problem. We create our own problems.

In stating that ‘we’ create our own problems, Gail was referring to what she called a ‘norm of our society and culture’ that has deemed Daniel, and others like him – those who refuse to conform to the standard model of what it is to be normal - as challenges for society. Looking across the document, Gail shook her head:

> **Gail**: Careers advice, housing, all these health plans and reviews that never happen. If I’m honest, kids like our Dan are just left to fend for themselves. This kind of thing [the Cerebra document] is written for kids who are going to go on and have some sort of life. Where’s the advice for people like us? We’ll be caring for Dan until forever.
>
> **Mark**: It makes sense to put all effort into ‘normal’ kids or those with mild difficulties because they’re the next generation going into society, but Dan doesn’t really go into society, does he? All this promise of health plans and reviews we just take it with a pinch of salt.
>
> **Gail**: When you’ve got a kid with disabilities, over the years you learn to lower your expectations of services and the government.

Consequently, Gail stated that she found the Cerebra document and transitioning (in any sector) more generally, as paying lip service to her son’s health. Despite its aims of increasing independence, the Holbrooks believed transitioning did not accommodate Daniel’s specific needs. Rather, it reiterated, the collective thinking of society, or as Gail expressed it:

> **Gail**: It [the cerebra document] just shows what everyone else wants for my son when he becomes an adult. It's the norm within our society. What if, as a family, we decided that school or college wasn't in his best interest and continuing to see Dr Roberts was. What then? We just have to go along with everyone else, y'know to include him [Daniel], superficially, in 'normal' life.

Echoing the findings of Rapp and Ginsburg (2013), Gail struggles to find a post-adolescence articulation of care, education and health that is suitable for her son. For Gail, this social norm of superficial inclusion stood to further segregate, rather than integrate, young people with learning disabilities. Furthermore, she described such a social norm as cruel and barbaric. In particular, Gail emphasised that this norm was not cruel for Daniel, since he remained 'largely unaware of what is going on around him', but it was cruel for the parents who have to watch as their children are constantly viewed as jarring an otherwise perfectly functioning social system. In this sense, standardised pathways of care (that reflect standardised models of adolescent development) can be considered as being one contributor to the psychological distress felt by carers:

> **Gail:** I read these leaflets and they say going into adulthood is exciting, you will be independent, you get a job, your own home blablabla but in a way it just reminds me that what we're dealing with isn't normal, he's never going to be grown up. He was never a normal kid and he won't be a normal adult. He will always be the same. He's himself. And that's fine for us but is it for everybody else? I couldn't care less to be honest, but it just goes to show that he doesn't fit in with what's wanted. And that's hard. People like our Dan just aren't wanted.

According to Gail, the information contained within institutional artefacts such as leaflets, documents and guides, were both inappropriate and insensitive to her family's situation. The Holbrook's case shows how standardised practices, along with their associated material artefacts, stand to reaffirm the desired norms of the day – which, according to the transition agenda, is to value responsible adults who are independent and engage in self-management and care.

Ethnographic Story 3 - Jason and Nic

Twenty-one-year-old Jason's lived 50 miles away from his parents in a supported living accommodation. Within his supported-living home, Jason shared a two-bedroom apartment with Barry, a 35-year-old man with Downs Syndrome. This living arrangement meant that both Jason and Barry received 24-hour home care from live-in paid carers. The main duties of Jason's carers were to provide him with daily support that enabled him to lead a fulfilled life. This included managing his finances, personal hygiene, meeting his nutritional needs and supporting him to engage with the wider community amongst many more caregiving duties.

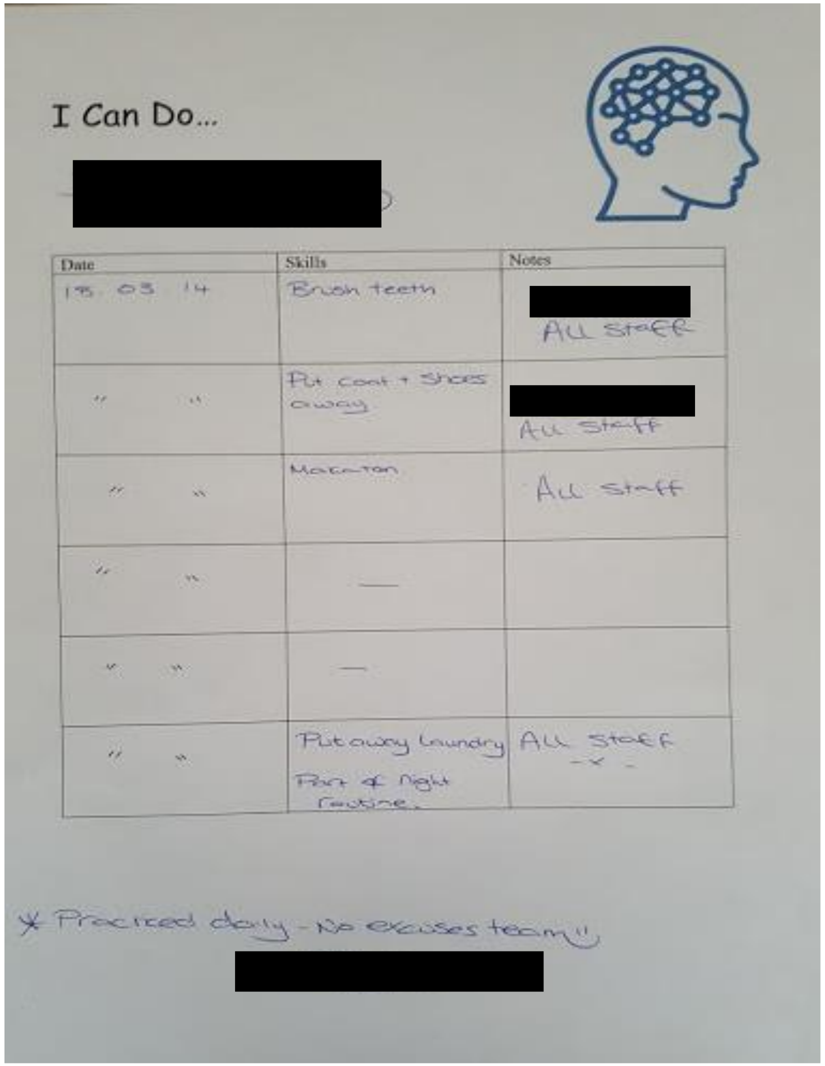
I first met Jason at his first (and only) TEC appointment in the late summer of 2015 before he was to be moved into Dr Barton's adult clinic at Carden. At this appointment he was accompanied by Nic. Jason was diagnosed with Lennox-Gastaut Syndrome when he was 6-years-old but had been seizure-free for the past six months prior to his TEC consultation. In addition to an AED regimen, Jason also followed a strict ketogenic diet. According to Nic his epilepsy was reasonably well controlled by his treatment plan. However, she suspected that there had been the occasional breakthrough myoclonic seizure – a slight jerking of his left arm - within these six months. When Jason finished his TEC appointment it was decided by Dr Barton that

Jason would graduate into his adult clinic. Dr Roberts agreed to this, stating that since he did not know the patient he thereby would not be of much use to his ongoing care.

When I met up with Nic and Jason a few weeks later at his apartment, our initial plan of going to a nearby park, one of Jason's favourite activities, was cancelled. The day had been sticky and humid with the odd thunderstorm so, coupled with Jason's intense fear of storms, Nic had decided that we would have what she called a 'pyjama day' - a day spent at home in pyjamas watching a movie. On this occasion, the movie was Jason's choice and, just as Nic had predicted, he chose his favourite - Disney's *The Jungle Book*. Jason sat with his legs curled up on the couch. He was wearing earphones that were attached to a silent MP3 player whilst he watched the film. He remained this way until the song *The Bare Necessities* began. At this point, he removed his earphones and gave his full attention to the film. Once the song had finished, he placed the earphones back in and continued to watch the action on screen whilst blocking out any sound. 'He does that' Nic told me, 'You just get used to his little habits'.

Pyjama days were not usual activities for Jason, 'We are skiving a little bit, but the weather's terrible – I don't want you to think I'm being unprofessional', Nic explained. When I asked what Jason's usual activities were, she handed me an A4 ring binder that was his care file. I took out a 5-page makeshift booklet that was stapled together and titled *My Skills – Jason Bates*. Specifically, the booklet contained two further sections '*I Can Do…*' and '*I am Learning…*' [see Figure 5]. Inspired by the Cerebra guide, Nic had generated her own version of a transition pathway. Nic's pathway - titled *My Skills* - reflected aspects of Jason's personal development that she believed best suited his individual needs:

Nic: We have a checklist that's standard throughout the company like wake up, breakfast, etc all things that need to be done every day. Check fire escapes are clear, what cleaning needs to be done and I could stick to that and I'd have done my job, but care is so much more than that. These are specifically Jason's checklist activities. Along with his doctor and social worker we came up with this something which helps him as he gets independent and heads into college. This is our transition if you like.



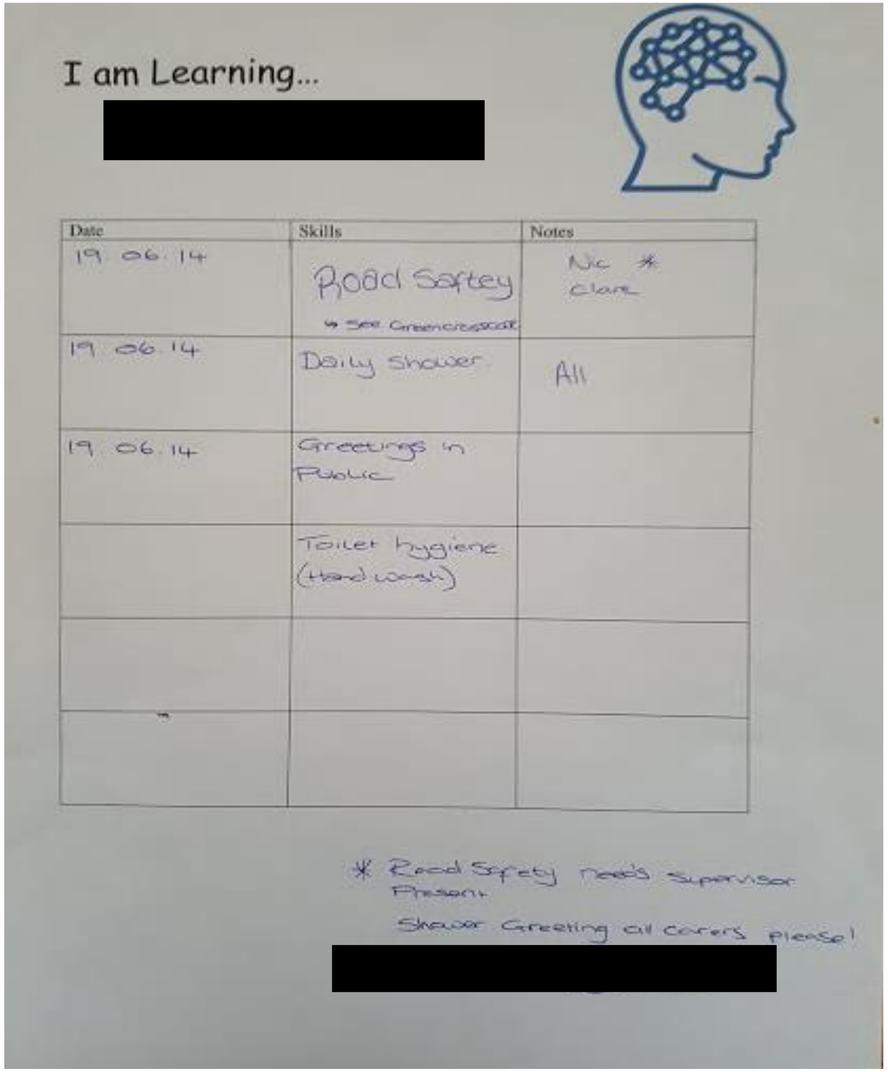
I Can Do...

[redacted]

Date	Skills	Notes
15. 03. 14	Brush teeth	[redacted] All staff
" "	Put coat + shoes away	[redacted] All staff
" "	Makaton	All staff
" "	—	
" "	—	
" "	Put away laundry Part of night routine.	All staff -x-

* Practiced daily - No excuses team!!

[redacted]



I am Learning...

[redacted]

Date	Skills	Notes
19. 06. 14	Road Saftey * see Greencrosscode	Nic * Clare
19. 06. 14	Daily shower	All
19. 06. 14	Greetings in Public	
	Toilet hygiene (Hand wash)	

* Road Safety needs Supervisor Present

Shower Greeting all carers please!

[redacted]

Figure 5. Photograph from Jason's 'My Skills' workbook

Since relocating from his family home and entering supported-living accommodation, Jason had enrolled in a local college. Just like his epilepsy care, Jason had not received any formal transition into the adult college. Speaking specifically of Jason's transition into adult epilepsy services, Nic told me that it had not been of much significance. Containing echoes of Dr Robert's judgement, Nic stated that since Jason had never been a patient at Longwater Paediatrics he was simply transferred into Carden, as any new patient would be.

> **Nic:** There's no harm to it [the lack of transitional healthcare], it's only leaflets and handouts but they're just not relevant really. Our situation is different to what they're aiming at. But nothing has changed he just has to see a new consultant every 6 months. There's no skin off our nose, as long as we transition him into adulthood ourselves then it's of no bother really. We do our own thing using bits and bobs like this [she points to the Cerebra guide].

Nic's claim that transition was not 'relevant' is followed by her understanding that the current way of practicing transitional care was aimed at others, that is to say it was for young people *without* disabilities:

> **Nic:** I wrote *My Skills* with his social worker and the doctor gave me this [Cerebra document] to help - just to give structure for the other carers who come on shift. It's sort of targeted at developing his social and self-management skills. So, if I am not working they, hopefully, help him carry out these tasks. We do it each day, practice, practice over and over - until it sticks with him. The brain is just amazing there's so much that we just don't know and even though he's severe [LD] he has a unique personality, which is

> developing all the time. We try to involve him in tasks that mimic the real world. We had this adolescent/transition training day. The LA [the Local Authority] are on this thing now were they keep repeating how the brain changes in young people. It was really interesting and ran by psychologists and doctors so they knew what they were talking about. That's why the checklist is about daily interaction – development is something that we can do every day.

I asked Nic why she had chosen to place a brain illustration in the corner of these checklists. Emphasising that she held a bachelor's degree in psychology, Nic explained the importance of 'rewiring his brain while he's young' through practical tasks, such as dishwashing, recognising money and interacting with shop assistants; activities that could be repeatedly applied in the real world:

> **Nic:** It's fascinating the changes they [adolescents] go through, it's all due to the brain and the way it develops when they're young. So basically, it's like these tasks develop his brain. But all these guidelines [points at Cerebra transition guide] and outcomes are designed on a large scale for teens or young people without LD. Basically to do the best for the highest number of people. So, we have kind of adapted our own to suit him.

Nic invited me to look further through Jason's personal care file whilst we stayed home on pyjama day. The file contained a plethora of transition information leaflets from various epilepsy, LD and SEN [Special Educational Needs] organisations, all of which were crammed into the A4 plastic wallets. Nic explained that these information leaflets were 'stuff we've picked up along the way', bits of information that she may (or may not) have found useful to the creation of Jason's personalised transitional care guide. I was struck by the number of images of the brain that adorned the file and its contents despite this being within a domestic/home (rather than clinical) environment. For example, one trifold leaflet was titled *Transitioning to Adulthood: The Basic Facts* and published by a SEN organisation. On the front cover of this leaflet was a lateral-view illustration of the brain. The illustration was a simplified depiction – cerebellum and brain stem removed - with different colours denoting the lobes of the brain (red frontal lobe, blue temporal lobe, green parietal lobe and yellow occipital lobe). Another SEN leaflet titled *Teenagers and Social Care* presented the brain as a series of interwoven pathways of red, blue, orange, green and pink. These illustrations, alongside the clipart of a brain that was sellotaped to the front of Jason's file, demonstrated the symbolic significance of the brain to the concept of adolescence and the transition into adulthood.

When the time came for me to leave later that evening Nic was extremely apologetic. She confessed that she felt guilty for not showing me 'Jason's full potential'. She blamed it on the weather and his fear of thunder:

> **Nic:** We really don't sit on our backsides all day; I don't want you to think that. I know today looked unprofessional and that we don't do our jobs properly, but we are efficient with our time. I hope it doesn't come across too bad. We're completely pushing for his development, for his independence to grow and I know in a few months he'll be fine with the new tasks [LAUGHS] his brain would've adapted and rewired to it all [LAUGHS]. And he'll be settled into college as well, he's got a bright future so long as we keep up with his plan. It's basic psychology. We're investing all this into him now so that he can have that bit of independence when he's older. Y'know it's been proven

> - these years are crucial. We do everything we can for him but caring is so much more than what it looks sometimes you've just got to have lazy days like these. It's like any member of your family you show them love through care and care isn't just what we have said the targets are. Care is so much more than looking professional – like I say it's like love.

These three ethnographic stories show how different families, with diverse relationships to the TEC, approached transitional care through the medium of one document: *Transition to Adulthood Table: A Guide for Parents*. These stories show how a family's use of a transition pathway goes beyond the institution's intentions for such artefacts in order to reflect individual families 'situated' needs (Suchman, 2007). As we can see, a guided pathway can produce a complicated response – e.g. the sense of security that was provided to Jillian Hill and the alienation experienced by the Holbrooks. Consequently, we are shown that institutional plans of intent do not speak for themselves but, instead, are worked through by families to reflect their own set of circumstances, their own family values and their own intentions for their young person's future. Taking these ethnographic stories as my point of departure, I now turn to discuss how the kind of transition care pathway that was being put forward by the institution (but not necessarily taken up by services users) came to resemble a social practice whereby young people were being turned into the idealised social subjects.

Part 2: Making Ideal Subjects: The values of transitional care

The above three stories demonstrated what it was like to transition with ELD via a health and social care system that was preoccupied with a normative understanding of adolescence [see Chapters 2 and 5]. For these families, the Cerebra document not only negotiated the transition process, but also had a further effect of reifying the dominant conceptualisation of adolescence as a time of increasing independence and responsibility (Hull, 2012; Mayer, 2004). My analysis of this document, alongside each family's way of interacting with it, characterises the transition to adulthood in a particular way. To understand this characterisation, I have extrapolated what I found to be the three dominant values that were intrinsic to the institutional practice of transitional care. These values are as follows: i) incremental journeys; ii) independent subjects; and, iii) technoscientific orderings [see Table 4]. These three values were distinctive, yet related, categories that show what the institution valued in both its ideal young patients and its own approach to care provision. Consequently, these institutional values, as I have inferred them, came to significantly impose upon the experiences of transitioning. I now move on to explain each of these values in turn and reflect upon their implications for young people with ELD.

Institutional values	Examples from ethnographic stories and clinical literatures
The incremental journey	The use of linear guides (i.e. Ten-Step Pathway, Cerebra guide). Notions of a 'right path'. Child-adult distinction.
Independent subjects	'Productive members of society' (D'Angostino et al., 2011). The 'othering' of Daniel. Tasks that mimic the real world.
Technoscientific ordering	EBM and the authority of science. Developmental psychology. Adolescent normativity.

Table 4. Institutional values of transitional healthcare

The incremental journey

By virtue of moving from childhood to adulthood, transition was marked as a phenomenon of change. Within the data this was specifically characterised as a journey - in other words, change that was concerned with incremental progress across time. Clearly evidenced in the Ten-Step Pathway [see Chapter 5], the journey of adolescence was also present in the *Transition to Adulthood Table: A Guide for Parents.* Both documents are examples of graphical depictions of the adolescent journey via colourful and easy-to-digest visual representation. Consequently, these materialities of care show themselves to be useful tools that promise to reduce the complexity of care for patients with multiple conditions. For Jillian, the *Transition to Adulthood Table: A Guide for Parents* was a method of mediating and filtering her encounters with health and social care services. For example, such visual depictions of the journey provided a road map as to what could be expected from various services at different stages of her daughter's adolescence, demonstrating how standardised pathways served to navigate what could be a complex and difficult phase of life (Martin et al., 2017). In this sense, Jillian relied on the document for guidance through a time where she may otherwise have become lost amongst the multitude of appointments, form filling and care assessments that her daughter encountered.

Jillian’s use of this document allowed her to organise an already busy life as her daughter moved into adulthood. Nevertheless, her statement that the document ‘keeps her on the right path’, reveals something intrinsic about how the concept of adolescence was communicated by the institution and understood by parents/carers. To be ‘on the right path’ implied that there was a correct way to transition into adulthood - further perpetuating notions of a singular, normative and linear journey (Blatterer, 2010; Burnett, 2010; Mayer, 2004). Yet, the Holbrook’s reluctance to end their relationship with Dr Roberts throws into stark relief the anxieties that emerged during this journey. The Holbrook family made clear that it was the infrastructure of healthcare that was responsible for their concerns. In other words, the fact of having two distinct domains of clinical care - paediatrics and adult - and having to bridge those domains is what caused them distress.

When compared with paediatric medicine, adult medicine has long been accused of not being holistic or family orientated enough, thereby requiring the development of transitional services in order to connect the two different approaches to healing (Munro-Prescott, 2012). Gail Holbrook questions the medical care of young people with learning disabilities within a culture that so clearly attributes a journeyed and progressive experience to the adolescent phase. For example, (and echoing the claims of 19th-century neurologist Esquirol [see Chapter 1]), stating that her son will ‘always be the same’ raises the question – to whom does transitional healthcare benefit, the young person with ELD or the institution? The following quotation from Dr Roberts opens up this presumed necessary distinction between paediatric and adult care. In my initial interview with the neurologist, I asked why he felt it was important that young people with learning disabilities transitioned into adult services rather than remaining under one consultant for all of their lives. His response was as follows:

> **Dr Roberts:** It just wouldn't be right to keep adults under paediatric care, it's impossible. The options to fix it i.e. have a consultant in LD for life isn't doable because services are so stretched. Nobody is trained in that way and nobody has appropriate knowledge to hone their speciality to all ages. Some doctors may think they are all-age neurologists, but I think they are working under illusions of grandeur and it's honestly quite dangerous. So unfortunately, they [the patients] do have to say goodbye to their paediatrician.

To conceive of a type of specialist clinical care (i.e. to have a neurologist that worked with both children and adults), one that meant there would be no need for transition, was in Dr Roberts' opinion impossible. Once again this 'impossibility' was tied to a lack of infrastructural support within the healthcare system since there was no training to accommodate continued specialist neurology services from childhood into adulthood.

This journeyed understanding of adolescence is not without criticism. Scholars have argued that it is somewhat outdated in the 21st century (Pitti, 2017; Blatterer, 2007; 2010). This is because the 21st century has become an era that is characterised by rapid technological changes and globalisation. Consequently, this age of uncertainty has heralded in new ways of defining childhood, adolescence and adulthood and how people move between each state. For example, since the post-war era, the rise of Fordism meant that stable employment (a typical defining characteristic of adulthood) was achievable - therefore adulthood was accomplished through stable employment

(Harvey, 1989). However, more recently we have witnessed a fast pace of global and economic changes that have made employment more precarious (Blatterer, 2010). This has been influenced by sociocultural drives such as mass-marketisation of higher and post-18 education and deregulated, flexible and non-unionised labour forces that are considered insecure temporary forms of work (Cartwright, 2015). Subsequently, stable employment is no longer a consistent indicator of adulthood. These social changes imply that the journeyed view can no longer be relied upon as a way of making sense of adolescence for all young people - with or without disabilities.

Independent subjects

As I have shown previously (particularly in Chapters 2 & 5), the practice of transitional healthcare had an objective – to help young people achieve independent adulthood alongside them demonstrating a certain degree of self-management with regard to care. If, as outlined in Chapter 4, we take the hospital to be a microcosm of society writ large (Street & Coleman, 2012), these goals of transitional care become reflections of the wider society's ideology - an ideology that young people will be entering once they transition into adulthood. The above ethnographic stories demonstrate how transitional care reinforced the sociocultural values of independence and responsibility. These values were clearly reflected in the transition literature when D'Agostino et al. (2011) claimed that transitional healthcare impacts a young person's 'achievement as self-reliant, independent and productive members of society.' (pg. 233). This is crucial within the context of a publicly funded health service, where intrinsic to such values, individual self-reliance and moral responsibility are preferable to a culture of dependency on the state and welfare (Pratt, 2006; Slorach, 2016).

Gail's aversion toward Daniel's move into adult services, speaks of this tension between the institutional preference for independence within the context of ELD. Specifically, Gail's dislike of the Cerebra document was due to her concern that it stood to 'other' her son (Lalvani, 2015). Consequently, Gail acknowledged that Daniel, upon reaching adulthood, was unlikely to participate in the world in the way desired under its preference for independent citizens. For Gail, the materialities of care (in the form of clinical leaflets and information sheets that she had received) stood to reinforce these social values and moreover, she considered them both inappropriate and insensitive to her family's situation. These feelings of being unwanted, jarring the system, and generally not adhering to social norms are important analytical ideas when thinking through what it is that formal standardised care does within heterogeneous populations.

Whilst the Holbrooks resist the institutional values for independent subjects, Nic shows us how these values were incorporated into her daily caregiving practices. For example, she encouraged Jason to learn tasks that 'mimic the real world' such as dishwashing, recognising money and interacting with shop assistants. This implies that as Jason grows into adulthood, although he will remain dependant on carers, he will be capable of 'mimicking' behaviours that are associated with independent adults. These appeals to individual independence provoked a sense of anxiety and alienation for the Holbrooks, whilst exerting a form of social pressure to appear compliant for Nic.

Despite these tensions, the families do, however, manage to make their circumstances work for them by tinkering their care practices around such pervasive sociocultural values. For example, the Holbrooks learned to negotiate the transition 'journey' by not taking too seriously the information contained within the leaflets. The family prepared themselves for interactions with the healthcare system by almost expecting system failures and by adopting a do-it-yourself attitude to formal, professional care. On the other hand, Nic literately tinkered with the material artefacts that she had ‘picked up along the way’ in order to create something new that she felt would be of better use to Jason. The Holbrooks were prepared to fight when necessary to defend their needs - but also have learnt which battles to pick. Unlike Jillian, who quite literally went by the book when navigating the transitional period, the Holbrooks chose not to loyally accept everything that the institutions communicated in order to transition in ‘the right way’. These cases demonstrate how social values impose themselves upon the lives of carers via institutionalised care practices and documentation.

Technoscientific Ordering

To characterise transitional care as a technoscientific process is to acknowledge that, whilst it was a practice founded upon principles of EBM, it was also embedded within particular social, cultural and historical networks (Latour, 1987; Sismondo, 2010). Haraway’s (1997) definition of technoscience offers a way of understanding the relationship between the material artefacts and the institutional values of independence and responsibility shown to be integral to transitional care. Haraway argues that the presupposed boundaries between categories widely assumed to be distinct and stable (such as nature/culture, technology/science or even childhood/adulthood) are instead ambiguous and contingent. Furthermore, transitional healthcare (along with its materialities of care) can all be considered techniques or practices of developmental psychology. Historically speaking, the fitness of a population was managed through ‘seeking to classify, identify, and eliminate or constrain those individuals bearing a defective constitution' (Rose, 2007). Thus, developmental psychology is a technoscience that exemplifies how (through science and technology) adolescent biology is opened up to be interpreted through the lens of social management. In this sense, transitioning was a social management strategy that aimed to mitigate the 'nature of adolescence'.

In the above ethnographic stories, we see the concept of adolescence (as a technoscientific category) being mobilised to establish care for young people with ELD. For example, the *My Skills* document that Nic created, was based on her own knowledge of adolescent psychology and the biomedical information that she had gathered through information leaflets. Furthermore, the dominant understanding held by both parents/carers and health professionals - adolescence as a turbulent time - was based on what they have garnered through 'science'[66]. It was this authority of science that justified the need for institutional intervention during the transitional period; turning young people into subjects for justifiable surveillance. This echoes Michel Foucault's essay *The politics of health in the eighteenth century* (1979/2014) within which he describes the 18th-century emergence of a privileging of childhood and a medicalisation of the family. This privileging of childhood and medicalisation of the family are what have laid the foundations for the impetus seen in child and adolescent research and practice today (Burman, 2016; Rose, 1999). Consequently, childhood and adolescence in contemporary society have become subjects of medical expertise that have extended into the 'management of life itself' (Rose, 1999; 2007). The very premise of the Cerebra guide attests to this management of life as a method of self-

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[66] Although participants may have reached this conclusion from other means (e.g. personal experience of adolescence), within the data it was clearly reiterated to me that adolescence was a turbulent period and this understanding was supported by 'science' as exemplified by psychologist Sara in Chapter 5.

surveillance for families to follow whilst away from the clinic. Additionally, Nic's adaptation of the care plan (to include her own knowledge of psychology) reinforced the authority of science and its truth claims in its application to managing complex groups of peoples.

The Cerebra document emphasised logical, linear and scientised steps for care. However, the antithesis of this linear and scientized approach to managing groups of people is demonstrated by the Holbrooks who show that care practices based upon normative assumptions of adolescence can actually prompt feelings of anxiety when applied to those who do not identify with normative expectations of adolescence. This (lack of) identification with normative conceptualisations of adolescence echoes Sulik's (2011) concept of a 'technoscientific illness identity', which is described as:

> …a type of illness identity that involves applying biomedical information and characteristics to a person's sense of self (…). Rather than simply possessing a particular biomedical marker or classification, the person identifies so strongly with it that he or she integrates the classification into his or her identity. (pg. 1062).

In this way, adolescence (as a technoscientific category) is not only inscribed upon patients but also to some degree is accepted and adopted as identity descriptors. Under this logic, all adolescents assume some risk of unmet potentiality and are all therefore rendered sites for intervention. As a consequence, the Cerebra document is strategic - in that it aims to guide and manage high-risk groups (adolescents) and mitigate such risk.

To experience transitional healthcare as a technoscientific process and adolescence as a technoscientific category is to understand them as aspects of biomedicine that, while currently viewed as inevitable [see Chapter 2], can also be considered practices and categories of hope. For example, Jillian believed that through the Cerebra document her daughter would ‘develop skills through the right people as opposed to winging it on our own.’ Technoscience, and its promise of progress, became substances of salvation for some carers of young people with ELD. Technoscience enabled Jillian and Nic to imagine the possibilities of a normative and biomedical adolescent journey, asking themselves what ‘would it mean to follow the guidelines, to develop the skills encouraged by the transition agenda?’ The possibilities of what these young people can become if they conform to the stratified, knowledge-defined process of transition is, at this point, unknown but for mothers like Jillian and paid-carers like Nic it appeared a safe place to start. Here, biomedicine is more than a system of healing, but rather it represents one actor in a much larger biomedical-society nexus through which hope, and possibility, can be achieved.

Conclusion

This chapter has taken materialities of care as a way into understanding the experiences of transitioning through three family’s interactions with the *Transition to Adulthood Table: A Guide for Parents* document. Specifically, we see that, however benign or well intentioned, these documents had a significant impact on how caregiving was enacted. My aim in presenting the values of i) the incremental journey, ii) independent subjects and, iii) technoscientific ordering, is to show that transitioning to adulthood becomes an intensely concentrated form of social conditioning. Under care arrangements of this kind, the intimate environments of family and the home are being reconfigured as relays within the distributed apparatus of caregiving. Furthermore, as part of this, expectation itself becomes a structuring device; i.e., expectations of independence and responsibility structure the care provided and the terms of its delivery. However, with the Holbrooks' resistance to the Cerebra document and Nic feeling the need to devise her own pathway for Jason, it appears that for young people with severe learning disabilities this method of surveillance may be ineffective. However, young people with ELD become excluded from this form of surveillance due to differing from the institutional model of what adolescence is, or as Gail Holbrook claims 'jarring the system'.

This finding resonates with the work of Rapp and Ginsburg (2013) who, when commenting on the transition from a high school setting into adult work or college said that young people with disabilities were 'promiscuous violators of the walls erected by medical manuals and school bureaucracies.' (pg. 192) Likewise, Haraway (1997) points out that technoscience and its subsequent practices (such as transitional care) provide chances to win or to lose. But who are the winners and who are the losers? In this chapter, we have seen that transitional care serves some but not others. The central argument within this chapter is that the experience of transitioning for parents/carers was significantly impacted by the material, bureaucratic and technoscientific apparatus that constituted this care practice (Hull, 2012). Furthermore, we can begin to see how transitional care was mobilised as a social practice that unintendedly marginalised those who did not conform to the institution's values and conceptualisations of adolescence, such as those with ELD.

This chapter shows how material artefacts were inevitably taken up in a variety of ways by different groups of people – in spite of the institutions intended use of these objects. Therefore, and similar to acts of stabilisation presented in Chapter 5, these material objects have a political character, in that they had the ability to reshape, not only people’s experiences of care, but also of the social world. Specifically, these material artefacts were capable of making meaning of the adolescent experience. In the next three chapters, I move forward this idea that transitional care resembled a journey. By considering the normative model of adolescence, I examine how this ‘journey’ gets renegotiated in cases of severe learning disability. Using the rite of passage as a loose theoretical framework, I investigate how institutional understandings of adolescence co-exists alongside parent experiences of caring for young people with ELD.

Chapter 7 – Transition and its Tensions: The Parentectomy

The preceding three data chapters focused on the institutional and material apparatus that supported and enabled the practice of transitional care. Attending to the material documents associated with the practice of transitional care, I argued that this care practice reflected wider social values, wherein adolescence was postulated as a journey toward independence and responsibility. However, this journey consequently marginalised those young people who did not conform to these values. Crucial to the context of this study, was that the specific nature of this journey was understood to be dependent on the severity of a young person's learning disability and epilepsy. In other words, the presence of ELD destabilised the expectations of growing up, and with that, disrupted the adolescent journey. This, therefore, raised significant points of tension for care. In these remaining three data chapters, I wish to examine how the assumptions and expectations of the institutional model of transitional care were reflected in the everyday experience of patients with ELD and their caregivers.

Transitional care may well be considered as reflecting the rite of passage between childhood and adulthood. Rites of passage are conventionally understood in anthropological literatures as a tri-partite process, involving the following stages: i) separation, ii) transition and iii) incorporation, first described by Arnold van Gennep (1909) and later developed by Victor Turner (1969). The institutional expectations of transitional care closely mirror these - i.e. a separation from family; characterised by psychological and physical transformations; followed by an incorporation into adult services. Furthermore, these expectations could also be seen in the organisation of the TEC itself, ordered around three distinct clinical spaces: i) the paediatric epilepsy clinics at Longwater, ii) the TEC at Carden, and iii) the adult epilepsy clinics at Carden. However, the experience of ELD transition, bears much less in resemblance.

Nevertheless, I found that thinking about transitional care in ritualistic terms helpful for considering the specific challenges encountered by young people with ELD, and for demonstrating how and where these processes actually broke down by virtue of a young person's compromised health and cognition. As the following chapters attest, the transitional shift from childhood to adulthood for young people with severe disabilities is one characterised by profound disruption, ambiguities and tensions, which in turn, holds significant implications for the practice and organisation of care. In the next three chapters, I want to focus on the specific occasions when the expectations and assumptions associated with the institutional model of transitional care were challenged by the idiosyncrasies of caring for a young person with ELD from the perspective of the families. In other words, how the rhetoric of transitional care did not reflect the reality of caring for young people with ELD. Each chapter will briefly introduce an expectation associated with the institutional model of transitional care: separation, transformation and responsibilisation, respectively. Each of these introductions will then be followed by a detailed examination of how these expectations were confronted in the everyday experiences of caregiving.

The Parentectomy: The expectation of letting go

To begin, this chapter examines what neurologists at Longwater Paediatrics and Carden Adult Epilepsy Services referred to as the 'parentectomy'. The parentectomy signified the assumption that, during the transitional period, young people would separate and become independent from their parents. Using the language of surgical removal, doctors described a parentectomy as a process that sought to increase patient independence away from their parents. Fitted to its medical context, the parentectomy was analogous to the surgical practice of cutting something (the parent) away from the body (the child) in order for the transition process to begin. More literally, however, the parentectomy sought to excise the parents, a central element of a young person's life, out of the management of their epilepsy care. In other words, the parentectomy was a curious term that was used by doctors to explain their frustration of having to deal with parents.

While patient independence and separation from parents was a significant expectation for young patients without a learning disability, the parentectomy was still apparent in cases when a young person had a co-morbid learning disability. For young people with ELD, however, it was less the case that a complete and marked separation occurred - in these instances the parentectomy reinforced a need for parents to diminish their involvement in their child's professional care management. As will be explained in this chapter, the primary institutional reason for emphasising diminished parental involvement was that young people with ELD were expected to become as independent as possible when they entered adulthood, i.e. living in supported accommodation or receiving care from paid support workers and social carers. Consequently, as we will see, the parentectomy for young people with ELD emerged in its own specific way.

Below is a description of how the parentectomy was assumed to work for young people without significant learning disabilities:

> **Dr Roberts:** I think it's great working with teenagers and young people. There are different challenges and you have to engage with them much more than with the parents. You've got to separate them off because over the years

> parents become really protective, and trying to get a young person to become independent, self-empowered, and to separate the parents off can be difficult. But our job…[PAUSE]… our patient is the young person, not the family, so we have to focus on the young person's health, but also their confidence, self-esteem along with the epilepsy management. It's often a bit of an issue actually, called a parentectomy, and it can be a really big problem.

The potential for a parentectomy to become a 'big problem' speaks to family relationships wherein either a parent, child or both may be reluctant to detach. Dr Roberts claimed that this continued attachment to parents, and vice versa, created an 'unhealthy co-dependency' within families. In turn, this co-dependency was assumed to inhibit a young person's growth into independent adulthood or, as he says, impede their capacity to 'behave in an appropriate adult manner'. However, a parentectomy was only ever an ideal of transitional care and not a condition for it. In other words, if it was necessary for parents to be continually involved their child's medical care, such as accompanying them in clinic consultations, then that was never prohibited. Although I only ever heard the term explicitly used by the neurologists in the study (Drs Roberts, Barton, Keegan and Lewtas), other health professionals also alluded to a similar notion of facilitating a separation between parent and child during transitional care. As the following quotes demonstrate, it was generally assumed that the separation of children (particularly, without learning disabilities) from their parents was a universal process, which enabled psychological maturity into adulthood:

> **Tina [Adult ENS]:** I know with my own kids there's just a tension there between all teenagers and their parents. It's just the natural way of life. Most

> teenagers don’t want their mum fussing over them. That’s just guaranteed to piss them off.
>
> **Penny [Paediatric ENS]:** Adolescence can be a really empowering time. It’s when we all start to become independent little people; it always has been. When teenagers start to show that they can be responsible, make the right decisions, that’s when parents should start to loosen the reigns a bit and let them live their own lives.
>
> **Sara [Paediatric Psychologist]:** Stepping back is just a part of life, but some parents and their kids find it hard to let go. This is where transition really helps.

These quotes illustrate that the separation from parents during adolescence was perceived as natural and organic. As a natural life process, the parentectomy was something that, whilst temporarily painful for young people and their parents to endure, could be an endearing experience for clinicians to witness:

> **Dr Roberts:** It reminds you how fleeting all of our lives actually are. I’ve known some of these patients since they were infants, really tiny babies. Then they become children, really active and with that curiosity for life and when they suddenly blossom into young adults it makes you think gosh where did time go? I see it with the patients and with my own [children] you learn to appreciate it [separation] as something that’s positive. It might be hard for them at the time but it’s a natural and actually a really nice thing to observe, these babies are growing into young adults who are right at the start of their lives.

For health professionals, the child-parent separation was revered as something almost sacred. It symbolised a time to initiate independence away from the natal home and allow young people to psychologically mature into themselves, this is something evidenced both within the data and supported by social psychological studies of adolescence (Beyers et al., 2003; Jager et al., 2015; Jones et al., 2018). Below, Penny describes one way that clinicians facilitated this parentectomy – by making a game out of responsibility roles:

> **Penny [Paediatric ENS]:** Transition is never a surprise to families; they know it's coming. Around the age of twelve we start to suggest to them know your meds, know who your doctors are. I always do a little test with them to keep it fun. A bit of role-reversal. I'll ask them about their medication, name or dose, or I'll ask what happens if you miss a dose. And you see them thinking and I say 'Oh I'm just testing you because they'll expect you to know all this when you get to Carden'. Sometimes the mums will try to answer, but I'll say 'Uh-oh, little Johnny has got to know this himself'. So even before we give them the teenager packs, we would have already planted the idea that they will be moving eventually and that it is up to them, not us or their parents. It's their healthcare - it's their responsibility.

For Penny, separation was both a separation from the paediatric environment and health professionals, as well as moving away from the childhood dependency on parents. She makes it clear that healthcare was a personal responsibility and subsequently transitional care was a means of reaching this state of responsibility. Practically speaking, facilitating a parentectomy involved informally assessing each family's capacity to 'let go'. In order to judge a young person's capacity toward independence and responsibility, health professionals would often pass judgement on the parenting-style between young people and their mothers and fathers. As Dr Barton comments:

> **Dr Barton [Adult neurologist]:** It’s unusual to see adults attending clinics with their parents. Sometimes they [parents] can be helpful - but not always. They can be clingy, very attached to their children and vice versa. That’s not helpful. That’s why we prefer to see patients on their own. You can tell if it’s [the parentectomy] going to be difficult or easy by how they interact. You can ask yourself: are the parents overly protective, do they let the child speak, does the child even want to speak or are they happy for mum to do it all? These things you can pick up on quite easily.

The above quotations exemplify what the parentectomy meant in adolescence without significant learning disabilities and how this could be facilitated by clinicians. The parentectomy symbolised the severing of parental bonds and was assumed to be a process that was natural and universal. For patients without profound learning disabilities, health professionals expected parents to diminish their responsibilised role in their child’s epilepsy clinical care while young people assumed a new, independent and accountable status. Specifically, the parentectomy was a method for instilling in young people the wider sociocultural values of independence and responsibility that were preferential, but not crucial, for care provision as they emerged into adulthood. However, this becomes a significant point of tension in cases of ELD since, the child-parent relationship continues well into the adult years. Although the parentectomy was used informally and as a somewhat tongue in cheek expression, this term reinforced the idea that teenagers came with a set of specific needs, thus turning them into a problematic patient group. As this chapter will discuss, young people with ELD were considered problematic by the institutional model of care not simply because of the ‘nature’ of adolescence but also because they came with ‘overprotective’ parents; parents who became a barrier to their child’s professional care management.

Part 1: Functions of the ELD Parentectomy: Autonomy and thanatophobia

From interview and observational data, I identified two key functions that the parentectomy served in cases for young people with ELD. These were 1) to facilitate professional autonomy and 2) to prepare for a time when parents could no longer care for their children (either because of old age or their own deaths). Alongside interview and observational data, I present two ethnographic stories that exemplify how professionals and parents gave meaning to the child-parent separation during the transition to adulthood. This is then followed by a reflection on implications of the parentectomy for ELD transitional care.

Professional Autonomy

For reasons of facilitating professional autonomy, a parentectomy was desired for all young people in the study as it enabled health professionals to work in a manner that they deemed as efficient. For example, whilst the TEC neurologists were often eager for young people without learning disabilities to attend clinic appointments alone, it became apparent that for patients with ELD the absence of ‘overly involved’ parents often made for ‘smoother’ consultations. As Dr Barton described, parents who were ‘trusting’ – i.e. those who trusted in the doctor’s recommendations without much conflict - served to diminish the risk that a clash of opinions may arise between parents and professionals. In other words, the absence of a parent often, but not always, made the job of adolescent epilepsy care easier:

> **Dr Lewtas [paediatric neurologist]:** As a paediatrician I can't do my job without parents. Over here [in paediatrics] we recognise the importance that they bring but sometimes there can be conflict, they think they know best and we think we know best [LAUGHS]. At least in paediatrics we're hardwired to deal with families but in adults they are often pushed for time and need to do their job as efficiently as possible. Parents unfortunately can get in the way. Don't get me wrong they can get in the way over here too but there's more space for that here.

In claiming that paediatrics has 'more space', Dr Lewtas is referring to an unequal distribution of infrastructure (Street, 2014; Street & Coleman, 2012). For example, there were longer clinic appointments at Longwater, meaning that parents could express any concerns they had without feeling rushed out of the clinic room. Another example was that of larger physical space in the paediatric consultation rooms, allowing for several family members to attend the consultation together. However, over in the TEC, which took place in adult services, there were no such resources available, clinic times were often shorter[67] and rooms were for a maximum of four people, two of which were medical staff.

The preference for diminished parental involvement during the transitional period was usually dependent upon how each individual parent contributed to the clinical consultation. For example, if a parent was considered 'overly involved' or 'argumentative' then this was deemed disruptive to the organisation of the clinic times

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[67] The average TEC consultation ran for 20 minutes (with a range of 8-30 minutes) whilst Longwater's average paediatric consultation was 35 minutes (with a range of 12-45 minutes). These times are based on an average of the patient consultations that I observed.

for the remainder of that day, therefore significantly impacting the amount of time spent with other patients. To actively manage such parents, clinicians would ‘round up conversations quickly’ - usually by referring young people and their families onto external services who may be better equipped to deal with their concerns - or more abruptly suggesting that the clinic consultation ‘stop here, until next time’. Simply put, there was a fine line between those parents who supported the clinical work of doctors and those who disrupted it. It was apparent then, that for health professionals, the ELD parentectomy was less about promoting independence for young people and more about parent-management during the transition period. However, unlike Dr Lewtas, other clinicians did not appear to question the infrastructural inequalities between Longwater and Carden that may have augmented this exclusion of parental participation. For these clinicians, the parentectomy was important for professional autonomy. Using an example from the social care context, the following ethnographic story exemplifies this idea of the parentectomy as a method for facilitating professional autonomy.

Ethnographic Story 1: Jason Bates

I first introduced Jason in the previous chapter. Jason lived away from his family home in a supported-living accommodation where his 24-hour care needs were met by paid carers. Nevertheless, his mother was still very much involved in her son’s daily life, mostly through 15-minute phone calls and the odd video call with Jason and his carers. Jason’s mother would call every evening, requesting an hour-by-hour briefing of her son’s day. One particular evening, after an unusually long 40-minute call, Clare (the owner of the care company wherein Jason lived) spoke pejoratively about the persistent contact: ‘A swift clean sever would be nice but sometimes you’ve got to hack away at it', presenting the mother's attachment to her son as if it were something harmful. Continuing our conversation, Clare acknowledged that Jason's mother only ever had her son's welfare in mind but stated that she 'had trouble letting go.' This inability to let go was compounded by the fact that when Jason first came under Clare's care, he was legally known as a Looked After Child [LAC] on a care order under Section 20 of the Children's Act (1989). This meant that Jason was officially the responsibility of the Local Authority[68].

When first accepting a then 16-year-old Jason as a client, the Local Authority informed Clare that she was likely to have 'issues with the mother' - with her being described as an 'interfering nuisance'. This was of particular interest since Clare informed me that many LAC do not have much parental involvement as there had usually been some safeguarding concerns regarding the parents in the first place:

> **Clare:** Over-involved parents are a rarity in LAC. Generally, looked after children become looked after because nobody's looking after them at home, but in Jason's case it was different. The Local Authority deal with him as a LAC but they're not used to dealing with parents really[69]. They think she's interfering with their work. And basically, they don't like it, they don't like her.

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[68] An explanation why Jason had a LAC status was never disclosed to me due to it being of a 'highly confidential and sensitive nature'.

[69] From reading the literature around LAC it appears that such heavy parental involvement may be unusual since in cases of LAC there may be concerns regarding neglect and abuse, which would not always correlate with a parent who is overly concerned about their child's welfare (Bazalgette, Rahilly & Trevelyan, 2015; NSPCC, 2019).

Consequently, the conflict between Jason's mother and the professionals arose because in LAC, a parentectomy has usually already taken place. In other words, Jason's mother was expected to have already relinquished her over-involved role. Yet, for whatever the circumstance surrounding his LAC status, she was more involved in her son's care than most other parents.

Clare suggested that it was the severity of Jason's disability that made his mother overprotective. As a child, Jason was diagnosed with Lennox-Gastaut syndrome, an uncommon form of epilepsy that, whilst presenting with prolonged seizures, is often resistant to AED treatments. Jason's adherence to a strict ketogenic diet seemed to offer some relief from his condition. He had problems with his gait (often, but not always, requiring the use of a wheelchair) as well as severe learning disabilities:

> **Clare:** I think because of how disabled he is, she worries. She's concerned all the time about his safety because he's really unsteady on his feet. Fast but unsteady. Also, I guess because he cannot talk, she asserts her presence by constantly reminding the staff that she's keeping an eye out for her son. She knows his diet regime inside out so she sometimes quizzes the staff. Just to make sure they're keeping up. It's not a bad thing but I guess she has trouble trusting carers.

Clare described to me specific occasions when Jason's mother went 'full-parent'. Going full-parent was an expression used by Clare to characterise times when, Jason's mum, perceiving that Jason was in receipt of inadequate care, would jump to his defence. Clare told me that Jason's mother had frequently threatened care staff with legal action whenever she heard something that she disagreed with, e.g. when staff did not make use of Jason's wheelchair whilst at the supermarket. Although his mother had never followed through with legal action, Clare explained this as an example of her ‘over-protectiveness’.

Jason’s mother’s behaviour echoes the findings of Schultz (2013) who argues that parents of children with ELD often feel the need - or burden - to advocate for their children well into adulthood. For Jason’s mother, ‘going full-parent’ appeared as a necessity in order to access the care that she saw fit for her son. However, for care professionals, these behaviours were viewed as impeding the work of health and social care since the behaviours frequently meant that more time was spent meeting the care needs of just one person:

> **Clare:** I get on with Jason’s mum just fine, but it’s taken a lot of time and effort for her to trust me. I think she’s quite distrustful of a lot of people to be honest. They had a bad time in the past and she said Jason’s last carers were stealing bits of cash from him and neglecting his hygiene. She can come across a bit over the top, full-parent. That’s what the LA warned me about before we got Jason, they said you need to watch out for the mother she looks for trouble. So that’s how she’s known by everyone because she’s so involved with her son’s care. They said she looks for trouble.

Claiming that Jason’s mother ‘looks for trouble’ is reinforced by the sense of public paranoia that surrounds the care of people with learning disabilities. Specifically, in recent years the professional care of adults with learning disabilities has come under public scrutiny with cases of abuse and neglect featuring in the media. Most notably was the BBC documentary concerning the physical and psychological abuse of patients at the private hospital, Winterbourne View (Kenyon & Chapman, 2011).

> **Clare:** She [Jason's mother] watched Winterbourne and it went to her head. The documentary was shocking, harrowing and was right to highlight what was going on in there, but it also made people paranoid. Not all of us are like that. The same is with the young lad LB, Laughing Boy.

Clare highlights the examples of Winterbourne View and Connor Sparrowhawk (Laughing Boy) as a direct contributor to Jason's mother's distrust of all services. The case of Laughing Boy (or LB as he was known to his family and the subsequent media campaign that was to follow his death in July 2013), is significant to the present study. At 18 years-old, LB was a transition-aged youth and his death raises serious concerns regarding the social assumption that adolescence is a period of independence from parents (Ryan, 2017). The common understanding of adolescence equating with growing independence, contributed to the failings of care that resulted in LB's death. LB had epilepsy and autism and died whilst under the care of an adult NHS residential facility. He was left unsupervised whilst taking a bath where he had a seizure and subsequently drowned. His death occurred despite it being documented in his care plan and despite his mother informing staff that he was to not be alone during bath time for risk of drowning. The ensuing court case found the Trust guilty of gross negligence. During the hearing, concerns were raised around issues of independence and privacy as LB was 18 years-old and technically a young man, however this was his first experience in an adult healthcare environment. Ironically LB's mother, social scientist Sara Ryan, had been writing about the issues of her son's transition in earlier posts on her personal blog 'My Daft Life' (Ryan, 2012). Here, she documented her growing concerns for LB's future as a young man with learning disabilities, her frustration with health and social care services (or lack of) and the ways she felt as if her concerns were ignored despite the amount of time the family invested in fighting for adequate care. There are similarities within Sara Ryan's work and Gail Holbrook's concerns that transition for young people with learning disabilities is inadequate [see Chapter 6].

Not only have these high-profile cases allowed the public to reflect on the professional care for those with learning disabilities, they also raise critical questions around the social practices (such as transitional healthcare) that are developed in the name of independence and individual responsibility. What we learn from Jason's case is that a parentectomy is a social and institutional expectation, rather than an act that necessarily facilitates health. For example, claiming that Jason's mother 'had trouble letting go' indicates that, from the professional's point of view, there was an expectation for her to do so. Crucially, a parentectomy asks us to consider what it is that defines adulthood but fails to consider how the child-parent separation is given meaning in instances when independence away from care givers is not always attainable. For Jason's mother, a parentectomy involved building a trusting relationship between herself and the health/social care professionals. This made for a version of the parentectomy that was time consuming and not at all like the swift, clean sever that was desired by Clare. In the case of ELD transitional care, the figure of the 'overbearing parent' was a symbol of obstruction to the practice of efficient professional care. Hence the policing of parents themselves was encouraged as it was the mother, rather than Jason, whom the Local Authority suggested was in need of management.

Parents and thanatophobia

Whilst the above data demonstrates the function of a parentectomy for health and social care professionals – to minimise disruption from parents - I now move on to consider how the child-parent separation was given meaning within the familial context. Clearly ‘parentectomy’ was not a term that was used by families, they did however refer to the approaching signification of separation or simply to back away from their children as they approached adulthood. The following interview extract from Denise and her 17-year-old daughter Maddy exemplifies how parents experienced this separation. Maddy had epilepsy with autism and moderate learning disabilities. Her learning and physical disabilities meant that, although able to communicate and express herself clearly, she required 24-hour care to help her with tasks such as cooking, personal hygiene, finance management and managing her home environment. However, Maddy, with a ferociously independent spirit, was eager to move out of the family home and into a supported living accommodation where she would have her own flat and live independently from her parents.

> **Denise:** It saddens me to see other kids grow up and have these life experiences that she never will. And I’m also sad for me and my husband because we will never have that [PAUSE] we will always be carers; we won’t get a break in the same way other parents do when kids grow up and leave home.
>
> **Maddy**: I’m leaving home and hitting the road and my flat says no one’s allowed in it unless I’ve said it’s ok for them to.
>
> **Denise**: [To Maddy] Yes, we know love. [To me] because she’s got this flat, she’s chuffed. I’m not sure she’s getting it that she won’t be on her own. She’ll always have stay-in carers there with her.
>
> **Maddy**: I can’t wait to go. I hate this house [inaudible speech].

> **Denise**: See, she's really independent and in that way she's just like every other teenager. It's natural to move away from your mum as you get older, but I think Maddy likes the idea of it more than the reality of it. [To Maddy] you'll miss us as soon as we drive off in the car, we'll say 'Bye Maddy' and you'll be going 'Oh mummy' [Laughs].
>
> **Maddy**: I won't [hugs her mother].
>
> **Denise**: [To me] She will. It's all talk with this one but really, even though I know it'll be hard - it's going to be tough not having her here - it's the right thing to do. I mean were not going to be here forever and that's were that distance becomes natural and in her best interest.

Unlike a parentectomy for reasons of professional autonomy, parents considered the child-parent separation as something that would benefit their children in the future. As parents watched their children age, they became increasingly aware of their own mortality. This is further emphasised below in an interview extract with Gail Holbrook, mother of 17-year-old Daniel who, in the previous chapter, spoke of the 'battle' of having a son with severe disabilities. Gail described this child-parent separation as follows:

> **Gail:** Dan's close to the age I was when I had him. It just goes by so fast and now he's a man - I feel dead old. I can't do things I used to be able to do with him. He's heavier and stronger and I'm getting weaker and older. If we weren't here then who is going to look after him the way we do? This is why it's better he gets used to other people now because me and Mark aren't going to be around forever.

Denise and Gail express a sense of the thanatophobia, or death anxiety, that fuels a parent’s motivation toward enacting a parentectomy. Thanatophobia is described as the feeling of dread, fear, apprehension or anxiety when one thinks of the process of dying, or ceasing to ‘be’ (Sinoff, 2017). Gail’s thanatophobia is triggered by her concerns about the quality of care that others can provide for her son. Her lack of trust for health and social care provision is reflected in her question ‘If we weren’t here then who is going to look after him the way we do?’ How death anxiety relates to the lives of people with learning disabilities is little understood (Arthur, 2003; Thackerey & Eatough, 2015), however the child-parent separation can be one way of unpacking this phenomenon. As the following ethnographic story shows, concerns around death and the facing of their own mortality had the potential to cause much psychological distress for parents of young people with ELD.

Ethnographic Story 2: Gwen and Maya

Most parents in the study experienced grief over the realisation that their children would never reach the full independence that society expected of them. However, this looming anxiety surrounding parental death was most poignantly expressed by Gwen Hooper, the mother of 19-year-old Maya Hooper. Maya’s medical records stated that she had acquired brain-injury at birth, which had resulted in global developmental delay and frequent severe seizures. Maya’s parents, Gwen and Paul, had been 37 and 46-years-old when their daughter (their only child) was born. Nineteen years later, as Maya prepared to leave the TEC and graduate into adult services, Gwen had experienced worsening symptoms of anxiety and depression for which she now received professional psychological therapy.

> **Gwen:** It got to a point where I was having recurring nightmares of Maya being left alone in a dark room - she'd be screaming out, really lashing out with her whole body, thrashing all over the pace - but me and Paul couldn't get to her. I would wake up sweating, pools of it. And this dream kept coming for about six months. I started losing sleep, I didn't want to sleep. And it's pretty simple, I just didn't want to let her go somewhere in case they didn't look after her the way that we did but, at the same time, I know it's best for her.

Gwen acknowledged that there was a tension between the need to make provision for her daughter's transition into adulthood alongside a deep-seated mistrust in health and social care providers. Since Maya was an only child and had ELD, she relied on her mother and father to do everything for her, from bathing to supervising feeds. To complicate things further, Maya became extremely agitated and aggressive whenever separated from her mother. Seeing her daughter's distress at moments of separation served to reinforce Gwen's own feelings of distress. Following Maya's referral into the TEC, Gwen admitted to having recurrent obsessive thoughts where she imagined a time in the future when she and Paul were no longer capable of caring for Maya:

> **Gwen:** We feel rushed by all this transition stuff; it's been an overwhelming experience. Well for me anyway.
>
> **Shelda:** How so? Why do you feel rushed?
>
> **Gwen:** The thought of what is going to happen to us is just [pause] unbearable. Sometimes I feel guilty because we decided, and it was an active decision, to leave having kids until a bit later in life. We put our jobs first basically, when Paul turns 66, I'm going to be 57 and Maya's only going to be 20. I mean oh

> my god she's not going to be looking after herself any better than what she does now. And Paul has health issues, we have to think about his health, and you realise the clock is ticking and I think god I'm not going to cope. And y'know this might be hard for you to understand but you can see your own death right there. It might be years away, but you realise that you're not going to be here forever, and you can't be there to fight and care for your little girl who can't do it for herself. When we die, she's alone in the world and who will care for her the way we do? You don't tend to think about it when they're little ones, you're too busy then. But as she's getting older and they talk about residential care, we've realised that the next place she calls home, she could be there for the rest of her life, so you need to make sure it's good now. In one way, you want to protect them forever, from the big bad world but then I think there's going to be a time when she wakes up and we're not there and no one else is going to wrap her up…
>
> [pause as Gwen cries].
>
> (cont…) With normal kids, even if they didn't have brothers or sisters you think well they'll have a husband or children of their own. But with Maya I only see her being alone. It doesn't bear thinking about.

Gwen's distress is compounded by the fact that she chose to have her daughter late in life and that Maya has no close living family who could step in if her parents were not around. The fact that young people with disabilities will continue to need support throughout their lives meant that parents were forced to confront their own mortality, a future when they will no longer provide and oversee care (Thackery & Eatough, 2015). While Gwen felt compelled to manage Maya's daily care needs, she was also attuned to what could happen if she did not sufficiently prepare her daughter to live as independently as possible:

> **Gwen:** I’m well aware of how it’ll be. If I reach 80 years old, she’ll be in her forties. I mean what the hell, can you even imagine it? Y’know, who says I’ll get to live until I’m 80. If I’m as involved in her care then as I am now, what kind of state will she be in when I pass away. It’s not fair to her – she’d probably think we’d just up and left her.

Gwen’s increasing anxiety, triggered by her daughter’s transition into adulthood, demonstrates the functions of a child-parent separation for parents and caregivers – to prepare for a future without them. Her comment that Maya will ‘probably think we’d just up and left her’ invokes feelings of abandonment, something she equally wished to protect Maya from. Here we see Gwen’s inner turmoil reflected in her struggle to ‘let go’ yet remain actively involved in her daughter’s care; believing that maintaining such a high level of involvement would ultimately be detrimental to Maya. However, what this story and other data highlight, is how the anticipated separation is compounded by the severity of a disability. In these examples, separation from the point of view of the parents is understood for the benefit of their children. Simply put Gwen believed that separation was a process of being ‘cruel to be kind’. For parents, the child-parent separation occurred in order to soften the blow, a necessary preparation phase ahead of a time when parents were no longer able to care for their children.

Reflection on the child-parent separation

Taken together, these two functions of an ELD child-parent separation - one for professional autonomy, the other for future preparation for parental death – shows the various ways in which separation is a driving force in the care provision for patients with

ELD. Furthermore, the child-parent separation emphasises the wider sociocultural beliefs of adolescence as a linear and incremental journey and reiterates the ubiquitous social value of individual independence that permeated the practice of transitional healthcare. For health professionals, the parentectomy meant that they were able to carry out their work as efficiently as possible. This appeal to efficiency illustrates the economic undertones that infuse contemporary healthcare practices and the adolescent experience more widely [see Chapters 5 & 6]. The examples of Jason's mother and the quotations from the health professionals, support past research where 'helicopter parents' – parents said to hover over their children - are significant barriers to transitional healthcare (Huang et al., 2011; Paine et al., 2014). Whilst there were hints at the enabling effects of a parentectomy for individual patients, the majority of the benefits of the parentectomy were for health professionals - to make their working environment easier.

Dudley and Carr (2004) suggest that parental vigilance in a child's healthcare, whilst providing reassurance that their child is receiving the best possible care, is also emotionally and psychologically draining for the parents – something clearly expressed by Gwen. Furthermore, the examples of thanatophobia are important because the experience of bereavement in people with learning disabilities has been found to increase a sense of 'disenfranchised grief' (Doka, 2002) – a type of grief wherein the intense experience of loss is unacknowledged and marginalised by a society (McRitchie et al., 2014). This sense of exclusion has been found to negatively impact a person with learning disabilities' acceptance of parental loss as well as bringing a sense of their experience being disregarded by professionals and institutions (Clute & Kobayashi, 2012). For the parents in the current study, death was never too far from their minds. Subsequently, separation became a way to cushion against a future without parents. However, there were some tensions at play here because there was no clear consensus from the data as to whether parents wanted to foster independence or not. For them, separation during adolescence was a complex and often contradictory process, that questioned their need to protect and advocate on behalf of their children alongside the requisite process of 'letting go'.

From the perspective of health professionals, parents could be revered or demonised depending on how well they 'let go' during the transition to adult services, thus enabling professionals to carry out their jobs effectively. However, any attempt to prematurely 'excise' the parent from a young person's clinical care had the potential to invoke a tense parent-professional relationship. The following quote is taken from an interview with Dr Keegan, an adult neurologist at Carden Epilepsy Services. Reflecting on his own medical training, Dr Keegan sums up the difference in parent-professional interactions within paediatric environments and adult ones:

> **Dr Keegan:** I did, very briefly, consider paeds but then it all feels a bit woolly and I was basically just interested in the science and neurology more widely. Plus, there's the fact that you're dealing with parents, families and sometimes external care providers. It just wasn't for me - to listen to highly-strung mothers [LAUGHS]. It's funny how demanding they can be when it comes to their child's health versus their own. In adults [adult healthcare] generally people accept that you've trained, your trustworthy, you've adequate knowledge of your field – you are the doctor and hopefully your recommendations, if you're any good, should make them better. But oh no not when it comes to mothers and their children, everything is questioned and scrutinised and judged [LAUGHS]. They might have pictures of Mickey Mouse on the walls, but paediatricians have a harder job when it comes to navigating around the family.

Emphasising what he saw as a persistent questioning from the family, Dr Keegan illustrates why adult neurology was his preferred area for medical training. With descriptors such as ‘woolly’ and an emphasis on ‘science and neurology’, Dr Keegan presents paediatrics as a field of medicine that is underscored by a clinician’s ability to manage their interpersonal relationships with the family. From Dr Keegan’s quote, we see that it was ‘highly strung mothers’ - those whom question, scrutinise and judge the clinical care that their children receive – that made the work of clinicians more difficult. Consequently, it would seem that adult neurologists have more professional autonomy and freedom than their paediatric counterparts. Thus, for the adult neurologists in particular, instead of treating parents as vital components to a patient’s ongoing care, parents were viewed as potential barriers to efficient care

Dr Keegan’s assessment of parent-professional interaction is supported by studies within clinical paediatrics that have highlighted how both patients and family members are frequently excluded from participation in the definition and treatment of clinical problems (e.g. Dudley & Carr 2004; Darbyshire, 1994; Vasli et al., 2015; Subramony, 2014). Specifically, these studies emphasise that the knowledge of a patient that is brought into the clinic by parents is frequently marginalised and excluded by clinicians; often seen as impeding upon efficient clinical care. In the next section, I want to further explore the role that parental knowledge played in the practice of transitional care.

Part 2: Tensions in knowledge and expertise

Who knew the patient best and who were the experts in a young person’s care were points of tension that were clearly identifiable across the data; highlighting the strained relationship between parents and professionals during transition. Dr Barton described an unnamed young girl (with mild learning disabilities) who had recently transitioned through the TEC and into his adult epilepsy clinic. The female patient had usually attended her TEC appointments with her mother, who Dr Barton described as a 'right busy body who always had a complaint waiting to be lodged somewhere'. Both Drs Barton and Roberts had suggested that the patient undergo temporal lobe surgery for seizure control. However, the mother was fiercely against this procedure:

> **Dr Barton:** Then on this one appointment the girl turns up alone, saying yes, she wants surgery. Patients are all different. Some are straightforward but sometimes there's a whole host of other things going on. Not just other medical ills but family ones too. Sometimes the best form of surgery is a parentectomy.

By 'straightforward', Dr Barton was referring to those young people who were without complex family issues, indicating an underappreciation for parents within a clinical transitional setting. Joanna Latimer's (2013) ethnographic work on paediatric dysmorphology clinics reflects on this parent-clinician relationship. In cases of genetic counselling, the family prove themselves vital to both the diagnosis and the ongoing treatment of paediatric patients. Families 'gift' the clinic access to the patient's genetic background in the form of their own bodies, family histories and photographs of siblings. Consequently, Latimer argues, a family's personal and social history becomes so tied-up with the practice of clinical work that it is impossible to distinguish the family on one hand and biomedicine on the other. By bringing along gifts (i.e. personal materials such as photographs of other family members or past diagnostic results) to clinical consultations, families fulfilled the role of 'the good parent'. In doing so, families supported clinicians in an ongoing and often co-created pursuit of the dysmorphology diagnosis. However, in contrast to Latimer's findings, ideas of the ‘good parent’ in this study was accomplished via complying with the clinician’s decisions.

The emergence of new forms of expertise and online biosocial communities

The tug-of-war between parents and professionals highlighted that each party claimed to hold specific expertise pertaining to caregiving for a young person with ELD, subsequently allowing knowledge and decision-making privileges over a young person’s care needs. This is best illustrated by comparing the following quotations from Dr Barton and Gwen:

> **Dr Barton:** Of course, every mother loves her child, but mother doesn’t always know best. As clinicians our judgment isn’t clouded by love for one child, but we see and need to treat hundreds of patients within what’s becoming an increasingly stretched health service. We can see that, we can see the system, they [parents] can’t. Basically, we have to get on with the job at hand.

Dr Barton asserts that clinical expertise was a balance between knowing the individual patient and knowing the system of healthcare within which care was practiced. Contrast this with the following quotation from Gwen:

> **Gwen:** I know what’s best for her, every mother does. I know Maya inside out. Alright I can’t give the technical names of medication and procedures, but every mother has their child’s wellbeing at the forefront of their minds. Some doctors want you to be like ‘Oh yes, whatever you say,’ but I think they don’t listen to us because they can’t be bothered with the extra work. Not that that’s necessarily their fault. We all know there’s not enough funding going into health and social care.

In comparison to Dr Barton, Gwen demonstrates that she does indeed ‘see’ that the health service was stretched and, yet, was simultaneously aware that her presence as a parent in the TEC was burdensome in the eyes of the doctors - something that Dr Barton assumes ‘highly strung’ parents were unaware of. According to him, having a bird’s eye view of the system affords professionals a more realistic understanding of patient care. On the other hand, Gwen shows an adequate understanding of the healthcare system and the political climate within which institutional caregiving sits. Unlike the symbiotic relationship described by Latimer, the parent-professional relationship in the present data shows transitional care as a process wherein families and institutions grapple with uncertainty and their own changing roles as a child matures into an adult. However, rather than being dismissive of parents as experts in their child’s care, the ethnographic data highlights how clinicians too are trapped in a system that only caters for ‘straightforward’ patients. Despite Dr Barton’s assertions regarding his privileged knowledge of ‘the system’, what he appears unable to see is how ‘the system’ is binding health professionals into a role where the complexity of engaging with parents is burdensome or, at the very least, surplus to their main duties of care.

Both Dr Barton and Gwen’s quotations exemplify the main reason for the tension within the parent-professional relationship – each party assumed a lack of understanding on behalf of the other. In other words, whilst parents were depicted as ignorant of professional care provision, parents assumed that doctors took for granted their life history with and knowledge of the patient. This parental perspective is supported by Tomkins and Eatough’s (2014) findings which suggest that, unlike the care delivered by professionals, familial care has a long biographical trajectory. This, ultimately, brings the past, present and future into the experience of caregiving. Gwen’s statement reflects that she has nurtured and cared for her daughter since birth. For Gwen, caregiving was integral to her own biography, past and present, unlike Dr Barton who was under pressure to 'get on with the job at hand' (i.e. to provide clinical epilepsy care for as many patients as possible). From his perspective, care is practiced through balancing individual patient needs against available resources. Therefore, whilst it was a sense of practicality that justified the clinician to assert his expertise, it was love over a lifetime that justified Gwen's.

Ethnographic Story 3: Little bouts of activism - Gwen

One of the consequences of taking an active role in a child's health was the establishments of lay communities of experts and support networks. The following account of Gwen's activities surrounding her daughter's health condition, exemplifies how a re-configuring of experts in care has emerged in a digital era. In contrast to Dr Barton's claim that parents were unappreciative of the overall healthcare system, Gwen's activities surrounding her daughter's care suggests that parents were active in both seeking out and disseminating knowledge concerning the care of young people with ELD. Taking the work on 'biosociality' (Rabinow & Bennett, 2009) and its variants (Heath, Rapp & Tausigg, 2004; Gibbons & Novas 2007; Rose, 2007; Rose & Novas, 2005) as theoretical touchstones, the following account shows how, contra to the ideal of the child-parent separation, transitional care incited a time for parents of young people with ELD to take more of an active role in their child's health and social care.

As a mother of a child with 'severe neurodisabilities', Gwen had set-up and continued to manage an online twitter account and a personal blog dedicated to 'spreading info on anything that impacts the care of kids like Maya'. Set up in 2012, this online account had amassed over 2,500 followers. Initially, Gwen had aimed to simply keep track of and archive anything of interest pertaining to her daughter's condition that she saw online:

> **Gwen:** I'd just see things that the Guardian had posted, or Epilepsy Research and I'd retweet it because I didn't know how to save these articles. In the end, I just decided to set-up a separate account solely for this reason. I guess people in a similar position saw the things I was 'saving' and have decided to follow me. That's how it initially started, a bit slap-dash but, through Twitter, I've met other bloggers or activists or whatever they call it and I agree with them that y'know we've all got a voice and if we're not happy with care then we can speak out. It's only little things but I know it helps. I'm not a full-on activist, I just have little bouts where I can help others online and they can help me.

Since setting up in 2012, Gwen focussed on informing other parents of children with neurodisabilities of any UK political and social developments that would impact upon their children's health and social care. Furthermore, through her blog, she also invited parents to write short pieces regarding their experiences of caring for children with severe disabilities. Moreover, Gwen claimed that parents of children with disabilities were likely to be 'incredibly informed' of their child's healthcare:

> **Gwen:** These are just the things that interest us. When you're so far from the norm you band together to help each other out. From the parents I know, we are all incredibly informed about what's happening locally and nationally that's likely to affect our children. One woman who contributes to my blog is a GP. She's really good at giving us the heads up about what changes are coming into place around medical issues. Another woman is a SEN teaching assistant. We all keep each other informed. I think as mothers of kids with

> neurodisabilities we have to be aware of what’s happening in the wider world and how political or legal issues impact us. You don’t get told about these things you have to find them out for yourself. For example, when they [the local CCG] stopped supplying incontinence pads we had to know how to appeal that decision and sort of fight our corner. The more you know, the more you’re prepared – it’s a lot of hard work.

Gwen’s ‘little bouts’ of activism demonstrate how definitions of expert knowledge was a changing and fluid concept. Through pooling together resources, such as a GP or SEN teaching assistant, Gwen formed a collective source of ‘experts’ that enabled her to advocate for her daughter’s right to care. The concept of biosociality (Rabinow, 1996; 2007) - the emergence of communities of patients (and their related others) around a shared biomedical identification - helps us to think through the social relations that underpin this parent-professional tug-of-war. Similar to the work of Heath, Rapp & Taussig’s (2007) who argue that digital technologies have mediated and enabled public discourse on genetics, Gwen shows how the internet has created a proliferation of information sharing. This information sharing challenges conventional notions of a split between lay people (parents) and experts (clinicians). However, Heath, Rapp and Taussig also suggest that biosocial activism in the digital age has produced a new form of governmentality and responsibilisation of parents, whereby increased public access to medical information means that the public is expected to be knowledgeable about their medical condition(s). This is a topic that will be further discussed in Chapter 8, nevertheless this claim regarding the responsibilisation of parents is further evidenced by paediatric ENS Eve, who recognised the efforts to stay informed that many parents of children with disabilities undertake:

> **Eve:** Adult services should appreciate parents more instead of trying to diminish their role in the child’s life. Everyone says parents are ‘*experts in care’* but it’s just another novelty, another other buzz phrase. I can’t tell lies, there are times when I think god, I could do this job better if you [a parent] weren’t in the room but that’s how it is. That’s how life is. I reckon parents are pushed away by clinicians because it makes their job easier. Simple as that. But I wouldn’t say it’s all their fault or that they are out of touch. Ideally, we’d love to engage with everyone who was significant to the child, to make them understand about their epilepsy. That’s what us nurses used to do when we would visit local schools. But you can’t do that now because there’s just no time for it and that’s not how the job works anymore. Things have changed and we don’t get paid to do that kind of work. Unfortunately, it’s easier to have a patient come in on their own and say what’s the problem, here’s the plan of action, next. And since the 2012 Act [Health & Social Care Act, 2012], the need to be cut and dry is getting worse you need to be more efficient with patients, you can’t let just one eat up all of your time. But when parents come in, they tend to speak their minds more and I suppose that is bad for the hospital because everybody’s so back to back with clinics. Time is really precious. It’s a shame.

Despite her rebuke of the phrase, Eve repeatedly informed me that, indeed, it was the parents of young people with ELD who were the ‘real’ experts in care. This meant that ELD patients had ‘experts at home’ and, making parents responsible for their child’s healthcare management (a topic that I explore further in Chapter 8). Consequently, the transitional care of young people with ELD was a straightforward transfer, or as psychologist Sara claimed “When the kids don’t know what’s going on, then we are only transitioning the parents". This is further supported by the following quotation from Eve, who reiterated the parents-as-expert status in cases of ELD:

> **Eve:** People assume that kids with complex needs are high in intensity, so they must take a lot from the service, but the parents manage things so well that most of the A&E calls are hardly ever from them. Also, compared to non-disabled kids, they have a bigger circle of support, so they manage really well in the community with GPs, community nurses, school nurse.

Gwen's active involvement in her daughter's care, alongside Eve's understanding of parents as experts, reflects the new forms of expertise that were emerging out of the ELD transitional care process. In this case, it is helpful to understand biosociality as a stratified form of belonging that was produced through the social exclusion of the non-compliant, non-normative or disabled subjects, such as young people with ELD (Rose 2007; Rose & Novas 2005). In other words, Gwen's online community (of parents, GPs, SEN teaching assistants and wider public) banded together to seek further support for their children whom they saw as excluded from the social practice of transitioning based on their non-compliant, non-normative and disabled bodies. Specifically, to the concept of a parentectomy, the online community was a reconfiguring of expertise and specialist knowledge.

In cases when young people will not reach full independence away from carers, the child-parent separation becomes multifaceted with parents turning to newer forms of knowledge sources (e.g. twitter and personal blogs) to help them continue the advocacy role for their children with disabilities (Schultz, 2013). Since the child-parent separation was almost redundant in cases of ELD (with parents continuing to play a crucial care giving role into adulthood), I argue that the institutional preference for a child-parent separation was a method of governmentality by-proxy (Rose, 1999). Crucially, an ELD parentectomy shows that health professionals were working within the constraints of the institutional arrangements of transitional care. Simply put, an ELD parentectomy was intended for the management of parents rather than for the increased wellbeing of young people. Thus, the child-parent separation in instances of ELD was a social management strategy - where new forms of expertise (e.g. parents as experts in care) were managed and contained, whilst traditional expertise (e.g. medical) was maintained.

Conclusion: The rhetoric and the reality

This chapter has shown that the institutional rhetoric - a child-parent separation during adolescence - was upheld in the practice of ELD transitional care. What we learn from the institutional preference for a diminished parental involvement in cases of ELD is that the term ‘parentectomy’ was invoked by health and social care professionals maintain their power (or expertise) over a young person’s care. The notion of the overbearing parent, highlighted how institutional health and social care was inflexible to the particular needs of individual patients with disabilities. Patients requiring, or even simply wanting additional support from their parents were viewed as burdensome. In this sense, a parentectomy increased the autonomy of professionals rather than to fulfilling any idealised notions of ‘the natural way of life’ or of developing independence into adulthood. However, the institutional preference for diminished parental involvement is further complicated by those with ELD wherein the continued care of parents/carers is of utmost importance to a young person’s transition.

From examining the parent-professional relationship during the transitional period, this chapter shows that tensions were predicated on a politics of expertise, wherein parents and professionals held claim that their expertise was best for caregiving. Therefore, a consideration of the changing role of expertise (particularly in a digital age), as well as how newer forms of knowledge proficiency (such as online activism) become entangled with caregiving would be beneficial to the study of transitional health. My central argument in this chapter, has focussed upon demands for a parentectomy by health and social care institutions that were ill equipped to deal with the extra 'burden' that parents bring. In other words, a lack of space, time and resources fuelled these tensions throughout the transitional period.

In presenting the parentectomy from two perspectives – the professionals and the parents. Here, we see that the role of the family during a young person's transition into adulthood comes with an intensified form of scrutiny from care institutions. Furthermore, the parentectomy demonstrated that ELD transitional care was a care practice by-proxy, since, rather than transitioning the patients it was the parents who end up becoming 'managed'. Subsequently, the parentectomy was central for understanding the liminality of youth. In other words, adolescence was understood by the institution as an ephemeral state that once a young person stepped out of the shadow of their parents then, and only then, were they fully accepted as independent and responsible citizens. In the following chapter, I explore further the liminality of transitional care and how conceptions of adolescence as a period of transformation shaped caregiving practices. However, through the conceptualisation of adolescence as a journey, I will focus on how young people with ELD were forced into a persistent liminal status whereby they never quite fulfil the social expectations associated with this coming-of-age rite of passage.

Chapter 8 – Transition and its Tensions: The out of sync mind/body

Building on the previous examination of the child-parent separation, this chapter focuses on issues of embodiment and adolescent transformations. Since participants assumed adolescence was a time of incremental change, I now wish to examine what does and what does not get transformed for young people with ELD during their transitions to adulthood. Specifically, I am interested in showing that there was an ambiguity concerning both the physical and psychological development of these young people. As we will see, this ambiguity was produced by a developing body and mind that appeared out of sync with each other and, subsequently, created a significant point of tension in caregiving practices for both professionals and families. To this end, I draw on the concept of liminality (Turner, 1969; van Genepp, 1909) to elucidate the ambiguous psychological and physical development of young people with ELD.

To some degree, young people with ELD are liminal beings – caught in a transient state and, thus, lacking classification or definitive identity. The presence of a significant learning disability challenges any idealised developmental period associated with adolescence. This creates an ‘out-of-sync’ mind/body relationship, one that fails to fulfil a conventional adolescent rite of passage (Kafer, 2017). This ambiguous and ambivalent status has repercussions for care, which will be discussed in this chapter. Split into two parts, I consider the more noticeable and apparent transformations of bodily change (specifically sexual development and physical appearances) and how this created a schism in the minds of the adult carers (professional and family) of young people with ELD. As such, my central argument in this chapter is that this liminal status not only influenced how adults treated young people with ELD but also occasioned modes of care that upheld expectations concerning age-appropriate behaviours (such as socially appropriate ways of interacting with others and physical appearances). This chapter demonstrates that the institutional model of transitional care falls apart in the context of ELD because these young people did not transform in ways that were considered socially desirable by the adult society that they would be entering at the end of their adolescent journey. I now describe how the rhetoric of adolescent transformation was promoted within the institutional model of transitional care.

The loss of innocence: The expectation of transformation

The stock phrase ‘a loss of innocence’ came to signify the move from a state of childhood into adulthood for the TEC health professionals. With roots in Romanticism[70], ‘a loss of innocence’ is a pervasive cultural representation of leaving behind childhood and becoming adult (Casaliggi & Fermanis, 2016). Innocence, as a signifier of children, has become tightly linked with what literary scholars term a westernised ‘cultural myth of childhood’ and synonymous with ideals of sexual immaturity, which ends during adolescence (Gubar, 2011; Kokkola, 2013). This conceptualisation of adolescence as the end of innocence was integral to the transitional care of the TEC.

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[70] French Romantic philosopher Jean-Jacques Rousseau distinguishes children from adults by emphasising the closer to nature and unspoilt traits of childhood that align with a quality of innocence (Rousseau, 1763). This ‘childhood innocence’ theme was further expounded by later-Romantic writers, in particular, William Blake’s (1789) *Songs of Innocence and Experience* and William Wordsworth’s (1804) *Recollections of Early Childhood.* The cultural and literary celebration of childhood innocence was further reflected in what was to become known as the Victorian ‘Golden age of Childhood’ (Kokkola, 2013), as seen in works such as Charles Kingsley’s *The Water-Babies* (1863) and Lewis Carroll’s *Alice’s Adventures in Wonderland* (1865).

For both health professionals and parents, an exact definition of adolescence was somewhat elusive and difficult to characterise. This ineffability of adolescence added to its liminal character; a state of being betwixt and between. As the following quotation shows, it was often easier to define adolescents by what they were not, rather than attempting to delineate what they are:

> **Dr Barton:** They're just, how can I put it, not as needy or innocent as children but not as self-sufficient as adults. They have to *become* adults, y'know they have to *become* self-sufficient, *become* self-assured. We all go through this; the party doesn't last forever [LAUGHS]. They're a funny bunch but for the most part they come out the other end unscathed.

Throughout the interview transcripts, both childhood and adulthood emerged as fixed points that participants largely agreed upon, thus, adolescence was made sense of through its known and stable opposites of childhood and adulthood:

> **Eve:** Children are innocent, they obviously need that guidance from adults. No way would you say to a child here's your prescription, take it as follows, off you go. You tell the parents then, as they get older, they become responsible for their own meds. It's only when they begin to get a sense of independence away from parents that they properly understand - as adults. We do what we can so that they become independent when they're older. If an adult doesn't take their medication well that's up to them, it's their responsibility if they fall ill.

Despite the elusiveness of what adolescence meant, Dr Barton and Eve's emphasis on the word 'becoming' echoes the sociological perspective of adolescents as human becomings, wherein society and institutions engage with young people as if they are not yet fully formed (Lee, 2001)[71]. The term *becoming* was not only a significant analytical concept in terms of sociocultural ideals for independence and responsibility, it also had a corporeal, more visceral meaning attached to it - that of a burgeoning sexuality.

For the adults in the study (clinicians, care professionals and parents), sexual maturity and changes in physical appearance emerged as two key signifiers of adolescent transformation. For example, during one interview paediatric ENS Penny described adolescents as 'budding and blossoming little men and women' who were experiencing the universal phenomenon of raging hormones. Similarly, transition nurse Suzy summarised the teenage years as consisting of 'sex, drugs and rock 'n' roll'. Each of these descriptions clearly denote changes in physiology and sexual maturation. In this sense, adolescence became the time when gender was made explicit via the physiological changes that occur (Schlegel & Hewlett, 2011).

Part 1: From Asexuality to Sexuality

Normative adolescence and developing sexuality are highly regulated and governed areas of the human lifespan (Priestly, 2003; Shakespeare, 2006). Within the TEC, the governing of adolescent sexuality was intensified. Interview and observational data suggested that moving from a state of asexuality to one of sexuality, provoked anxiety for the adults who cared for young people with ELD. As the two ethnographic stories

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[71] Further to this, social scientist Nancy Lesko comments that the "adolescent [during the 20th century] came to occupy a highly visible and recognizable place, as a being who was defined as 'becoming', as nascent, unfinished, in peril … [or] in today's terms, 'at risk'" (pg. 41), echoing my argument in Chapter 1, wherein the transitional literatures are preoccupied with notions of psychosocial risk and how to avoid such risk during the transitional period.

below demonstrate, this anxiety was underpinned by feelings of social awkwardness. These stories present how the sexual development of those with severe forms of learning disabilities was considered in stigmatising and stereotypical ways: adolescent males were perceived as predatory, whereas females were treated as vulnerable. Consider the following group interview extract with the adult ENSs where we discussed the sexual health of teenagers with epilepsy. When I asked if they modified their practice or approach to care to reflect the needs of those with learning disabilities, my question was met with a long silence, until Tina eventually spoke up:

> **Tina:** Kids with LD are fine, pretty straightforward – not really an issue with sexual health there. But when they grow up, especially with young men, there can be a voracious appetite [LAUGHS]. They're strong and obviously they aren't always aware of that strength. Same with girls too, but girls are different.
>
> **Shelda:** How so?
>
> **Tina:** Well**,** they are curious, there is all these changes going on and they're just like everybody else - they want to explore what's going on. But with girls it's more about protection and keeping them safe and, if possible, letting them know what behaviours are appropriate and what's not.
>
> **Sandra:** The amount of pregnancy terminations within an LD population is shocking, I don't know the figure, but I remember just being astounded that this was still going on to that extent. The problem is it's a difficult topic to bring up. Parents don't really want to think about it until it presents as an issue but possibly at that point it's too late.

From this extract it is clear that ELD adolescence was perceived as a dangerous and risky time, justifying the need to govern and 'protect' this population. Tina provides a clear distinction between the sexual lives of adolescent males and females with disabilities. The following two ethnographic stories build on this distinction, showing how gender stereotypes reinforced particular modes of care for young people with ELD.

Ethnographic Story 1: Predatory male sexuality - Carlton

Carlton was a 19-year-old male with epilepsy, autism and cerebral palsy. He was a TEC patient under the care of Drs Keegan and Lewtas. Whilst Carlton was able to verbally communicate, he was extremely selective about when and with whom he chose to speak (for example, over the 9 months that I visited him on a fortnightly basis I never heard him verbally communicate). At 6ft 3in and weighing over 230lbs, Carlton's body mass was intimidating, furthermore, he was physically strong and agile. His physicality, coupled with the fact that he had daily 'meltdowns', meant that Carlton required male-only carers who were able to restrain him as his mother Dani was no longer capable of this. Despite his adolescent growth spurt, Carlton disliked socialising with other teenagers and became anxious around new faces, especially if they were adults. This meant that Carlton was only truly comfortable in the company of children – something that was becoming increasingly problematic as he matured into adulthood. It took five home visits before Dani and Carlton's carers felt comfortable enough to invite me on a day out to a nearby forest, reassured that Carlton would not feel distressed by my presence.

It was a late summer afternoon when we arrived, and the forest was quiet and secluded except for a dog walker and a couple of hikers in the distance. "Carl don't go too far!"

Dani would shout if her son began to wander further ahead from us; he would stop and wait until we caught up with him. We walked for at least 30 minutes without passing any other people. However, when a group of three adults with four children approached us Dani muttered to herself “Oh shit”, before ushering Carlton to walk on the side of her that was furthest away from the people. As soon as he was close enough, she grabbed hold of his hand and did not let go.

“He can be funny around other kids, especially the little ones.” She whispered to me. She explained to me that Carlton had a six-year-old brother whom he always tried to play with. Unfortunately, Carlton unaware of his own strength, would play too rough and playtime would often end with his little brother in tears. This made his younger brother afraid of Carlton. Dani continued to tell me that sometimes Carlton would run over to children that he did not know and get excited and start jumping or clapping his hands, which scared them and, in turn, upset Carlton to see the children afraid: “It’s just a situation I’d rather avoid.” said Dani. Just as she predicted, Carlton saw the children, smiled and began to stomp his feet and make loud vocalisations. Firmly, Dani kept repeating “Come on, there’s a good lad, come on,” until the walkers and their children passed us by. When they did pass, Carlton stopped for a moment, looked back at the group of strangers then continued walking in the direction that we were going.

I was intrigued by Dani’s moment of apprehension, more so because nothing had actually happened. What was the situation she seemed so anxious to avoid? When we stopped for lunch, I asked her for more information regarding Carlton’s (and her own) reaction to the children we had seen earlier:

> **Dani:** I just don’t think he understands that he’s not like them anymore and that he might scare them. It’ll just look worse the older he gets. It’s wrong to see a man wanting to play with young children. I know he would never hurt children but rather he sees himself the same as them. He probably identifies with them more than people his own age. Children make more time for him; they will actually play with him. But you can see the parents are a bit weary. And he does this rubbing thing on his thighs, right near his groin - just a tic he has - since he was little, he’s always done it. But you can imagine what others would say if he does that in front of little ones.
>
> **Shelda:** What do you imagine would’ve happened if Carlton had been free to do what he wanted when the children passed?
>
> **Dani:** Nothing. He probably would’ve just ran over and stood there, clapped and stuff. Maybe rubbed his groin. Nothing bad would have happened it would have just been a bit awkward for everyone.

Although not explicitly stated by Dani, there was an underlying fear of Carlton being misunderstood as behaving in a way considered sexually perverse towards the children. For it to be ‘just wrong’ to see an older male wanting to play with children indicates a concern regarding the perception of adult males with learning disabilities and their relations with young children. It is reasonable to consider if this situation would have been as similarly ‘awkward’ if Carlton had been a female. An interview-based study of caregiver attitudes suggests that females with intellectual disability are perceived as innocents whereas males are perceived as having greater motivations towards displaying and acting upon sexual interests (Young, Gore & McCarthy, 2012). In this case, it was the possibility of being socially judged that backgrounded Dani’s actions when she noticed the children approaching. She subtlety restrained Carlton's behaviour by asking him to stay by her side and to hold her hand since there was an implicit fear that his actions would be misunderstood as sexual or harmful in nature.

Carlton's case demonstrates that for young people with ELD, whilst they are indeed in the midst of a liminal period due to their physiological and behavioural changes, there is also the expectation for them to emerge from this state of liminality and behave 'appropriately'. However, Carlton's persistent liminality and how it will be socially judged is something his mother fears will 'only get worse' as he enters adulthood whilst his preference for the company of children stays the same. In other words, it was not the case that Carlton did engage in inappropriate behaviours, it was closer to the fact that at some point during the transformative, transitional period the adult gaze deemed his choices and preferences as such.

Ethnographic Story 2: Vulnerable female sexuality - Kate

In contrast to the predatory perception of young males, young females were perceived as vulnerable and at risk of exploitation from others. This was best demonstrated through 18-year-old Kate, who was attending her second TEC appointment with Drs Lewtas and Keegan. Kate, who had temporal lobe epilepsy and a learning disability, had undergone surgical sterilisation as a contraceptive method. This was considered by her mother and her two neurologists to have been the best choice for Kate as it eliminated all risk of an unintended pregnancy. Kate arrived into the TEC, one day, accompanied by her mother and grandmother. She held her grandmother's hand and was giggling as she entered the room. Kate found it difficult to maintain eye contact with the male doctors so, instead, she kept her head down and would shyly cover her mouth when prompted to speak. When providing Dr Lewtas and Dr Keegan with a summary of her daughter's medical changes since her last appointment six months ago, her mother explained that Kate had undergone tubal ligation:

> **Mother**: We chose this because she lives away from home with carers. She's always had an interest in boys, a really big interest and we've always worried about that. It's sick to think but people like our Kate can be taken advantage of. When she started growing a bit and getting her monthlies, we thought it best she goes on the Depo as soon as possible.

For a year prior to her daughter's sterilisation procedure, the family had tried Kate with the Depo-Provera injection[72]. However, her mother and grandmother decided that, due to Kate's needle phobia, a more permeant contraceptive solution was better suited. Additionally, Kate's grandmother believed that the contraceptive injection had caused an increase in her granddaughter's seizures. Thus, for both mother and grandmother, the surgical sterilisation procedure seemed the only appropriate means of addressing the risk of unwanted pregnancies, with the additional benefit of avoiding Kate's needle phobia. When the consultation ended and the family had left the room, Dr Keegan stated:

> **Dr Keegan**: I'm happy to see the parents took a wise decision. Kate has always been that way inclined, enjoying male attention. I remember there was an issue last year and she was engaging in some really dangerous behaviour, some pretty bad stuff. She was found letting one of the boys in her school y'know [PAUSE] touch her. The family made the best decision there.

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[72] The Depo-Provera injection is a female contraceptive method that releases the hormone progesterone into the blood stream, preventing pregnancy for up to 13 weeks.

Kate’s past sexual exploration was a substantial cause for concern for the adults around her, subsequently tubal ligation was the result of that concern. Reasons behind such a permeant decision were described in terms of protection from Kate’s increasing vulnerability as she grew into adulthood. However, sterilisation does not stop sexual activity itself or any sexually transmitted infections, but only the potential for a pregnancy. This paternalistic approach to controlling the sexual lives of young women with learning disabilities was also emphasised by paediatric nurse Penny. During one clinic consultation, a female patient aged 16-years with a moderate learning disability attended with her foster parents. After they left, Penny told me that the girl’s biological mother, who also had learning disabilities, had seven other children:

> **Penny:** They’re [females with learning disabilities] seen as not even having an interest in sex. I think this is what has happened and keeps happening with her [biological] mother. It baffles me how this woman can go on having sex, then have all the children taken away into care and nobody steps in to intervene. All of her children have disabilities too, some really severe, it’s not fair on them. When I talk about sexual health with girls with disabilities, I may word things differently, but the content is the same. For those with mild or sometimes a moderate learning disability, I don’t approach sexual health any different from people without learning disability. Most of the time, their lives are no different from mine or yours and they will be having sex, so it’s really important to cover the same topics. There is an expectation, which is sad and dangerous and based upon ignorance, that these girls don’t have sex and that’s why some professionals don’t talk about it.

Both Penny’s statement and Kate’s story can be characterised in terms of a protective and paternalistic attitude to providing sexual healthcare to young females with learning disabilities. Moreover, these show that transitional care practice agendas that promote increasing independence and responsibility, clash with protectionist and paternalistic approaches when caring for young women with learning disabilities. Here the female disabled body, similarly to its male counterpart, is monitored and governed in line with social expectations of appropriate ways of being an adolescent. Kate’s ‘interest’ in boys and her sexual exploration was, in the eyes of her carers, deemed inappropriate and risked her being taken advantage of. Consequently, we can see that this particular tension between what is considered appropriate and inappropriate behaviours for a young, female with learning disabilities, is decided upon by the non-disabled adults within society. In other words, whilst sexual exploration may have been an expectation for a non-learning-disabled adolescent, for Kate it was deemed dangerous. Simply put, sexuality in those with learning disability was dealt with by either ignoring the existence of a sexual life or controlling sexual behaviours in safe, clean ways, such as sterilisation.

What we learn from both Carlton and Kate’s stories is that the sexual lives of young people with learning disabilities was deeply gendered and discussed in narrow and stereotypical terms. Furthermore, it was clear that these young people’s personal choices became significant points of tension for caregiving. For example, Carlton’s choice of playmates was prohibited because of how it may be socially judged and Kate was seen as incapable of knowing and understanding her own choices.

ELD transition: Gender, taboo and liminality

To say that sexuality, as well as issues of gender, were made distinct within the TEC is unsurprising when considering that the biomedical treatment of epilepsy is a gendered practice (Morrell & Flynn, 2003). Specifically to the TEC, a gendered understanding of adolescence manifested through the Teenage Epilepsy Information Packs, which were compiled by the paediatric nurses Penny and Eve. The packs were a collection of information leaflets that Penny and Eve decided were valuable for a transitioning patient population. From the age of twelve onwards, young people would receive the packs in envelopes - pink for girls and blue for boys. They covered topics such as 'Clubbing'; 'Alcohol and Illegal Drugs'; 'Driving'; 'Transition'; and 'Careers'. Besides the coloured envelops in which they came, the difference between the girl pack and the boy pack was that the girl pack contained further leaflets titled 'Contraception Advice' and 'Pregnancy and Epilepsy'. It was noteworthy that the content of the '*Contraceptive Advice'* leaflet did not discriminate between males and females and discussed contraception options for both sexes. Nonetheless, this leaflet was absent from the blue envelopes:

> **Eve**: These packs could probably do with reviewing; it's been a few years since these envelopes were looked at.
>
> **Penny**: Yeah, we could do with looking over them. All the information is up to date like phone numbers of Longwater and Carden departments but it's a bit twee, the pink and blue, and of course boys should be aware and know how to use contraception. But then again, clinically speaking there is a real difference in treating young women with epilepsy compared to young men. Real issues

> around getting pregnant whilst taking certain medications like sodium valproate.

In women of child-bearing age with epilepsy, the choice of medications may have teratogenic effects (i.e. disrupt in-utero development) on an unborn child (Bromley et al, 2014; Stephen et al., 2019). Therefore, in epilepsy patients, adolescence triggered a differentiation between the male and the female body. However, there was a hesitancy on the part of health professionals to engage with young people with ELD and their families on issues of sexuality and sexual health. Issues of sexuality in learning disability populations are taboos (McCarthy, 2014), rarely discussed in the transition literature but highly significant in this study. Below, Dr Keegan clearly states why sexual activity in young women with epilepsy raises concerns:

> **Dr Keegan**: Many young girls don't realise that different medications can have different effects on contraception and pregnancy. We have to make sure they understand, to save from any risk to themselves or baby in the future. I think as early as possible we should have those talks and not wait until they are here in adult services for that.
>
> **Shelda**: And what about in girls with learning disabilities is that any different?
>
> **Dr Keegan**: No [PAUSE], well of course it's different, managing contraception is more problematic when there's a cognitive issue. But it still needs to be confronted. They are still capable of carrying babies. It's just a difficult topic with learning disabilities so we feel more comfortable waiting for the family to raise the issue.

However, when considering the sexual health of young women with learning disabilities, the approach was less proactive and more reactive, for example ‘waiting for the family to raise the issue.’ This reflects Kulick and Rydström (2015) ethnographic study that explored taboos in the sexual lives of people with learning disabilities, arguing that the discomfort in broaching such topics lies within the carers rather than in the people with learning disabilities themselves. Yet the hesitancy to actively engage with young people with ELD and/or their families on topics of sexual health is linked to adverse outcomes, e.g. unintended pregnancies (Borawska-Charko, 2017). Despite health professionals stating the importance of discussing topics of sexual health in epilepsy, in each of the clinical consultations that I observed (paediatric, teenage and adult) I did not witness any health professional initiate any such conversation for young people (male or female) with learning disabilities.

The hesitancy of TEC clinicians (as well as parents) to take seriously both the sexual health needs and preferences of those with learning disabilities was due to feelings of awkwardness, embarrassment and protection:

> **Penny:** Their minds remain the same, but their bodies are different. That’s where it gets awkward. They’re treated like children but with body of an adult and that means hormones, puberty, the lot. Let’s just say they’re not asexual.

> **Tina:** I remember there used to be a time when people thought that young girls with disabilities didn’t have sex as if it’s wrong to even think about that happening. And so, there was all these hushed up abortions because nobody would talk about contraception with these girls.

> **Gail:** It got a bit out of hand really [LAUGHS] at one point he'd just put his hands down his pants in the Asda. Y'know brazen as anything and you'd have to sort of smack his wrist like he was a kid again. I laugh now but I was mortified at the time.

In these instances, we see a schism – the adolescent's expression of sexual desires alongside the institutional and familial methods to restrain these desires. When young people with learning disabilities, who were perceived as having minds that remain child-like, engaged in 'adult' sexual behaviours there was some reconciliation for the adult carers to do.

In another interview, Paula (adult ENS) acknowledged that taboos concerning the sexual lives of people with disabilities were detrimental to adequate care provision:

> **Paula**: There was a time when everybody thought girls with learning disabilities couldn't be sexually active or they turned a blind eye. Truth is these girls need contraceptive management just like all the other patients and maybe more so because they're more likely to have additional difficulties with pregnancy, labour and even any congenital conditions being passed from mum to child. It seems harsh, but these things must be considered and not treated as taboo.

Sexual taboo is something written into social convention and organises our social worlds into safe and unsafe; clean and unclean (Douglas, 1966). Things, people and events that are considered unsafe or polluting need to be surveilled and policed. Bernert's (2011) ethnographic study on the sexual lives of adult women with intellectual disability[73] found that most participants identified themselves as adults. This identification resulted in participants having expectations of sexual autonomy and, therefore, making ‘sexuality limitations’ (e.g. prohibited overnight stays with male companions in supported living accommodations) difficult to understand and deal with.

What we learn from the first part of this chapter is that the expectation of adolescent transformation was further complicated by behaviours that were deemed socially inappropriate for young people with ELD. Specifically, while it was assumed that sexuality emerged during adolescence, this expectation was not applied to ELD. This had significant implications for practice, particularly around the providing a care service that reflected the needs and preferences of those with learning disabilities whilst maintaining a sense of safety and order for the professional and familial carers. Consequently, the adolescent expressions of carnal desires, alongside institutional methods to curtails these, is what created a schism in the minds of the adults surrounding them. The process of sexual maturation, and the associated loss of innocence, is how adolescence has developed to be seen as a function not only of the brain (as I argued in Chapter 1) but also of the body as a whole. The work of Dutch visual artist Rineke Dijkstra (Beach Portraits, 1992-2002) emphasises this point well. Through her series of photographs of adolescent bodies in swimwear, Dijkstra depicts the awkward physicality that encompasses bodily transitions into adulthood. Dijkstra describes her work as documenting the embodiment of awkwardness that adolescence is; characterising it as a liminal state where the one, (children) splits to become the

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[73] The participants in this study are described as having cognitive functioning and adaptive skills which “varied greatly, ranging from one highly independent woman who attended college to women requiring direct supervision and assistance.” (p 130, 2011).

two (men and women). The work of Dijkstra was a clear analogy for how the adults in the current study saw their transitioning teenagers; as liminal, socially awkward beings. As I now turn to show, this liminal social status was aggravated by notions that appealed to appropriate ways of being and appropriate ways of 'looking disabled'.

Part 2: (In)visibility of disability: Appropriate ways of looking disabled

I now want to consider what it was about physical development that created a tension point for caring. The ambiguous character of the ELD adolescent experience and how it manifested itself in social interactions are discussed below. In the two following ethnographic accounts, I will consider the physical appearance of young people with ELD and how these shaped perceptions of disability and notions of age-appropriateness. In particular, I focus on how the bodily appearances of young people with disabilities, such as the presence of facial hair or preferences for designer brand clothing, prompted unease in the adults that cared for them.

Ethnographic Story 3: Proper men, little women

Alongside her routine clinical duties, paediatric ENS Eve was managing a film project that was to produce a short, informative animation about the TEC. This animation would be available via Longwater's website. During the initial stages of the animation project, a group of health professionals[74] were consulted on the structure and content for the animation. In one particular consultation session, the group were deciding on what style of short film (animation or live action) they wanted to develop. To help with their decision, Ade, a freelance filmmaker working with the Trust, brought along examples of both film styles. The example live-action film that Ade presented was a

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[74] This included Eve, Penny, psychologist Sara and an unnamed nurse, as well as being facilitated by freelance filmmakers Ade and Nadia.

promotional video that he had produced for another NHS trust, Meadow House. Meadow House was a hospice that provided respite care to under-25s with severe learning disabilities and life limiting medical conditions. The 7-minute-long film showcased the services provided by Meadow House; we saw young people engaging with play therapists, singing along to a karaoke, and trips out to the beach, cafe and shops. Further into the film, we watched a scene that presented Meadow House's sensory room. This was a darkened room equipped with LED bubble tubes, a ball pit and a fibre optic fountain light. The young person featured in this scene was a male who had a substantial amount of facial hair that made him look older than Meadow House's under-25 clientele. The film zoomed in on him laughing in slow motion as he sat in the ball pit and threw the plastic balls in the air. At this point Eve joked, "Enjoy it while you can mate, there's no sensory rooms in adult care." Another nurse responded with "Are you sure he's not already an adult?" and there was an awkward, almost groupthink, laugh from the rest of the health professionals. "Well he's enjoying that ball pit a bit too much to be an adult," said Eve "The moustache throws you a bit."

I noted my own reaction to this clip. Watching this scene prompted me to jot down in my field diary French neurologist Jean-Étienne Esquirol's description of 'mentally retarded children' as '*arrêté dans son development*' meaning that they are to be what they are for the rest of their lives. I too was surprised at seeing an older adolescent male, with what appeared as more of a man's body than a boy's, engaging in activities that are associated with childhood. There was a sense of the uncanny – as though this young adult should have grown out of finding joy in such activities but had not yet done so. Why was it uncomfortable to see a (young) adult enjoying activities that are largely reserved for children? For me, in that very moment, the scene made me think back to the concepts of 'age-appropriateness' and Developmentally Appropriate

Healthcare [DAH] that dominated the transitional healthcare literature (See Chapter 1 for a discussion of this). This scene had opened a fissure that I could not seem to reconcile. On the one hand, society infantilises people with learning disabilities, providing narratives of vulnerability and imperatives for able-bodied citizens to offer social protection (McLaughlin & Coleman-Fountain, 2014). However, on the other hand, we project onto people with learning disabilities the need to appear independent and behave in a manner that is considered appropriately ‘adult’ (Pols, Althoff & Bransen, 2017). But who decides which behaviours and activities are age-appropriate? Judging from my own and the group’s reaction, an adult enjoying a ball pit was not one of these age-appropriate activities, unless they are being used in an ironic or nostalgic way (Chen, 2017). When the film ended, paediatric psychologist Sara questioned, “It’s not really fair is it? We all looked at that and judged. It looked weird but after he’s twenty-five all this sensory stuff stops and he’s in the real world.” Eve nodded and said, “But they all become adults, proper men and little women. There’s a physical growth but with these kids the mind doesn’t match that. It’s just…” she trailed off and shrugged. The group remained silent.

Reflecting a deeply ingrained prejudice that resided in us all at that moment, the group demonstrated a shared belief that disability equates to helplessness and innocence. The group’s reaction exemplified a conflict between acknowledging that people with learning disabilities have needs and preferences all of their own; whilst reconciling that acknowledgement with dominant paternalistic and ‘age-appropriate’ approaches to care practices for those considered vulnerable. This anecdote raises important issues for consideration. Firstly – and echoing Gail’s point in the previous chapter that her son Daniel ‘jars’ the system – we see that the neuro-atypical adolescent persistently presents as a troubling figure for the running of social practices designed with the typical adolescent in mind[75].

Secondly, there is the issue of paternalism. As a society we permit interference (e.g. from institutions of health and social care) in people’s lives and recognise cases where people cannot make meaningful decisions for themselves. Yet, there is difficulty identifying when and where people need specific protections. As the comments about the young man’s moustache illustrate, adolescent physical transformation forced the health professionals to momentarily grapple with the logics of care and choice (Mol, 2008). His choices (such as time spent in sensory rooms or ball pits) would become unavailable to him once he ‘ages-out’ of the paediatric/young-adult health and social care system and finds himself in the adult environment. It is through taking away his choice that a seemingly ‘appropriate’ care is enacted.

Finally, whilst liminality is an expected state for adolescents to occupy, they are only ever expected to occupy it for a limited time, i.e. liminality ends once a young person becomes adult. However, in this case, we witness an attempt to artificially end a period of liminality, i.e. to force on to these young people the appearance of growing up. The following ethnographic story considers yet another aspect to this adolescence-disability-liminality nexus. Through the next story of Maddy and her interest in fashion and textiles, we are shown how disability becomes invisible through social expectations concerning appropriate ways of ‘looking disabled’.

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[75] The 2014 cases of Kajieme Powell who, despite having schizophrenia, was killed by US police officers for non-responsiveness and as well as the fatal shooting by police of Ferguson teenager Michael Brown tragically highlights this point (Elman, 2015)

Ethnographic Story 4: Disability in Fashion– Maddy and Denise

When I initially met 17-year-old Maddy she was attending her first TEC appointment with her mother Denise and father Christopher. Dr Roberts had diagnosed Maddy with autism and epilepsy when she was 4-years-old and she had been under his care ever since. When Maddy and her parents entered the clinic room, I was struck by how well put together she looked in her clothes. She wore a simplistic black A-line skirt with a blue and white Breton style top and elegant indigo pumps that were finished with grey pearlescent stones. In the crook of her left arm hung a small navy Longchamp tote bag. The ensemble was topped with a navy beret that was dramatically tilted to the side of her head. As Maddy and her parents took their seats, Dr Barton stated that she was the best dressed teenager they had seen all morning. At this, Maddy gave a great big smile, then her mother stated that her daughter wished to be a fashion designer one day and particularly admired French fashion, with her icon being Coco Chanel. Maddy was nodding her head in agreement. However, for the remainder of her TEC consultation she did no further communicating. Despite being prompted multiple times by Dr Barton, it was always Denise or Christopher who answered his questions. When the family left the clinic room, Dr Barton stated that he thought Maddy should have engaged a little more considering her age. However, Dr Roberts responded as follows:

> **Dr Roberts:** I forgot to mention Maddy’s extremely well composed, I mean she looks great and appears like any other normal teenager. But she can be cripplingly shy - her disability gets in the way of her engaging. You wouldn’t think she has a learning disability [by] looking at her, but it is quite severe.

By stating ‘You wouldn’t think she has a learning disability [by] looking at her.’ Dr Roberts reiterates a social expectation that there is a particular way of ‘looking’ disabled (Buse & Twigg, 2018; Vinoski Thomas et al., 2019). It was unexpected for a disabled person to appear so ‘well composed’ and the very fact that Maddy violated this expectation is what caused Dr Barton to expect her to be less dependent on her family when communicating in the TEC.

Dr Barton’s assumption regarding Maddy’s capacity to contribute to the consultation must have been glaringly obvious to her parents since, when we met again three weeks later at the family home, Denise was still unsettled by it. Throughout our interview Denise referred to other occasions when Maddy had been mistaken for a ‘normal person’. She told me that it was the outcome of Maddy’s love for fashion and people’s expectations of what disability ‘looks like’:

> **Denise:** A lot of parents with teenagers like Maddy dress them in scruffy clothes y’know clothes that they’re not bothered about ruining or getting dirty. I’m not a snob but I’ve always made a point to dress Maddy in the same standard or quality of clothes as I buy for her brother or myself. She has a real love for fashion and art and textiles anyway – this is something she cares about and as she’s getting older this is her way of having independence through her choice of clothes. I know that it might look different to see people with learning disabilities in designer clothes and I’m not wasting my money – I just treat all my children the same. I know some kids with learning disabilities get themselves dirty or have continence issues, but she doesn’t have any of that, she’s more OCD, keeps herself clean if anything. So yeah, I do realise that she doesn’t look learning disabled and that makes people treat her as if she’s

> normal. It’s something I’ve noticed more and more as she gets older but, it’s not her fault that she’s got great style [LAUGHS] and if people want to make judgements of the kind of person she is based from that then that’s their fault. That’s why he [Dr Barton] kept asking her questions and I’m thinking for god’s sake she hasn’t got it in her to answer you.

Buse and Twig (2018) explored the role of dress and clothing choices for the residents of a dementia care home. The findings of this study emphasised that dress represented a significant part of the care environment, with the potential to shape experiences of care and construct the identity of its residents. The authors concluded that clothing choices are relational and shaped by social expectations. This study helps us to understand Maddy’s choice of clothing as a violator of social expectations concerning the look of disability, expectations of disabled people and appropriate ways of being. In Maddy’s case, the assumptions of others regarding her learning disability, was complicated by her clothes and outward appearance. Furthermore, her family was drawn into this decision-making process regarding Maddy’s freedom to express herself through clothes, ultimately leading to a complex blurring between not ‘looking disabled’ and being disabled. Clothing and outward physical appearances, are techniques of ‘preparing the body for the social world’ (Mauss, 1979, pg. 11). However, in the eyes of the health professionals, Maddy’s clothing presented her as something that she could not be – an independent teenager capable of managing her own healthcare needs. Subsequently, Maddy challenged their expectations on what a disabled teenager should look like. Once again, liminality revealed itself to be a condition of ELD transitional care.

Further into our interview, Denise took out her mobile phone and showed me various pictures of Maddy with her family. “Look,” Denise said, “she’s exactly like the rest of us to look at.” There were pictures of Maddy in a variety of outfits - all that she had picked out for herself – and there were pictures of the family gathered together at a party. These pictures, Denise explained, gave the impression that her daughter was a ‘normal’ teenage girl:

> **Denise:** I guess it was the way I was brought up. I would never let any of my kids look anything less than their best. She looks like any other normal person. But that’s part of the problem. She loves to get her hair coloured and blown. She’s quite glamourous and it confuses people [LAUGHS] it’s like she can glamour people into thinking she’s just like them.

Normality and glamour - as opposed to looking learning disabled – were the attributes that caused Maddy’s condition to become momentarily invisible in the eyes of the public and care service providers. In the below interview extract, Denise provides an example of when the invisibility of Maddy’s disability impacted the health and social care that she received. To put the following extract into context, a year earlier Denise had applied for Maddy to take up a place at a specialist autism residential care home for part of the year. If successful, Maddy would have been able to have her own living quarters (a bedroom and a bathroom) with a communal kitchen, garden and lounge area shared with other young people with similar long-term conditions. The residential home was privately owned but young people and their parents could apply for a funded place from their local authority. However, at the time of our interview, the local authority had declined Maddy’s application on the basis that she was not, in Denise’s words ‘as disabled as others’. In what follows, Denise emphasises that it was adolescence and Maddy’s transition to adulthood that reinforced this tension wherein Maddy appeared more well and able than her mother felt she was:

> **Shelda:** You said, ‘they thought we lied on Maddy’s residency application’. How come they thought you’d lied?
>
> **Denise:** Before we put the forms in, we’d all gone down to visit the residential as a family to check out the facilities. When we visited, there was someone from the LA [Local Authority] checking it out with us. Well we thought they were checking the place out, but I guess she was us checking us out as well. We were there for half a day and got a general feel for the place - we all fell in love with it immediately. Maddy made friends with a girl there within five minutes of walking through the front door. It was fantastic but within two or three days of submitting the forms, the LA queried her application. They said that they wanted to check if the diagnosis of autism was correct and if her seizures were as severe as I said they were. Not only that but they sent another person out to our house and I don’t think that’s their usual practice if I’m honest. I think they were checking the facts. When this woman came to the house, she basically demanded to see Maddy’s room. Something about matching the suitability of the residency bedroom with her home bedroom. It was all rubbish to be honest, but I let her see it anyway because Maddy has nothing to hide. She said again, are you sure its autism and not asperger’s or ASD and then she went on to give me a definition of ASD y’know saying even though her diagnosis might say ASD she might be mild. I was livid to be honest, so I put it simply and said why don’t you phone the clinic and speak to her doctors and nurses, check her A&E files when she’s nearly died from

> seizures. Anyway, it’s been awful and it’s getting worse. Whether it’s because when they transition the services are limited but again it’s because they see Maddy and think well she’s normal. Or they think she doesn’t need the amount of care that Chris and I are saying she needs.
>
> **Shelda:** It’s getting worse?
>
> **Denise**: Yeah she looks as though she can hold a conversation. As a child its ok to ignore people or look shy but as an adult people think she’s being rude or she’s weird. They don’t see that she’s got a disability. It’s something that only reared its head when she became a teenager. Unless you’re in a wheelchair they just don’t want to know. Y’know she doesn’t look as disabled as she is and that’s what people don’t get, but no learning disability is the same. They see us applying for benefits or care funding and they’re thinking that we’re just [SIGHS] trying to swindle. It’s horrendous. There was none of this when she was little.

Denise’s emphasis on wheelchair use as the ultimate signifier of disability meant that for Maddy (with her appearance of ability) good care had been denied to her. In this case, ironically, it was her appearance and passing as normal that contributed to this stigma (Garfinkel, 1967; Goffman, 1963). Whereas many stigma studies describe the visibility of a condition, such as ELD, as socially stigmatising (Jacoby, 2008; Kirabira, 2019), it was the fact that Maddy’s appearance obscured her ELD that her mother felt was the problem. For Maddy, someone whose disability was at first invisible, there was a risk of being denied access to necessary care or being assumed to be ‘not engaging’ as Dr Barton claims. The stigma that is felt here by Denise is reversed; it is a stigma that is due to the invisibility, rather than the visibility, of her daughter’s condition (Brune & Wilson, 2013; McRuer, 2006). These two stories show that young people were challenging the normative assumptions associated with both disability and adolescence, which in turn produced a significant tension for the provision of caregiving.

Liminalities and Ambiguities

These two ethnographic stories show the substantial role that a changing physical appearance played during the transition to adulthood. Furthermore, they highlight two main preconceptions to be addressed when considering the development of social and institutional care practices for young people with disabilities. First, these stories illustrate the deep-rooted preconceptions regarding what disability 'looks' like within the sociocultural imaginary of able-bodied people. For example, the surprise in Maddy's well composed appearance prompted expectations of social engagement that she was unable to fulfil. Second, this preconception led to certain assumptions being made regarding a young person's capacity to participate in society in ways considered appropriate for their age group. For example, the provocation of awkwardness at seeing a man play in ball pit and the expectations of Dr Barton and the local authority for Maddy to be less disabled than she was. What we learn from these two stories is that adolescence, accompanied by severe and profound learning disability, was an ambivalent, ambiguous and liminal experience.

Whilst the above examples exemplify how physical appearance impacted care practices (e.g. from accessing and funding of available care home placements to the minutiae of how doctors interact with patients), they also show how abled-bodied people related to those with disabilities. Specifically, how serious the personal choices of people with learning disabilities were taken. For example, Carlton's choice of play mates, age appropriate recreational activities or Maddy’s choice of clothing. These were important, and often personal, choices that had been made by the young people themselves – yet they were restricted or prohibited by the adults around them. This shows that, whilst there is the rhetoric of independence within the institutional model of transitional care, these stories highlight that the independent choices made by these young people with ELD in fact became points of tension, awkwardness and often considered inappropriate. Therefore, whilst these young people with learning disabilities did in fact make independent choices, those choice often lay in opposition to the values of the society within which they sat.

Conclusion: The rhetoric and the reality

This chapter has demonstrated that the conflict between treating young people with ELD as innocent children or as responsible adults was further confounded by the confusion brought about by visible bodily changes. Such evident ‘adult’ transformations (e.g. facial hair or dressing well) signified an ability to behave in appropriate or normative ways. However, as we have seen these young people deviate from such expectations. The presented ethnographic stories throw into sharp relief the liminal, uncanny and sense of social awkwardness that pervaded the transitional care experience when a young person had an asynchronous mind/body development.

What we learn is that young people with ELD were infantilised by conflated assumptions of childhood, disability and innocence within the context of a society that expects adolescents to grow into independent and responsible adults. This meant that for the adults in this study, both professional and familial carers to young people with ELD, transitioning to adulthood was a moment of grappling between two logics – to treat these young people as dependant, innocent children or to project onto them ideals that constitute self-governing adults. From the above data, these instances of liminality appeared to be ongoing moments of continued negotiation, wherein a solution to ‘appropriate’ care was never quite reached. In presenting the liminal character of ELD transition to adulthood, this chapter builds upon the previous one by elucidating the reasons why transitional healthcare becomes a subverted practice for this patient population. I argue that this is the case because young people with ELD do not transform into their anticipated adult status in ways that society expects of them.

Through analysing moments when the sexual and physiological development of young people with ELD came under scrutiny from carers, we see that this group of young people challenged common perceptions of adolescence as a period of incremental change toward a stable form of adulthood. Therefore, rather than accepting the diversity that people with learning disability may bring with them, including their own non-normative, independent and socially awkward choices, institutional models of transitional care neglected such choices in order to uphold expectations of social propriety. Rather than the asynchronous mind/body being recognised or accepted, these stories show it to be treated as if morally accountable, wherein ELD individuals become a persistent source of trouble for neurotypical populations (Garfinkel, 1967; Maynard & Turowetz, 2019). To understand adolescence as a time that occasions a loss of innocence is to see the liminality of young people with ELD. They are both in and amidst ephemeral physiological changes whilst remaining unclassifiable since their disability renders them incapable of becoming the idealised adult citizen. Consequently, I conclude that in postulating adolescence as a transformative period, whilst rhetorically concrete (for example in the clinic adolescence is given a certain stability through establishing the practice of transitional healthcare), it remained practically amorphous for ELD transition. With this in mind, the final data chapter presents how Longwater and Carden were attempting to resolve this discord of ELD transition.

Chapter 9 – Transition and its Tensions: The paraclinical workforce

The previous chapter argued that, despite the rhetoric of transitional care, it is almost impossible to alter the liminal status of young people with ELD. Whilst young people with ELD did indeed transform from childhood into adulthood, they did so in ways that were particular and unique to them. This transformation is what I characterised as a persistent liminality that was predicated upon an out-of-sync mind/body development. In this final chapter, I will reflect on the institutional efforts to enrol families into caregiving as the transitioning process advanced towards it end. Within the TEC, the end of the transitional journey was marked by the end of the joint adult and paediatrician clinical consultations. When a young person no longer attended the TEC, they were said to have 'graduated' into either Dr Barton or Dr Keegan's adult epilepsy clinics. By examining the 'graduation' period – a period that was symbolically similar to the reintegration phase of a rite of passage - I aim to show how institutional practices of care focussed on making the families of young people with ELD responsible for their children's ongoing healthcare management and needs whilst the institutions, themselves, gradually reduced their own involvement in a patient's care.

To this end, I discuss the Parent Skills Passport [PSP] initiative - a quasi-clinical training scheme for parents of children with severe and profound disabilities, such as those with ELD[76]. Using the PSP as an illustration, I discuss how parents were being

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[76] Although the PSP was yet to be formally implemented into Longwater Trust, the initiative aimed to eventually enrol all parents of children with profound and multiple disabilities onto the scheme before they transitioned into adult services.

responsibilised for their child's ongoing healthcare needs well into adulthood, shaping families into what I have termed a 'paraclinical workforce'; an unpaid labour force wherein parents, rather than trained medical professionals, were expected to perform specialised care duties. This chapter is significant in showing the contradictory character of transitional care at the field sites. In particular, whilst modes of responsibilisation may seem counter to the parentectomy discussed in Chapter 7, upon deeper analysis we see how these two expectations work with each other to shape a particular experience of transitioning into adulthood with ELD.

Good for the taxpayer, good for everyone: The expectation of responsibility

Increasing a patient's personal responsibility toward their own healthcare as they moved into adulthood was a common way of rationalising the practice of transitional healthcare. The institutional transitional care model upheld that young people should become personally responsible for their own care needs through particular behaviours - such as, diminishing their attachment to both parents and health professionals that they may have become accustomed to whilst under paediatric care. Moreover, becoming a responsible patient was viewed as an obligation for young people (without profound disabilities) to attain as they moved into adult society:

> **Dr Barton:** We all need to take care of ourselves, not just those who are ill. When they [young patients] do self-care, and eventually take responsibility for their own health, everyone benefits. Knowing their type of epilepsy, medication, or even just the phone numbers of the hospital, all these little things, decreases the chance of making things worse in the future. It could be simple miscommunications regarding treatment, or bigger psychosocial

> problems as they adjust to the condition. What's good for the patient is good for the taxpayer is good for everyone.

For Dr Barton, not taking responsibility for one's epilepsy management risked poor health outcomes. However, intermingled with such 'responsibility' and 'self-care' imperatives were ideas of welfare economics and citizenship (Craddock, 2007). Dr Barton's claim that 'What's good for the patient is good for the taxpayer is good for everyone' clearly reflects the principles of a UK healthcare system that is based upon a moral economy, whereby obligations of citizens must be fulfilled to 'contribute', 'help' or 'ease the burden' of a publicly funded healthcare service (Kierans, 2018).

Responsibilisation has become an important concept to attend to within publicly funded health and care services (Jones, 2018a). As a feature of national health policy, responsibilisation aligns with what can broadly be characterised as the predominant neoliberal discourses[77] that constitute citizens as 'empowered', 'self-governing' and 'activated' (Clarke, 2005). Consequently, citizens are rendered responsible for making efficient use of public services. Efforts to promote self-care in patients with chronic conditions, such as ELD, was set out by the Department of Health as 'collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively' (DoH, 2005, pg. 10). Contemporary messages of public health are concerned with advising individuals of what *they* can do to contribute to the health of the population through examination and adjustment of their 'lifestyle behaviours' (Lupton, 1997), illustrating what sociologist

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[77] My use of the term neoliberal is in refence to both economic and social ideologies that can broadly be characterised as neoliberalism. However, I refrain from consistent use of this term in recognition of the contentious debates that surround it (examples of such debates include Eriksen et al. [2015] and Bell & Green [2016]).

Nikolas Rose (2007) refers to as neoliberal governmentality, wherein the state continues to exhort control over individual bodies but does so at a distance. It is within this mode of responsibilised care provision that transitional practices and the TEC were located.

According to the health professionals, the idealised responsible patient remembered their medication name and dosage, turned up on time for appointments and engaged with clinicians to support their own epilepsy care, to name but a few examples of what was expected of young people entering adult services. The intentions behind such processes were to see young patients taking an active role in solving the problems and daily management of their own healthcare. Furthermore, displaying responsible behaviours showed a maturity or as Dr Roberts's stated a 'readiness to transition' into adult services. For example, rather than being reactive and passive, young people were encouraged to be active and assertive during clinic consultations – an expectation we saw placed upon Maddy in the previous chapter.

Once these ideal behaviours were evidenced, Dr Roberts said that young people were ready to 'graduate' into Carden Adult Epilepsy Services. However, studies have shown that when young people do not have capacity to participate in self-care, the task inevitably falls to the parents during and post-transition (Heath et al., 2007; Schultz, 2013). In this way, assessing the 'readiness to transition' into adult services of young people with ELD was not of high priority to the TEC health professionals since, in their view, they would only be transitioning the parents:

> **Dr Roberts:** For young people with more complex needs, those who are profoundly disabled, then transitioning to adult service doesn't always mean improved quality of life but it does mean change. In those cases, there is no

> way of determining when they are ready because rather than seeing the child take responsibility, the responsibility remains with the parents. It's more about transitioning the parents and they do undergo the transition process. Just like the kids, parents have to adjust to new doctors, to a new environment. So yeah, I would say in the most severe cases, when they don't have an understanding of what is going on, then it is the parents who are being transitioned.

Due to a young person's 'lack of understanding', Dr Roberts maintained that parents are the ones who will ultimately shoulder the responsibility of care as their young people move into adulthood, thus making ELD transitional healthcare a transition by-proxy. As the following ethnographic stories attest, this turned a supposed period of emerging adulthood into a significant point of tension since, in cases of ELD, the young person would never attain the sociocultural values of individual independence and personal responsibility.

The making of a 'paraclinical' workforce

For young people with ELD, not meeting the expectation of the responsibilised patient - by virtue of a compromised cognition - excluded and marginalised them from the full transition journey. Since these young people were never going to reach a state of independence wherein, they would become responsible for their own healthcare needs, there was, consequently, a re-distribution of responsibility for young people's healthcare needs onto the shoulders of their parents/carers. The Parent Skills Passport [PSP] represented one strategy for responsibilising parents/carers. Operating under the principle of parent empowerment, the PSP was a method of managing the ongoing burden of a patient population with complex and profound disabilities. Through this method, the institution expressed their need for, what I have termed, a 'paraclinical workforce'. In other words, a workforce wherein parents were supporting the institution, rather than being empowered themselves.

Ethnographic Story 1: The Parent Skills Passport

Nearing the end of fieldwork, I met with Transition Nurse Suzy for a final time. She wanted to share with me the emerging findings of a piloted parent training scheme that was being trialled across Longwater Hospital. Suzy had attended an inhouse seminar, where the speakers had discussed the PSP scheme [see Figure 6]. The pilot project had taken one patient with complex health needs [CHNs] from five of Longwater's clinical departments[78] and had enrolled them on a scheme that provided them with the opportunity to learn quasi-medical skills that were relevant to their child's specific needs. Describing the PSP's aims, Suzy enthusiastically told me that this was something that she had already considered for the future of transitional healthcare at the Trust. The scheme aimed to equip parents[79] with quasi-medical training to obtain 'advanced' care skills. This quasi-medical training included learning how to perform tasks such as suctioning in young people with a tracheostomy, administering buccal medication and performing catherization. Furthermore, Suzy emphasised that these skills were 'transferable'. This meant that once a parent had completed a component of clinical training and attained a 'stamp' in their PSP (a hard copy passport-style booklet that would evidence their completed training), they would then be able to apply this skillset across different settings such as home, schools and even other

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[78] This included neurology, nephrology, pulmonology, cardiology and gastroenterology departments.

[79] This included paid carers /support workers but, for readability and clarity, I have chosen to use the term parents. I asked Suzy if parents could fail this assessment, she told me that she was 'unsure, but doubts it'. She explained that the certificate, which was to be presented when a parent completes their assessment, was more of a symbol of participation than of actual certified approval.

hospitals. Subsequently, the PSP acted as a certification process, a symbolic representation that would inform health, social care and education professionals that a parent was capable of completing quasi-medical tasks.

Safe, effective, continuing care for children with complex long term conditions

SAFER CARE ACROSS CARE SETTINGS

- A record of standardised training and assessment, providing assurance that parents and carers are competent to care for children with complex long term conditions, from basic washing and dressing to advanced tasks such as tracheostomy care.
- Ensures a safe, effective, flexible workforce, providing person centred care in the most appropriate setting, enhancing the quality of care through continuity across care settings and reducing length of stay.

USED BY PARENTS AND CARERS

- Details core and additional competencies required when caring for children and young people with complex long term conditions.
- Specifies when individual competencies are required, how they should be assessed and requirements for refresher training and re-assessment.
- Acceptable and transferrable across care settings (hospital, hospice, school, home).
- Documents training received and competencies assessed by the Passport holder.

VIEWS OF PARENTS

"A brilliant idea! It would most definitely cut down a lot of stresses and confusion between community's staff, parents and carers"

"This will really help. We find it frustrating when we come into hospital or new carers are trained to do a procedure a different way to how we were taught"

"In the past, as parents we have had no refreshers, updates etc. unless equipment has changed"

For further details please contact [redacted]

Figure 6. The PSP promotional poster.

Although not a definitive part of transitional care, the idea behind the scheme was that parents who attended the course would become equipped in the necessary care skills relevant to their child before reaching adult services. Stressing the PSP's capacity to ‘empower and support’ parents, Suzy felt that the scheme would be perfectly suited for implementation during the transition phase of a patient’s hospital career:

> **Suzy:** It’s perfect timing for those transitioning. When they leave paeds and go into adults they will be equipped with these fantastic skills and really know how to provide care for their loved ones. I mean how much better would parents feel if they say look, I know how to perform a tracheostomy or, I don’t have to wait for a nurse or for it to reach an emergency point. It’s handing the power back to parents to look after their own children.

Suzy offers an image of the PSP as a gift, something that the institution is ‘handing back’ to parents. In other words, the PSP was presented as an intervention that was in the interest of the parents rather than the institution. Suzy showed me an A4 information sheet that outlined the scheme [see Figure 6]. She took her finger and underlined the word ‘empower’, reiterating its importance, and stated:

> **Suzy:** Look it will *transform* how parents see themselves as they move into adult services. With the right set of competency skills, safely assessed, they will feel confident and empowered to care for their own kids.

Similar to notions of consumerism in healthcare, responsibilisation is a sociocultural trend that operates behind narratives of ‘patient empowerment’, ‘shared decision making’ and ‘patient choice’ - however, ultimately, such narratives aim to reduce the role that a welfare state has in matters of healthcare (Brown, Maslen & Savulescu, 2019; Mol, 2008; Rose, 1999). This is something that is becoming increasingly significant since, as of 2012 with the passing of the Health and Social Care Act, the British Coalition/Conservative government has been accused of leaning towards the privatisation of the NHS (Slorach, 2016). Modes of responsibilisation, such as the PSP, reflect this shift towards future privatisation and the prevailing concept of the patients as consumers rather than recipients of health and care services. Whilst increasing patient responsibility may be viewed as a positive movement[80], it is nonetheless one that fervently excludes those who are unable to access or communicate their opinions in ways that are in line with such trends (Scott & Wilson, 2011; Liebenberg, Ungar & Ikeda, 2015).

Similarly, the PSP raises a whole set of unanswered questioned that are tied up within this training package. Here, we have a demonstration of trained health professionals seeking to assess parental competency skills; that, one could argue, are the responsibility of professionals who have undertaken years of clinical training. Although there may be questions concerning the politics of expertise within transitional care (see Chapter 7 for a discussion of expertise and its subsequent tension in the parent-professional relationship), I feel it is more pertinent to view the PSP as a question of support rather than expertise and empowerment. That is to say, in requiring parents to undergo a form of quasi-clinical training, the PSP enables us to ask the following questions: Whom is supporting who? Do parents truly need the support/empowerment that is assumed to come with further training or does the institution need parents capable of undertaking clinical care? From the perspective of the institution and its clinicians, the purpose of the scheme was to provide parents with needed support i.e. to feel empowered, parents must undergo quasi-clinical training.

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[80] Examples of recent DoH policies encouraging the responsibilisation movement include Jochelson (2007), Wanless (2002) and DoH (2006).

Rather than the delivery of healthcare being in place to support the family, the PSP showed itself to be a method of outsourcing clinical care to non-clinical carers. The extent to which the scheme would financially benefit Longwater Hospital was never discussed in detail, since this was currently unknown. However, it is not difficult to see that every parent taking care of their child's medication or dialysis or changing needs, lessens the burden of care for medical staff. Consequently, the families of these patients were increasingly being seen and treated as a valuable resource, with parental love and care being attributes that could be exploited:

> **Suzy:** I can see the CBU really taking this on board. They [the researchers piloting the PSP] said that the research behind it has shown that it significantly reduced costs. Other clinicians I've spoken to who have attended the training seem to think that it could help with workload as well as see a drop in A&E admissions. And parents feel really empowered, they can do these skills, and they don't have to waste their time coming all the way into hospital.

Acknowledging that there is likely to be a cost benefit to the PSP shows quite clearly that this scheme was a mode of outsourcing care - it becomes both a labour-saving device and a cost-saving exercise, rather than a care enhancing initiative. Nevertheless, Suzy tells me that this is what makes it a 'win, win' scheme as it benefits all; patients, parents, and the institution.

Through examining the PSP, what we see is an opening up of an indeterminate realm of what can be considered paraclinical (Padilla, 2018). What we are witnessing is a reconstituting of what counts as clinical care, who the workforce is and the reconfiguration of what constitutes workspaces. Therefore, the consequence of the PSP would be a quasi-professionalisation of parents and the provision of 'caregiving' in the form of courses, assessments and training. Padilla's (2018) ethnographic study into peritoneal-dialysis in rural Mexico develops this idea of the paraclinical realm with the concept of 'homework'. 'Homework', in a clinical sense, shows us what happens when services diminish and care is moved into the home environment - creating a paraclinical space. Padilla found that in Mexico there was little hospital-based dialysis for patients with chronic kidney disease, therefore in order to support the growing kidney patient population they (patients, as well as the clinicians) were reliant upon home dialysis. Describing how people created an extra space for home dialysis, Padilla shows us the training package that carers received so they were capable of performing tasks such as changing solutions and working through the daily regime[81].

Whereas Padilla writes of a para-clinical space, the PSP reinforces the notion of a paraclinical workforce, wherein NHS staff will provide free training to an unpaid labour force, i.e. parents. Effectively this reduces parents to unrecognised and unpaid medical staff; something that this is ironically contrasted with the PSP posters statement of 'ensuring a safe and flexible work force' [see Figure 6]. The payoff of such a care provision comes at the cost of increased medical responsibilities and caregiving duties for parents. This raises an ambiguous relationship between the trained and technical type of care that is usually delivered by doctors or nurses and the home environment care that we usually associate with families. The type of care that

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[81] Padilla describes how chronic kidney disease patients are required to attend a course to show they are competent in dialysis. They are required, by healthcare providers, to take pictures of their home dialysis in order to prove they have it set up. Subsequently, chronic kidney disease patients are treated in totalitarian terms. They are also forewarned not to simply bring in pictures of a neighbour's dialysis space. This assessment is like an exam and patients may not pass. If they do not pass, they will not be given the dialysis solution.

was encouraged by participation in the PSP is distinguishable from the kind of care we give to people who are sick in our household – when we look after them with food and warmth (Wilkinson & Kleinman, 2016). The PSP required families to go beyond this typical familial care and undertake a more technical type of care, one that required specific and standardised training and assessment.

Since the PSP was only in the pilot stages, I found it difficult not to speculate about the implications of such a scheme. For example, does participation have the potential to lead to further problems of liability later down the line? What, if any, would be the sanctions attached to this certificate? Could parents be refused care on the grounds of completing this course? Suzy seemed to believe that no harm would ever come to the patients because of this scheme:

> **Suzy:** I think most parents will jump at the chance to have a more medical understanding of their child's condition at no extra cost to them. It'll be free. The parents who have done it have said nothing but good things about it. But I just think something like this would be good for CHN parents as a bit of a refresher or a chance to learn something new during transition.

Within this quote there is a valid internal logic. Whilst Suzy concludes that the PSP will be welcomed by parents, if we take a step back the entire premise becomes problematic. Whilst parents may indeed welcome the chance for quasi-clinical training therein lies the question as to whether they should be in a position to have to 'jump' at this opportunity in the first place. This quote is important to keep in the forefront of our minds when considering the impact of responsibilising parents with added caregiving duties through methods such as the intensified PSP.

Conclusion: The rhetoric and the reality

This chapter has explored what happens when individuals, through choice or not, become violators of the expectation of responsibilisation into adulthood. In these circumstances, the answer it seems, is to shift responsibility onto the shoulders of families and parents. The PSP is an example of what happens when the idealised attributes of patient independence and responsibility into adulthood cannot be met. Crucially, there was a moral obligation – a social contract of sorts - that was made clear by methods of responsibilisation; as Dr Barton claimed, ‘What’s good for the patient is good for the taxpayer is good for everyone.’ This not only highlights what personal attributes transitional care practices value in its patients, but outwardly links these values with how the wider society views its ideal citizens. The data examples in this chapter demonstrate how the transition healthcare agenda is symptomatic of the growing UK healthcare trends towards increasing patient responsibility. For example, documents published by The Kings Fund such as ‘Supporting people to manage their health’ (Hibbard, 2014) and ‘People in control of their own health’ (Foot, 2014) reinforce the ideal of mobilising ‘patient choice’ as a means of making patients more responsible for their own healthcare (Mol, 2008). Furthermore, the notion of empowerment was significant in the justification of responsibilisation within transitional care practice. Empowerment was shown to be in the interest of more individualised and self-governing initiatives. Nevertheless, what was left unanswered in the enactment of such practices was the impact for parents of being asked to undertake duties that are normally the domain of health professionals.

The PSP accommodated the individual context of learning disabilities and complex health needs by emphasising the importance of patient empowerment and assuming that it would be the parents who would take over this role. However, whilst these continuing responsibilities and caregiving obligations of parents may seem in opposition to notions of the parentectomy (since parents were crucial to ongoing care), this again reiterated the contradictory, changing and fluctuating character of transitional care for young people with ELD. In other words, messages of diminished parental involvement intermingled with practices aimed at promoting responsibilised families. Crucially, these two mixed messages demonstrated not what was needed of the institution to support the families it provided care for, but what was required of the families to support the work of the institution. Efforts to create and maintain responsibilised families suggest that much more than healthcare management was at stake; here we are glimpsing the emergence of a sociocultural practice wherein citizenship and personhood become enmeshed in disability politics throughout the adolescent period. From the data it was apparent that the responsibilised and independent citizen was the intended outcome of the transition process. This was evidenced through not only the data presented in this chapter but also by Longwater’s transition policy and the Ten-Step Pathway (Chapter 4), the Cerebra transition guide (Chapter 5) and the parentectomy (Chapter 6) where the focus was always on self-management. Personal attributes of independence, responsibility and self-management were no longer transitioned from the parent on to the child but remained with the parents of young people with ELD into adulthood and beyond.

Chapter 10 – Conclusion

The Dignity of Care - Reflections on disability and the problem of normalcy

…if you are not like everybody else, then you are abnormal, if you are abnormal, then you are sick. These three categories, not being like everybody else, not being normal and being sick are in fact very different but have been reduced to the same thing… (Michel Foucault, 2004, pg. 95)

> "I take my time to think about his future. It really breaks my heart. If I could have him as a little kid all over again I would. There's more acceptance for disabled kids. Kids are supposed to be dependant and reliant on mum and dad. Kids are supposed to be told what to do. Kids get in the way. It sounds cruel but kids are supposed to be useless. But what about useless adults? Is he useless? Of course not - not to us. I'm just trying to prove a point. Dan is useless to the rest of society. He won't get a job, get married, or reproduce. He will just take, take, take but not give anything back. And although nobody these days says your kid is useless, y'know it's not like a Charles Dicken's novel when nobody knew what to do with people like Dan so they'd lock them up somewhere out of town. It's not like that now. But also, it's not like world is saying we appreciate people like Dan, thank god we have disabled people in the world. Nobody says that. And that's sad because the rest of the world is missing out on how enriching it is to have someone like him in your life. It's hard, hard work but you see life for what it is and you take nothing for granted.

> It makes you a better, kinder person when you realise that to be human means to be many different ways.”
>
> [Mark Holbrook, father to 17-year-old Daniel Holbrook].

In Mark’s reflection, we see the conflicting relationship between the social expectations of adolescence and the experiences of caregiving for young people with ELD. Mark shows us that being an independent adult engenders an ideal type, i.e. to have a job, get married or to have children. Implicit in Mark’s words is a critique of the taken for granted notions of what a ‘normal’ child, adolescent and adult is; subsequently, claiming that the consequences of not fitting this mould of normalcy is to be ‘useless to society’. As Mark reflects on his son, he provides us with an important principle for caring and that is to acknowledge that ‘to be human is to be many different ways.’

This thesis is the first of its kind to ethnographically examine the practice of UK transitional care for those with ELD. By focussing on the institutional arrangements which shape what it means to be an adolescent in present day UK society, I have documented how young people with long-term conditions have become the focus of targeted health practice and service development. However, the complexity of an additional learning disability coupled with a long-term health condition is little understood or addressed within current transitional programmes. Furthermore, I have argued that if we want to fully engage with the issues presently shaping adolescent health, we must first understand the wider issues influencing collective understandings of adolescence, health and disability.

Throughout this thesis, I have challenged the underpinning assumptions about adolescence that have guided the development of transitional services and I have done so by examining the practices and understandings of social actors involved in adolescent healthcare. I began by ethnographically examining the TEC as the focal point of ELD transitional care. By taking the reader on a journey from the clinical and institutional context of ELD transition into the lived experience of caregiving within the family, I have revealed the disjuncture between the rhetoric of transitional healthcare and the reality of care practice as it is played out in people's daily lives.

Situating transitional care within its institutional and social context exposes the sociocultural arrangements that shape adolescence for those with ELD. As I have shown, the institutional preference for young people to become independent and responsible adults is tied up with larger social and political agendas (as well as technological changes) that influence our understandings of this phase of life (see Chapter 2). As such, adolescence (and the care practices developed around it) must be understood within the political, institutional, cultural and familial contexts within which it sits. It is therefore insufficient to view transitional care as a bounded phenomenon that is simply a limited number of consultations that take place within a specialist clinic (i.e. the TEC). To do so would be to examine only one aspect of the transitional care process and thus limit our understanding. For young people with ELD and their parents, transitioning into adulthood happened as part of the ongoing business of everyday life and across many locales. It was not just clinicians and healthcare institutions which guided this process but also the wider sociocultural expectations of what being an adolescent encompasses. My use of the rites of passage framework (see Chapters 7-9) shows that the expectations of what adolescence is (or is not) was woven into the fabric of clinical care as a practice. Nevertheless, there was little concern as to how these expectations play out when young people develop in atypical ways.

This study builds on Rapp and Ginsburg's (2013) ethnography of transitioning into post-18 education in New York City. It demonstrates that, in the UK clinical context, there is currently no appropriate alternative for those young people who '[*promiscuously violate] ... the walls erected by medical manuals and school bureaucracies*' (Rapp & Ginsburg, 2013, pg. 192). In other words, my study, along with that of Rapp and Ginsburg, highlights the inflexibility of transitional care when it comes to the specific needs of people with learning disabilities as they move into adulthood – whether this be in education or clinical settings. This thesis thus contributes to the fields of STS and social studies of medical practices by examining the often taken for granted ways of ordering and organising care practices reflected in clinical and education transitions. It also contributes to the fields of clinical psychology and neurology by examining how their disciplinary practices influence the daily lives of those with ELD and their carers. Furthermore, by presenting a case-study of an institutional practice and exposing how it is made to work (or not work) for those with severe forms of learning disability, this study engages with the wider field of disability studies.

What this thesis shows is that to care for those with severe forms of disability and long-term conditions, as they move from one stage of life to another, is hard work. However, it is in the course of carrying out that work, that we are reminded of the particularity and distinction of the person in society. Mark's specific acknowledgement that his son Daniel can never 'give back to society' reflects the transactional principles that govern and bind social relations, i.e. reciprocity (Mauss, 1990 [1924]). Yet, this alters considerably in the context of disability. Caring for young people with ELD is, likewise, often carried out despite the lack of rewards. Caregiving, in all its forms, is a task that values human life beyond ideas of normativity and provides ‘enriching’ and ‘kinder’ ways to engage socially. Nevertheless, the findings of this study suggest that there is a long way to go to truly privilege the person – rather than the ‘standard’ – as a mode of caregiving, particularly for those with severe forms of disabilities and long-term conditions. However, to forgo standards is not what this study proposes. Rather it recommends a commitment to an engaged ethics of care. This would mean continual acknowledgment that standards sometimes produce expectations of patients that they are unable to fulfil. This approach would recognise that standards often fall short of what it means to give care. On the other hand, an engaged ethics of care would recommend acknowledging that different orientations to care provision may be suitable for those who are considered neuro-atypical or having different needs. However further study is needed on *how* this engaged approach to transitional care could be implemented when clinical practice is heavily influenced by traditions of medicine (i.e. paediatrics being time limited), partial funding allocations and national cuts for health and social care services which instead of caring often end up doing the opposite.

In undertaking this research, I sought to understand the experiences of providing care for young people with ELD as an institutional and personal concern. The profound declaration by Mark in the opening of this chapter points towards what this study can teach us about caregiving in cases of severe and significant disabilities. In this closing chapter, I wish to draw attention to three key lessons that might aid the future development of transitional care and its study. They are: (i) that transitioning has to be considered a negotiated and situated process, if it is to be inclusive; (ii) that the diversity of disability must be recognised within systems of care; and, (iii) that we need alternative ways of conceptualising adolescence in the context of disability. I will conclude with a short reflection on dignity in care and the importance of ethnography in so doing.

Transitioning: A negotiated and situated process

The first lesson draws attention to the idea of transitional care as a negotiated and situated process. It is tempting to exemplify transitional care as a tale of triumph, something that is wonderfully progressive and inclusive of adolescent healthcare needs (Blum et al., 1993; Viner et al., 2015). However, this study shows that the truth is much more complicated. As shown in my account of the institutional arrangements of transitional care (Chapters 4-6), we see that in the development of this practice (in the context of other activities - i.e. policy, management and research), achieving standardisation was the preferred goal. However, standardised clinical care practices are ideals that alter considerably in the practical, local contexts and, as shown in Chapters 4 and 5, are vulnerable to the vagaries and political tensions between clinical departments. In this case, a rift emerged over 'whose problem' transitional care actually was – paediatric or adult services? In the end, Longwater had the financial resources to enable the development of transitional services (e.g. the CQUIN sponsored role of Transition Nurse held by Suzy), whilst Carden did not.

Despite efforts to do so, transitional care could never be standardised owing to its contingence on routine institutional practice, diverse social actors and cultural expectations. This included professional relationships, family bonds, institutional resources, traditions of medicine, social policy and the particular expectations of adolescence. Furthermore, this study has also shown that social and cultural influences are embedded within biomedical systems of care, such as the social values attached to individual independence and personal responsibility. These values, and the assumptions they give rise to, fed directly into the development of transitional care, policy and research, consequently, privileging those young people who could conform to these socially constructed ideals of adulthood. As such, young people with ELD were viewed, and treated, as disruptions to both the clinical and social order.

However, in situating transitional care within its institutional context, the contributions of this study do not suggest failings on the part of the professionals (or institutions) who worked tirelessly to deliver the best care that they could. Rather, it is to acknowledge the constraints of a system that did not cater for diversity within its patient population. Specifically, this system was designed around a utilitarian ideal, which insisted that clinicians deliver efficiencies of care to the greatest number of people. Crucially, these ‘efficiencies’ took place against the backdrop of decreasing financial resources within the NHS and new UK legislation (i.e. The Health and Social Care Act, 2012). Furthermore, transitional care cannot be conceived of as separate from the familial context. Despite, efforts to remove parents from the equation - as illustrated by the ‘parentectomy’ (see Chapter 7) - parents were inevitably an integral part of formal and informal caregiving. Therefore, transitioning for ELD patients is necessarily a co-construction between families, professionals and young people themselves.

Diversity and Disability

The diverse character of disability is something that this thesis has shown to be profoundly important to experiences of transitional care. Altering continually throughout the life course, disability in adolescence raised significant tensions as the body continues to develop. In Chapter 8, I presented examples of young people’s sexual maturation and personal preferences (as expressed through particular behaviours), and how the developing mind/body raised challenges in caring for both professionals and families. Furthermore, rather than static, states of dependency change throughout the life course of young people with ELD. These changes were clearly evidenced by Mark saying that '…kids are supposed to be dependant and reliant on mum and dad', whereas adults are not. This implies that, as young people with ELD move into adulthood, their continued dependency on parents and institutions is considered undesirable and abnormal.

Preference for a state of normalcy, is an indelible part of medical and social culture, and impacts profoundly on patient's care (Carlson, 2010; Ferguson & Walker, 2014). This was shown in Chapter 8, where Maddy's 'normal' appearance confused health and social care professionals. Ultimately, in her mother Denise's opinion, this 'appearing as normal' prevented Maddy from receiving the necessary care that she required. Over the course of this thesis, I have argued that transitional care entrenches the dichotomy between what can be considered 'normal' and 'abnormal' in adolescence. To paraphrase Foucault (2004) - if you are not like everybody else, then you are abnormal, then you are sick. This turns young people with ELD into biomedical 'challenges' to be overcome, rather than acknowledging that their transition is markedly different from the social norm.

Crucially, in transitional care, human worth and personhood were configured in terms of one's capacity to become the expected culturally defaulted adult rather than acknowledging 'that to be human means to be many different ways'. As a consequence, the findings of this study call for a de-trivialisation of both adolescence and the unfair classification of learning disabilities as pathologies and abnormalities. The all too neat classification of disability discounts the complexities and contradictions of the range of cognitive capacities within an epilepsy population, therefore preventing a thorough dissection of how this condition is constructed in everyday caregiving practices. Diversity in disability must be recognised in order to establish new ways of conceptualising adolescence that is inclusive of such young people and their carers ongoing health and care needs.

Re-conceptualising Adolescence

Throughout this thesis, I have argued that conceptualisations of adolescence (as forwarded by clinical perspective [see Chapter 2]) are shown to be ill-fitted to an ELD population. Assumptions and expectations of adolescence (such as separation, transformation and reintegration), marked in all manner of ways via rites of passage, are subverted by the continual liminality experienced by the patients and indeed their carers. The fact that these young people would never travel through adolescence and come out the other end in the ways that society expected of them is best illustrated in the paraclinical workforce and the PSP [Chapter 9]. As a mode of enrolling and maintaining responsibilised parent/carers, the PSP was developed in response to the caregiving that parents continue to provide post-transition to adult services. Here, we see that transition was not so much about the institution supporting young people to become self-reliant adults, but was more about asking the parents to support the clinical work of the institution.

Furthermore, in the field sites and transitional care more generally, transition services were time-limited; meaning that transitioning from child to adult services largely occurred when the individual ‘aged-out’ of paediatrics. However, aged-defined approaches to care were not necessarily about supporting the process of transitioning to adulthood for young people with ELD. An important distinction to be drawn here is between transitioning between services, and the process of moving from childhood to adulthood (Beresford, 2004). What we have learned in this study is that developing adolescent care practices, ideally, ought to involve supporting a young person to move towards a new life stage, whilst simultaneously accounting for their particular circumstances. This is something that cannot be dictated by the narrow constraints of age-defined and time limited services.

Adolescence is not a category that exists ‘out there’ and yet it is treated as such within transitional care. This is seen in continual reference to the ‘storm and stress’ or, as Sara states in Chapter 5, the ‘terrible’ nature of adolescence. Yet from reviewing studies of youth within anthropology and sociology, we see that adolescence is a contested category that is both culturally and historically situated. Nonetheless, the TEC treated the concept of adolescence (and its assumed challenges) uncritically; as if care practices should mirror a normative developmental trajectory. For those who do not fit such clinical models of adolescence, this is marginalising in that it once again reifies dichotomies of normality and abnormality in disability.

Taken together, these three lessons have significant implications for practices surrounding health, adolescence and disability. Consequently, there needs to be an explicit recognition that the point of transitional care is to care for people and to support them into the next stage of life. Such an approach would be committed to the unique and diverse needs of disabled young people, rather than attempting to fit them into a preferred standardised institutional model of adolescence. By recognising the above insights, I suggest a re-examination of the effectiveness of transitional care practices in the context of young people who will struggle with gaining independence, who will move into the adulthood in non-standard ways and who will have reliance on carers indefinitely.

The Dignity of Care: Reflections for transitional practice

I suggest a methodological and practical reform to transitional care, one that focuses less on arbitrary categories, such as adolescence, to an approach that focuses on dignity. What would it mean to re-examine the transitional care practices in this way? Primarily, it would suggest a deep consideration of caregiving itself; what is it, and what are the contexts within which it gets done? One way of making dignity central to transitional care is to be ‘engaged in practices to make people’s living conditions more socially beneficent and humane’ (Wilkinson and Kleinman, 2016). With transitional care so explicitly aimed at producing self-reliant, independent and productive members of society (D'Agostino, Penney, & Zebrack, 2011) then maybe here is where the roots of suffering and harm begin.

The concept of dignity is not fixed to an age or specific ability but is, instead, focused on recognising the often-ignored reality that ‘to be human means to be many different ways’. Treating people with dignity means not only to include them in social practices, such as transitional care, but to acknowledge that inclusivity for its own sake is problematic. In this suggestion, I am again reminded of my half-sister Danielle, who was never fully included in our childhood games [see Chapter 3]. To provide dignity in care would require acknowledging that moving from childhood to adulthood is a process that is unique to everybody. Crucially, there is a need for dignity in care because programmes for transitioning cannot operate outside of the practical realities of living with ELD and caring for a young person with ELD.

It is my intention that this thesis will ignite more reflexive and pluralistic dialogues – better communication between professionals, parents/carer, young people and the wider lay public – about how we truly care for young people with disabilities and chronic conditions. This study of one specific medical situation has broader appeal for helping to understand the intersections of caregiving, disability, adolescence, and social practices. Whilst I have concentrated upon clinical coming-of-age practices, transitions happen in a variety of domains of social life including education, employment, social care and personal relationships. It is my hope that these findings are transferable to such other locations where young people with learning disabilities face pervasive sociocultural ideals of independence and responsibility rather than that of care and dignity. In taking an ethnographic approach to the study of the TEC and surrounding activities, I hope I have also shown the significance of fieldwork – of being there, amidst the action, to understand the fine-grained and taken for granted affairs of everyday life (Garfinkel, 1967). This has been crucial to analysing how mundane routines, that are deeply embedded in the fabric of medical work, produce and reproduce certain power relations, cultural values and so-called ‘challenges’ of care. In conclusion, the ethnographic perspective has proven itself to be a potent way of grasping the complexities of transitional care, instead of reducing it to a set of challenges to be fixed. Only in this way is it possible to bring to the fore the complex and multiple character of transitioning to adulthood for those who are considered different from sociocultural norms.

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Appendix 1. Parent/carer information sheet and consent form

Transitioning to Adult Healthcare

Information for Parents and Carers

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and feel free to ask if you would like more information or if there is anything that you do not understand. Talk to others about this research if you wish. The research is funded by Epilepsy Action and sponsored by The University of Liverpool.

This information sheet tells you about the study and what will happen if you take part and provides information on the conduct of the study. This study is will be exploring the current practices of transitional care for those young people who have epilepsy and a co morbid learning disability and their associated health professionals and parents/carers.

Who is doing the research?

Shelda-Jane Smith is a PhD student in the Department of Public Health and Policy at the University of Liverpool. The research is supervised by Dr. Ciara Kierans, Dr. Adele Ring and Professor Bridget Young.

What is the purpose of the study?

The purpose of this study is to better understand the healthcare practices surrounding the transition of young people with epilepsy and a co-morbid learning disability (ELD), by finding out about the experiences of patients, families and health professionals involved in the transition process. Transition to adult services can be a challenging time for young people and their carers. We are hoping that the information gathered from the study will help us better prepare young people and their families for the transition to adult medical care. The research is in response to calls to improve transition services nationally and across specialities. The research will be running until

October 2017 and is being undertaken as part of a PhD qualification by the researcher Shelda-Jane Smith.

Why invite us to take part?

You have been invited because you have been identified as a parent/carer of a young person under the care of [redacted] for their epilepsy and co-morbid learning disability and they are aged between 14 and 25 years. The study is looking to invite 15 young people and their carers and relevant health professionals to take part.

Do we have to take part?

No. You only take part if you decide you want to. If you do decide you would like to take part in the study you will be asked to sign a consent form to say that you have agreed to take part when you meet the researcher. If you decide later on that you no longer wish to take part then you can leave the study at any time without giving a reason. This would not affect the standard of care that your child receives.

What will happen if I take part?

This research study will be asking you to be involved in a few ways, depending upon what you feel comfortable with.

Narrative interviews: You will be asked to take part in at least one narrative interview (preferably two if possible). The interview/s will involve you talking to the researcher about your experiences of transitional care. These interviews are expected to last between 30-60 minutes and will be audio-recorded. Once transcribed, the recording will be destroyed.

Fieldwork: The researcher may also spend some time with you when you and your family attend clinic at the hospital. From this she will take field notes, which is like a research diary. The length of time you participate for may vary depending on what you are comfortable with.

Where will the research take place?

The interviews will be carried out in a place of your choosing. This will be negotiated with you at your discretion. If you need to travel, reimbursements will be provided. Observational work will be clinic based.

Are there any disadvantages or risks in taking part?

We do not expect there to be any risks associated with participating in this research study. However, if you feel uncomfortable at any time, then you can stop and/or leave the study without having to give a reason.

Are there any benefits in taking part?

You will be providing much needed information for the growing area of research concerned with transition. Your experiences and opinions will help us to better understand transitional care for young people with ELD from the perspective and experiences of a health professional. The research findings will be used to inform developments of current transition pathways and may be used to inform health policy.

Will my information be kept confidential?

All the information that you give us will remain confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998. The narrative interviews will be digitally recorded and transcribed. After transcription the audio recordings will be destroyed. Only the researcher will have access to the interview audio files and field notes. Any information which you provide us with during the study will be stored in locked filing cabinets or password protected University of Liverpool computers.

Anything about you, including any quotes which are used in the write-up of the study, will have your name removed and a different one put in place, so that you will remain anonymous. At the end of the study the research data (consent forms, anonymised interview transcripts, field notes, and your contact details) will be kept securely in locked filing cabinets and/or password protected University computers. This will be kept for ten years. Please note that if you do tell us something that meant you or others were in danger or could come to any harm, the researcher would have a duty to tell her supervisor about this.

What if I do not want to continue?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this.

What will happen to the findings?

After the study has finished, the findings will be used to form the researcher’s thesis for her PhD. This will be marked by two examiners. The research will also be published in academic journals and presented at conferences.

If you want, you will be consulted throughout the study about the findings to get your ideas, opinions and criticisms of what the research has found. At the end of the study you will be provided with a summary of the findings, and you can request the final report if you would like it.

Who is organising/funding the research?

The research is funded by Epilepsy Action, a registered charity which aims to improve the lives of those with epilepsy. The study is sponsored by The University of Liverpool.

Who has reviewed the study?

The study has been reviewed and received favourable ethical opinion from Haydock Research Ethics Committee.

Disclosure Barring Service.

In order to carry out this study the researcher has obtained a Disclosure Barring Service check which you can request evidence of from the researcher.

What if I am unhappy with the research or there is a problem?

If you are unhappy or there is a problem, please feel free to let us know by contacting the researcher, Shelda-Jane Smith on [redacted] or by email: sjes88@liverpool.ac.uk, who will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with, then you should contact The University of Liverpool's Research Governance Officer, on [redacted] or at ethics@liverpool.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make."

Further information and contact details.

Shelda-Jane Smith
PhD Researcher
Department of Public Health and Policy
Office 3:14, Whelan Building
The University of Liverpool

Tel: [redacted]
Email: sjes88@liverpool.ac.uk

Thank you for taking the time to read!
This information sheet is for you to keep

Participant Identification Number for this study:

CONSENT FORM

Parents/Carers

Title of Project: **Transitioning to Adult Healthcare**

Name of Researcher: **Shelda-Jane Smith**

Please initial all

1. I confirm that I have read and understand the research information sheet dated______________for the above study. ☐

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

3. I understand that any quotes generated from the study may be used in any publications which arise from this study and will be anonymous. ☐

4. I agree to be audio recorded during study interviews. ☐

5. I understand that all data will be stored securely and is covered by the Data Protection Act 1998. ☐

6. I would like to receive a summary report of the study and am happy for the researcher to store my contact details on a secured database in order to send the report to me when it is available. ☐

7. I understand that the above researcher will have access to my child's medical details related only to the research study. ☐

8. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent.	Date	Signature

Thank you!

Appendix 2. Interview Guide and Schedule

Narrative Interview Design

Using a three sub session framework as developed by Wengraf (2001) a model of narrative interviewing has been designed.

Sub-session 1

Ask a single question designed to elicit the full narrative
Example:
"I would like you to tell me the story of when you moved from the children's hospital over to the adult hospital so far, include all the events and experiences which are important to you. Start wherever you like. Please take the time that you need. I'll listen first, I won't interrupt, and I'll just take some notes for afterwards."
(Only if necessary, the interviewee is encouraged to answer this question with reassurances and prompts)

Interviewer to make notes of topics that the narration is about. The initial narration continues until the interviewee indicates clearly that they have no more to say.

10-15 minute break in which interviewer reviews notes and prepares questions for sub session two.

Sub-session 2

Continued immediately after break. The interviewer asks for more story about the topics raised in the initial narration. Follow the order they were raised using the language used by the interviewee.

Sub-session 3

To be conducted on a separate occasion. Further questioning arising from preliminary analysis of sub session 1 and 2 and therefore a more structured interview with predetermined questions.

The above design is based on a model, the researcher is aware that it may not always be possible to conduct sub session 2 on the same day. However, what is important is that there will be at least two separate occasions where the researcher can further develop topics that where raised in the initial narration.

Semi Structured Interview Design - Health Professionals

Individual Work and Professional Background

What is your official position within the epilepsy service? Tell me a little bit of what your work involves. What expertise/skills does it require?

How long have you worked with the epilepsy service?

How did you come to develop an interest in epilepsy?

Multidisciplinary Work

In which aspects of your role do you work closely with others in the epilepsy service? In which aspects of your role do you work more independently?

In your opinion does epilepsy transition requires a multidisciplinary approach? If so, which disciplines do you think are relevant?

When working clinically with adolescents, how often do you collaborate with external health-related organisations i.e general practitioners, family planning services, psychology, genetics?

When working clinically with adolescents, how often do you collaborate with external social-related organisations i.e social care, schools/colleges, community learning disability teams?

In your opinion what are the benefits to working in a multidisciplinary environment? What are the challenges?

Have you ever found there to be institutional or professional barriers that can hinder multidisciplinary clinical practice? Can you give any examples of how this may have manifested?

In your opinion, are there any aspects of the current political climate, particularly in regards to healthcare provision, which influence your work and the healthcare for adolescents?

Would you say there was a difference in the culture of care between paediatrics and adults?

What do you think of the move towards establishing a specialism of adolescent medicine in the UK?

Working with young people and their carers

In your opinion, do patients and families have particular concerns about coming to adult services/leaving paediatrics?

What information is given to patients and families prior to transition? Who is this given by and in what format?

Are there any aspects of working with young people with developmental disabilities and their families that you find particularly challenging?

What are the particular challenges associated with adolescence? In your experience, how does clinical practice with adolescents differ from that of younger or older patients?

When do you see an independence from parents begin to emerge? How do you make sure patients understand what is being conveyed to them?

In your opinion, do patients (or families) have a good understanding of their epilepsy when they transition (i.e. aetiology, medication, or seizure type)? How does this compare with patients with developmental disabilities?

In your opinion, do families have a good understanding of epilepsy in general?

Transition

How would you define a successful transition?

How important is transition rather than transfer? In your opinion what are the consequences of transfer rather than transition?

In your opinion what are the benefits of having of having an intermediate teenager clinic over other suggestions such as to stay in paediatrics, to

What is taken into consideration when deciding the appropriate time to transition? How much control do patients and families have in deciding when to transition? How is this impacted by other co-morbidities?

Have there been any major changes towards how the transition work operates from when it was established? If so, why?

What are some common tools that you use while working with transitioning adolescents (assessments, technologies, equipment, surveys, diagnostic instruments, reference manuals)?

Transition Research & Development

In your opinion, what has caused the influx in transition related topics at this site and further? What is the resulting effect of this?

Is this the nature of this research an observational stance or interventional? What comes next?

How much of the research incorporates clinical, psychological and social aspects of transition and healthcare.

How much of this research gets through to policy and is this adequate?

Where do you think the future lies in epilepsy research?

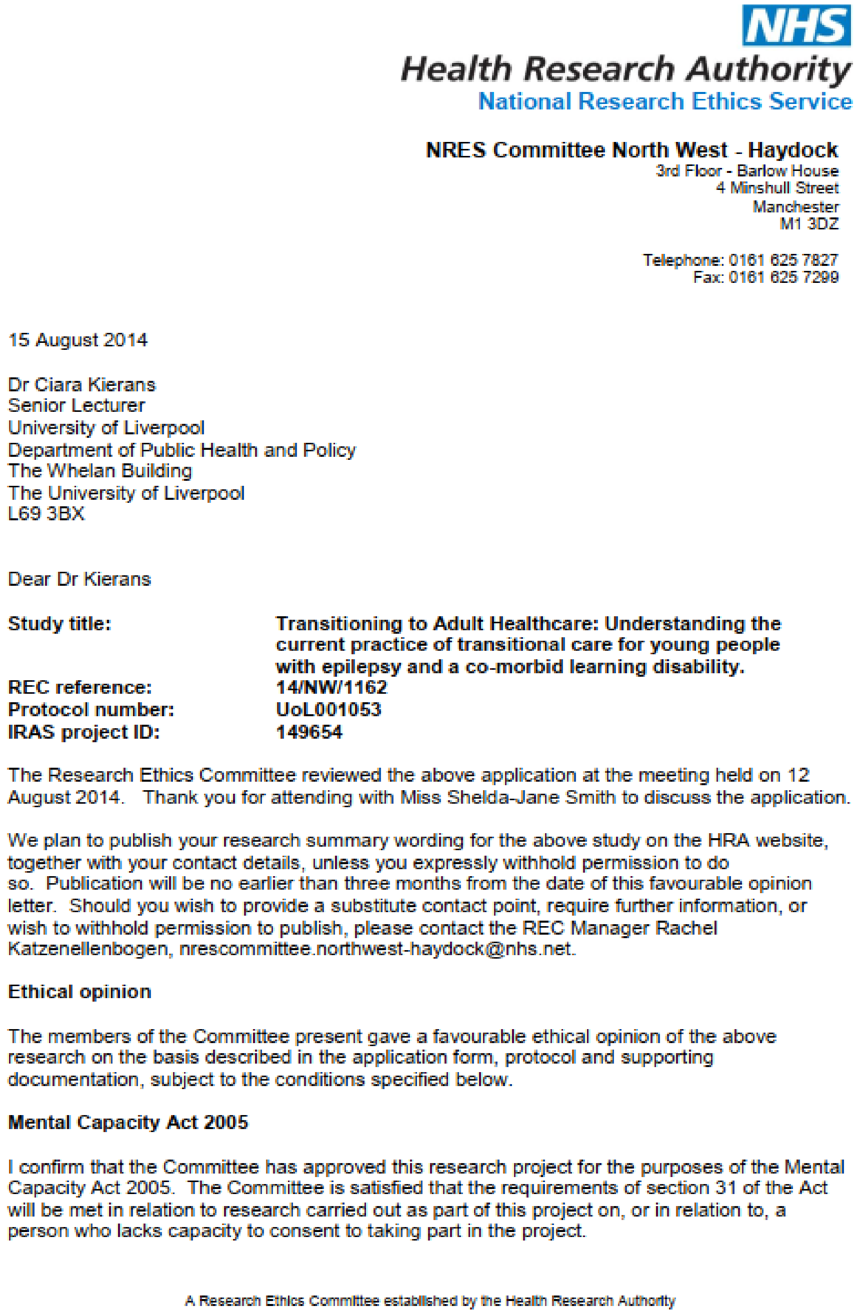
Other Considerations

What aspects of working with adolescents do you find rewarding? What do you find difficult?

Is there anything that we haven’t covered that would help me understand transition of ELD better?

Do you have any particularly strong opinions about the specialisation in adolescent medicine?

Appendix 3. Research Ethics Approvals



NHS
Health Research Authority
National Research Ethics Service

NRES Committee North West - Haydock
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7827
Fax: 0161 625 7299

15 August 2014

Dr Ciara Kierans
Senior Lecturer
University of Liverpool
Department of Public Health and Policy
The Whelan Building
The University of Liverpool
L69 3BX

Dear Dr Kierans

Study title:	**Transitioning to Adult Healthcare: Understanding the current practice of transitional care for young people with epilepsy and a co-morbid learning disability.**
REC reference:	**14/NW/1162**
Protocol number:	**UoL001053**
IRAS project ID:	**149654**

The Research Ethics Committee reviewed the above application at the meeting held on 12 August 2014. Thank you for attending with Miss Shelda-Jane Smith to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Rachel Katzenellenbogen, nrescommittee.northwest-haydock@nhs.net.

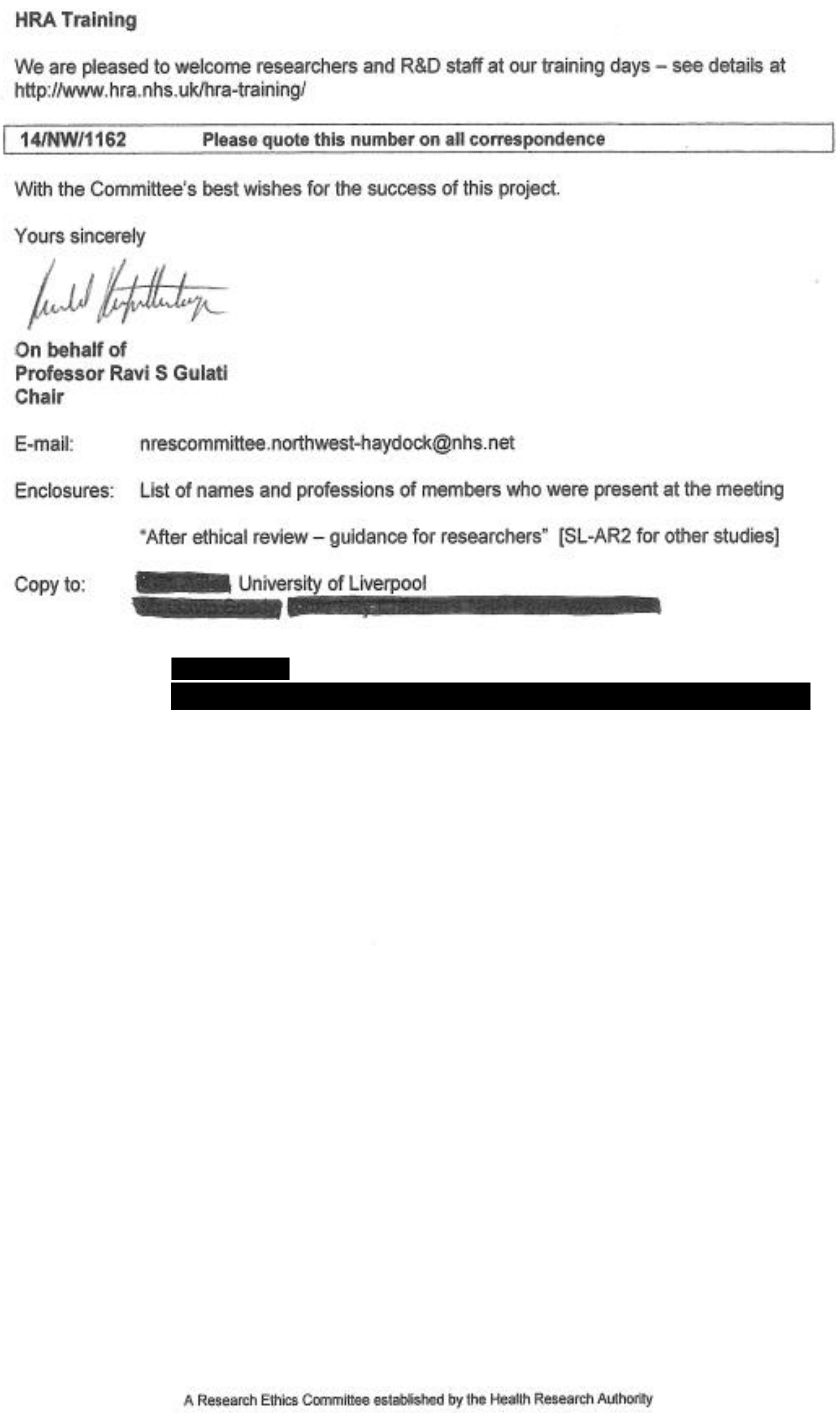
Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

A Research Ethics Committee established by the Health Research Authority



HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

14/NW/1162	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Professor Ravi S Gulati
Chair

E-mail: nrescommittee.northwest-haydock@nhs.net

Enclosures: List of names and professions of members who were present at the meeting

"After ethical review – guidance for researchers" [SL-AR2 for other studies]

Copy to: [redacted] University of Liverpool
[redacted] [redacted]

[redacted]

A Research Ethics Committee established by the Health Research Authority